'It's all very blurry.' Exploring the messy realities of living with hepatitis C.

A thesis submitted for the degree of Doctor of Philosophy

January 2014

Heather Louise Mack   BA (hons)

I declare that this thesis is my own work and has not been submitted in substantially the same form for the award of a higher degree elsewhere.

ProQuest Number: 11003490

ProQuest 11003490

Contents

1

Dedication

This thesis is dedicated with much love to my Grandad Tom, who knew I could do it and is missed every day.

Also to my sister Jennifer Rose, who is *My Hero.*

Acknowledgements

First and foremost, deep and heartfelt thanks to everyone who participated in this research in all its forms and who made the data generation period one of the most enjoyable and stimulating experiences of my career to date. Although it was not possible to include all the data within this thesis, your contributions and participation are greatly appreciated.

To each of the participants whose interviews are central to the constitution of this thesis; who allowed me into their homes, support groups and places of work and generously gave of their time in sharing their experiences with me. Without you this thesis would never have been possible. Thank you.

Special thanks to my always patient and understanding supervisors, who pushed me to see this PhD through to the end, nurtured my intellectual curiosity and who always had time for me. To Dr Karenza Moore for her enthusiasm for my work and support with the especially sticky patches. Also for her empathy, awesome knowledge - and for being someone I aspire to be like. To Dr Ian Paylor for encouraging me to do a PhD in the first place and for his kindness and practicality. Later for helping me to keep things in perspective and for the engaging conversations which reminded me why this work is so important.

Particular thanks must also be extended to Mr John Stewart for encouraging me as an undergraduate and for advising me to follow my passion, to Dr Donna Reeve for her generosity with her time and to Dr Cheryl Simmill-Binning whose thoughtfulness and wise words at the outset, have stayed with me on this enormous trek.

Thanks also to my PhD examiners, Professor Alan Roulstone and Dr Chris Grover for their helpful suggestions and refinements and for giving me the opportunity to thoroughly defend my work.

To my fellow PhD students for their support and for being ace; particularly Dr Kellie Thompson, Dr Paula Doherty, Dr Tony Sparkes, Dr Hugh Asher and Dr Susie Balderston.

Especially to Dr Laura Snell, whose daily support, frequent baked treats, musical interludes, long discussions, love and (editing) advice have sustained me on this 'PhD rollercoaster'. I hope we stay friends until we are very old.

Parts of the work included in this thesis have been published in:

Paylor, I. and Mack, H. (2010) 'Gazing into the Scarlet Crystal Ball; Social Work and Hepatitis C', *British Journal of Social Work*, 40, (7), pp.2291-2307.

'It's all very blurry.' Exploring the messy realities of living with hepatitis C.

A thesis submitted for the degree of Doctor of Philosophy

January 2014

Heather Louise Mack   BA (hons)

Abstract

Across the UK, 200,000 – 500,000 people live with chronic hepatitis C. Spread through blood to blood contact, the main route of transmission in the UK is via sharing injecting drug use equipment. The negative perceptions which accompany this, coupled with the hidden nature of the illness and the slow course of the infection, have enacted and materialised hepatitis C as a low priority for services and policy. There are treatments which can eradicate the virus, though treatment can exacerbate and produce severe impairment effects and disablism.

Given the lack of attention afforded to hepatitis C experience in the UK, at the heart of this PhD study are 21 people with the virus, who participated in qualitative interviews. Findings are structured around topics currently under addressed in UK literature; including the period following diagnosis, the post treatment experience, the impact on employment and the experience of claiming social security benefits.

The accounts generated in these interviews were much *messier* than anticipated. The concept of 'mess' has emerged as central to the constitution of this thesis and, as I show, central to responding to the needs of those living with hepatitis C. The practical implications and manifestations of this messiness are theorised using the concepts of metaphor, liminality, pharmakon and pharmakos. The thesis also applies insights from the field of disability studies, a discipline which has not been used extensively to theorise the experiences of living with hepatitis C.

The thesis engages in an important and timely discussion of the everyday realities of living with hepatitis C and the role of professional health and social care support. Particularly given the contingent nature of living with the virus and the state of flux participants found (and find) themselves in, due to public service reforms and new treatment development. It shows that despite the current (and increasing) dominance of medical responses to hepatitis C, there is an urgent need for other professionals, including social work and those working in disability studies, to address hepatitis C.

Glossary of terms

It has been necessary to provide a glossary of terms at the beginning to this thesis, as some of the terms are used before they are fully explained. This has proven to be unavoidable in the drafting and redrafting of the thesis and further challenges the linear presentation of research accounts.

Acute infection. Infection lasting less than 6 months.

Antibody test. The first test undertaken to determine whether someone has hepatitis C. This test detects hepatitis C antibodies. The presence of hepatitis C antibodies in the blood does not necessarily mean someone is *currently* living with hepatitis C, just that they may have been exposed to the virus. Current hepatitis C infection is determined with a PCR test (see below).

Asymptomatic. Displaying no signs or symptoms of infection.

Chronic infection. Infection lasting longer than six months.

Co-constitute. To engage in an active process of bringing realities and things into being in a way which acknowledges that phenomena shape and are shaped by processes and things with which they intra-act.

Combination treatment. The standard treatment for hepatitis C at the time of interview. Two medications taken in combination, Pegylated Interferon and Ribavirin.

Cirrhosis. Permanent scarring or damage to the liver which impairs its ability to function.

Direct Acting Anti Virals (DAA). Medications which act directly on the virus.

Disability. Distinct from impairment, disability is the disadvantage or restriction of activity caused by contemporary social organisation which takes little or no account of people who have impairments, thereby excluding them from full participation in mainstream life (UPIAS, 1974: 14).

Enact. To bring specific objects or realities into being. In my view, the term enactment recognises that what is brought into being is contingent - continually engaged in a process of coming into being, without one fixed final product at the end of, or separable from, those processes.

Fibrosis. The development of scar tissue on the liver as a result of inflammation or damage.

Genotype. The strain of hepatitis C virus. There are six types – known by numbers i.e. genotype 1, 2, 3,4,5,6 and these can be divided into subtypes i.e. genotype 1b. Knowledge of genotype is important for determining the type and duration of treatment.

Hinterland. A term used by Law (2004) to refer to the work and relations which accumulate and bundle together over time and through specific research practices. The work that comes before to shore up understandings and realities in particular ways.

Illness. Illness is used throughout the thesis in conjunction with (and intertwined with) impairment. Commensurate with Thomas (2007), illness is understood as a category of impairment. Illness in this context is used to describe the state of being unwell due to hepatitis C. Illness can be long term (chronic) or short term so is particularly suited to describing the unpredictable nature of living with the virus. Within the thesis, participants described themselves as 'ill' but not necessarily as 'impaired'.

Impairment. Impairment is used in the thesis in a functional (but not necessarily medical) sense. Impairment is a variation or difference in a person's body which may restrict movement or activity in some way (Thomas, 2004). It is deliberately not used in this thesis to

describe a 'lack' or a 'loss' and is clearly differentiated from 'disability.' Within the thesis, impairment was not a term used participants, but is retained in the thesis when discussing the work of other academics or referring to functional aspects of living with the virus. .

Impairment effects. A term taken from the work of Carol Thomas (2007; 136) which refers to restrictions of bodily activity and behaviour that are *directly attributable* to 'impairments' rather than *those imposed upon people because* they have designated impairments (disablism)' (emphasis in original text).

Intra-act. Differentiated from the term 'interaction' which implies a separation between relations, in intra-action there is no such separation.

Liminal. Taken from Turner (1966) and later used by Murphy (1981, 1988) among others. Liminality refers to being in between, neither one thing nor another.

Materiality. That which is material and physical; matter, blood, bodies, structures.

Metaphor. Frequently used to mean giving something a name which belongs to something else. I follow Ricoeur (2003) in understanding that metaphor and reality cannot be prised apart from each other and that metaphor should be considered, not as a creative addition to language but fundamental to making it.

Method Assemblage. An active gathering of relations and objects which carry with them assumptions about reality and at the same time, contribute to enactments of that reality. Method assemblage includes research questions, interview schedules, researchers, participants, tape recorders, transcription pedals as well as assumptions about reality research methods and political understandings.

Multiple. Not singular and fixed but numerous and overlapping. Expressed by Mol (2002) as 'more than one less than many' – meaning that there may be more than one enactment or reality, which are not separate and bounded but mingle together.

Ontological politics. Connected to the notion of multiple defined above. If multiple enactments of objects and realities are possible, then the notion of a single answer or interpretation ceases to exist. So decisions have to be made about which interpretation to accept and which reality to bring into being, which in the case of this thesis, is highly political. These debates about what to bring into being are ontological politics.

PCR (Polymerase Chain Reaction) test. The PCR test is the second test in the process of diagnosing whether someone has hepatitis C. It determines whether the virus is currently replicating within the blood. If the test is positive this means someone is currently living with hepatitis C.

Phenomena. Taken from Barad (1998). Phenomena do not pre-exist but are remade and co-constituted in intra-action with other phenomena. Thus the term phenomena is used to describe 'objects' such as hepatitis C, ' treatment' 'stigma' relations and emotions, recognising the continually intra-active nature of the constitution of reality (see Fraser and valentine, 2006).

Pharmakon. Used by Plato and later by Derrida (1981). Pharmakon is the thing which is both poison and remedy, simultaneously. It is undecidable and contingent.

Pharmakos. Related to the term pharmakon, pharmakos means scapegoat.

Pharmakoi. Plural of Pharmakos.

SVR (Sustained Virological Response). When the hepatitis C virus remains undetectable in the blood six months following treatment.

Triple therapy. The use of three different medications to treat hepatitis C. In April 2012 the combination of interferon, ribavirin and direct acting antivirals were approved for the treatment of hepatitis C genotype one.

Viral Load. The amount of hepatitis C virus in the blood.

Chapter One: Introducing the research

Introduction

In this first chapter, I pave the way for the rest of the thesis. I explain why investigating the lived experiences of people with hepatitis C in the UK, is particularly important at this point in time. I outline how the research has been shaped by participant priorities and the current political and economic climate, as well as existing academic work. I introduce the rationale for the research, together with the aim and research questions, before exploring how during the study, practical experiences of fieldwork and my theoretical influences co-constituted each other. I briefly explore my personal and professional motivations for the research, before summarising the content of forthcoming chapters to guide the reader through the thesis. At the close of the chapter, each of the participants is briefly described.

Researching the experience of living with hepatitis C

At the heart of this thesis are in-depth interviews with 21 people who lived with, or had lived with, hepatitis C in the UK. The thesis explores their experiences prior to diagnosis and through testing, treatment and beyond, with the intention of exploring the impact of hepatitis C on their everyday lives. Their support and information requirements remain an explicit focus throughout.

Given the dearth of qualitative studies which exist in relation to the experience of hepatitis C, particularly in the UK, the thesis explores a broad range of themes and issues which were highlighted as important by participants. The thesis makes both the messy nature of living with the virus and the messy experience of researching it, visible. In doing so, what is included here is necessarily both partial and situated - a 'cut' (Barad, 1998) in participant lives at a specific point in time. The findings are thus not intended to be representative of

any part of the experience of hepatitis C, given its contingent and shifting nature, but are intended to document and validate the experiences of participants in this study and to stimulate and invigorate discussion around responses to hepatitis C. The thesis provides important insights across a number of areas, including participants social support requirements, welfare benefit, employment and post treatment experiences. It contributes to alternative enactments of hepatitis C and people with it, in addition to and beyond, the current medical focus.

Rationale for the research

At present a significant proportion of existing qualitative research focuses on hepatitis C from nursing and healthcare perspectives, especially research in the UK and Northern Ireland (Glacken *et al.*, 2001; Grogan and Timmins, 2010; Frazer *et al.*, 2011a, 2011b; Tait *et al.*, 2010). A key focus of research in relation to hepatitis C is harm reduction (Taylor *et al.*, 2004) among people who use drugs, including how to reduce the spread of the virus and how to encourage access to testing and treatment (Harris *et al.*, 2012a). Whilst this is undoubtedly important, this means that the needs and experiences of those who are diagnosed with hepatitis C, or who access treatment, appear to be of limited concern. Indeed, this lack of research interest beyond access to treatment treats their needs as having been adequately addressed. This thesis shows that the opposite is true, that a new set of needs and challenges arise post diagnosis which are inadequately supported at present.

The voices of those with hepatitis C, especially in a UK setting, are scarce in research, in comparison to the amount of quantitative research available. In addition, some have noted that people with hepatitis C are often represented only as participants in clinical trials (Korner and Treloar, 2006; Korner, 2010). Thus, it was important for me to include some of the voices of people living with hepatitis C at present, both to develop recommendations for services and to encourage the inclusion and representation of people with hepatitis C in

wider society, particularly in debates about services and welfare reforms, given the rapid changes taking place.

The twists and turns of the research process

I initially planned to explore the experience of living with hepatitis C from the perspective of those living with the virus and the professionals supporting them, by interviewing people with hepatitis C and then using these interviews to develop and inform the sample and interview schedules for professionals; my intention was to explore how the perspectives of both groups could contribute to improved services. During the course of generating the data, I found that the experience of living with (and working with) hepatitis C was far more complex and, indeed messy, than I had initially anticipated: The tools used to generate accounts and the data mutually informed and constituted each other, and the support and information needs of participants with hepatitis C went far beyond what was provided by services. These needs (and participant accounts of these needs) were shaped by cultural, societal and political forces and expectations, with serious and far reaching implications for participant wellbeing. Participant accounts also highlighted a need for the involvement of a much wider range of professionals. As a result, the concept of mess (see Law, 2004) has emerged as vital in this thesis and both necessitated and explained the focus on the accounts of people with hepatitis C, rather than in conjunction with professional accounts as initially planned.

Personal and professional motivations

Initial interest in the experiences of those with hepatitis C arose in the context of my undergraduate degree in social work, where hepatitis C was covered under the module 'Social Work and Drug Use' and was introduced as an issue of increasing concern for social work. This was augmented during my final placement with a statutory Social Services team,

working with physically disabled adults. Whilst on placement, I worked with Sandra[1] who was preparing for discharge from hospital after an amputation, but whose referral also indicated a positive hepatitis C status. Sandra expressed extremely negative views around hepatitis C (and around the professionals who had disclosed her status to me) and resisted my attempts to discuss it again for the duration of our work. When I talked it over with my Practice Assessor at supervision, she explained she was unfamiliar with hepatitis C and did not often come across it in the course of her work.

As a result of this less than ideal encounter, I reflected on how I might have facilitated more positive discussion, but also on the potential wider role and implications for social work with people who have hepatitis C. This led to an undergraduate dissertation on the interaction between hepatitis C, social work and harm reduction (Mack, 2007) which further ignited an interest in doing empirical work in this area. The PhD has thus enabled me to engage and combine a passionate interest in hepatitis C and the role of social work in drug use and health more widely. In addition, as the PhD progressed, I came to understand that my status as a disabled woman also influenced the research and I became interested in what disability studies could offer in understanding the experience of living with hepatitis C.

Originality and importance of the research

The thesis makes important contributions, first and foremost in exploring the experience of hepatitis C in the UK, from within the social sciences and especially social work. It challenges the sole focus of medicine in responding to hepatitis C.

Where much of the existing qualitative literature focuses on reducing hepatitis C related harm for those who use drugs and encouraging them into testing and treatment, the participant sample was made up of those not currently injecting drugs and who were able to

---

[1] A pseudonym.

access treatment and who would thus appear to be well served by existing services, (for example: GPs, hepatitis C clinics). Further, including the experiences of co-infected gay men in the research highlights the importance of responding to those with co-infection and makes suggestions for how services might respond in the future.

This thesis adds to and intersects with a number of bodies of work, most obviously to the hepatitis C social research literature. It also contributes to literature which explores participants' use of metaphor to describe experiences of illness and to an emerging body of work which investigates how hepatitis C is materialised through social and political forces (Fraser and valentine 2008; Fraser and Seear, 2011). It applies research and theory which had only previously been applied to hepatitis C in an Australian context, to a UK setting. It illuminates in new and important ways the experience of living with hepatitis C (and its treatment) in the UK; including how people with hepatitis C see themselves, how culturally prolific diseases (Weiss, 1997) are made and remade depending on context, the people they affect and material conditions. It applies insights emerging from the field of disability studies – a discipline which to date, has not been applied to the experience of hepatitis C and explores the application of the concept of psycho–emotional disablism, (Thomas, 2007; Reeve, 2008) both in direct and indirect forms.

Furthermore, it addresses a number of areas which are currently under explored in existing literature, notably the experience of post treatment, welfare benefits and employment, the experience of HIV and hepatitis C co-infection, and participant feelings around identifying as disabled. It makes practical contributions concerning information and support requirements. Vitally, it recognises and argues for increased recognition and involvement from social work in providing this information and support, maintaining they are uniquely placed to address many of the issues participants raised in the thesis.

The diverse nature of the chapters, the broad range of experiences and the inclusion of different bodies of work enact the contingent, multiple and complex nature of living with hepatitis C. This explains, in part, the difficulty in responding adequately to hepatitis C, but also the highly political and ideological way in which services are constituted. The thesis has a distinctly political aim: to call for greater response to hepatitis C in the UK (including co-infection) and to emphasise the commonality of experience and needs among others with chronic illness.

Research aim and questions

As was explained above, the current research focus in the UK is on hepatitis C and drug use, specifically harm reduction, or on encouraging people into testing and treatment. I wanted to investigate what happened *after* diagnosis in order to improve professional responses to hepatitis C. Thus the aim of the thesis is to explore understandings, experiences and social implications of living with hepatitis C in the UK, focusing on the following specific questions:

1. What are the support and information needs of people living with and being treated for hepatitis C in the UK?

Whilst talking about their support needs, it became clear that participants' needs (and perceptions of them) were shaped by understandings and expectations related to the cultural position of hepatitis C. Therefore, research question two was formulated:

2. What do participant accounts reveal about the cultural and social position of hepatitis C in the UK at present and how can this improve our understanding and response?

Initially I understood this cultural position to relate to the stigma around injecting drug use. Hence research question three:

3. Do people with hepatitis C experience stigma and discrimination?

Whilst the experiences of stigma and discrimination were enacted and are addressed in the thesis, the concept of psycho-emotional disablism is also applied to the experience of hepatitis C. Thus whilst the original research question still stands, the thesis moves beyond it by exploring structural barriers and oppression on an inherently political level.

An introduction to the concepts used in the thesis

Within the thesis, a number of theoretical concepts are used to unfold and explain particularly messy aspects of living with hepatitis C. They are introduced briefly below.

Metaphor

Explored in chapter six, metaphors have been recognised as fundamental to how we see the world and function within it (Lakoff and Johnson, 1990), in particular in illuminating (Lupton, 2003) and shaping (Sontag, 1991) experiences and aspects of illness. Despite this, there has been little explicit discussion about the role of metaphor in participant accounts of hepatitis C. A particularly important and fresh contribution that this thesis makes, is an exploration of how participants used a comparison with cancer, and the way this was both *used as* a metaphor and *became* a metaphor for being 'undeserving' of support.

Liminality

The term liminality was used by Turner (1966) and later by Murphy *et al.*, (1988), to describe being 'in between', neither one thing nor another; for example, neither well nor ill. Liminality is a highly relevant concept given that it makes the contingent and constructed nature of the world visible. The thesis shows that participants experienced liminality because society continues to disable them both structurally (Willet and Deegan, 2001) and psycho-emotionally. Liminality is also relevant given the association between people experiencing

liminality and the concepts of pollution or contagion (Willet and Deegan, 2001). Participants described finding themselves in liminal spaces, where there was little in the way of support or recognition, at numerous junctures in their lives, though this was sometimes a powerful position. The specific implications of this will be returned to and explored throughout.

Pharmakon/Pharmakos

Pharmakon and *pharmakos* are two separate but interrelated concepts, explored in greater depth in chapter seven. *Pharmakon* that which is simultaneously poison and remedy, and undecidable (Derrida, 1981). *Pharmakon* is used to explore how particular enactments (i.e. remedy) are privileged in talking about and providing support for hepatitis C, but that a clear division between poison and remedy is impossible to maintain, which has particular implications for people with hepatitis C. The related concept *pharmakos,* meaning scapegoat, is used to draw together similarities between people with hepatitis C and (other) disabled people. The ways in which participants, hepatitis C and treatment are enacted as *pharmakos* are explored through chapters seven and eight. The use of this concept, in particular, marks a unique contribution of the thesis given that it has not been used to explore hepatitis C to date.

The structure of the thesis

Chapter Two *'Crafting hepatitis C realities in social research'* reviews existing literature. It traces the development and enactment of hepatitis C related knowledge, via prevalence rates, policy responses and testing and treatment options. It draws on research from countries outside of the UK owing to the small body of research that currently exists there. There is exploration of the cultural position of hepatitis C, and how hepatitis C has been materialised as an illness associated with injecting drug use. It explores aspects of the literature which have relevance to the forthcoming chapters including: disclosure, diagnosis,

professional and peer support, HIV co-infection, awareness, the dominance of medicine, welfare benefits, employment, and the role of social work. The last part of the chapter introduces selected disability studies literature, for the purposes of this thesis, and explains the shift from exploring stigma to paying attention to psycho-emotional disablism (Reeve, 2012a).

Chapter Three *'Getting messy; theoretical underpinnings'* explores in depth the way the practical realities of fieldwork shaped my theoretical understanding of hepatitis C - and the world - as messy, contingent and intra-active. It is closely intertwined with chapter four (hence the similar title) and deciding on the orders of these two chapters was particularly difficult given the changes in epistemological and ontological understanding which took place during fieldwork. The decision was taken to explore the 'concept' of mess first, but then to move back and forth.

Chapter Four *'Getting messy; the practical realities of fieldwork'* describes the research methods I used to generate participant accounts of the experience of living with hepatitis C and the decision to focus solely on participants with hepatitis C. I explore ethical approval processes, research design, recruitment methods, interviewing modes and ethical issues that arose in the course of the fieldwork, as well as the analysis and early dissemination practices. This chapter and chapter three make original contributions in that they apply Law's (2004) arguments, specifically around mess, in applied and practical ways in relation to hepatitis C.

Following on from this, the data chapters weave findings and relevant literature together - each one intra-acting with the last, developing a cumulative (if still partial) reality and contributing to a new hepatitis C hinterland (Law, 2004). The findings chapters are intentionally chronological to guide the reader through the thesis, but chiefly to show how participant experiences diverge from this chronology and linearity. They simultaneously

make visible the dominance of medicine and the inadequacy of current responses to hepatitis C.

Chapter Five, *'She said you're positive - I thought 'positive for what?' first encounters with hepatitis C'* explores participants' initial experiences as a means of giving context to the other findings chapters which follow. It addresses participants' experiences of undiagnosed illness and invalidation (Wendell, 1996, 2006), problematising hepatitis C's 'asymptomatic' nature, before moving on to explore experiences of diagnosis and how these contribute to the enactment of hepatitis C as a low priority. The chapter makes an important contribution in providing a recent addition to the diagnosis literature, and in documenting participants' need for post diagnosis support. It also explores how representations of the virus in current awareness raising campaigns, both draw from, and reinforce, current service responses. Participant experiences of structural disablism are explored, as well as the impact on participants' psycho-emotional wellbeing.

Chapter Six is entitled *"People with HIV and cancer get all the publicity'. Talking about hepatitis C: metaphors, comparisons and implications.'* This chapter investigates the cultural position of hepatitis C. It foregrounds specific metaphors used by participants to talk about the virus and treatment, explores strategies used to manage the interaction with others and how information provision shapes hepatitis C and participants' sense of self. Participants' use of the metaphor 'silent killer' is considered, specifically the way this is used to reinforce the personal importance of treatment. Comparisons with two high profile illnesses, cancer and HIV are discussed in depth. Here the concept of a hierarchy of impairment and the implications for participants' wellbeing and identification with other groups are explored.

Chapter Seven *"Left in limbo' Hepatitis C treatment; pharmakon and pharmakos'* explores participants' treatment experiences and support requirements, which were crucial in their accounts. It explores how medicine enacts and materialises people with hepatitis C in

specific ways, which both reinforce the need for treatment and potentially marginalise additional needs. The concepts of *pharmakon* and *pharmakos* are used to unfold and explore the ambiguous experience of treatment and the position of people with hepatitis C, and to draw out similarities and intra-actions between the oppression and exclusion faced by people who use drugs, people with hepatitis C and (other) disabled people.

Chapter Eight *'It was an awful shock to still feel like I did'* explores participant experiences of post treatment effects and support needs, including how post treatment support might look, the role of self-management programmes and the concept of recovery.

Chapter Nine; *"And you're thinking, am I ill enough?' welfare benefits and employment with hepatitis C'* explores participants' experiences and sense of entitlement to claim welfare benefits. It weaves current debates about welfare reform with participant accounts of trying to claim benefits, and cultural understandings of hepatitis C with understandings of the benefits system as psycho-emotionally disabling (as explored by Reeve, 2008, 2012a). Later, participants' experiences of employment, specifically in obtaining reasonable adjustments under the Disability Discrimination Act (1995, 2005) (now part of The Equality Act, 2010) and the degree to which they felt they were covered by existing legislation are also addressed.

Chapter Ten *'Concluding thoughts'* brings together the main research findings and discusses how the thesis has addressed and shaped the research questions. It describes the unique and original contributions that this thesis has made to a number of existing bodies of knowledge. The thesis ends by suggesting areas for further research.

Appendix one details a range of *'Recommendations for policy and practice'* given that the length of the thesis prohibited their inclusion in the final document.

A brief introduction to participants

Below I provide a short introduction to each participant in order to provide context to the chapters that follow and to maintain a focus on their personhood, consistent with viewing hepatitis C in the context of participants' everyday lives. Most of the participants chose pseudonyms. Others chose to keep their own names.

Morgan was 56. She found out she had hepatitis C in 2008, although she had been tested six years previously. At the time of interview, she had finished 24 weeks of combination treatment and was waiting to see if she had attained SVR. She has since cleared the virus. Morgan was unsure where she had contracted the virus but recalled incidences of medical treatment abroad a number of years ago. Morgan lived alone but received support from her children and her friends whilst on treatment. She emphasised that it was important to her to live close to nature. She was self-employed as an alternative health practitioner and described knowing something was wrong when she began to feel dizzy and unwell at work. She had stopped work at the time of interview due to the side effects of treatment and post treatment.

Laurie was 44. He lived with his wife and two children and described his family as extremely supportive. Laurie was made redundant part way through treatment, though he was back to work at the time of interview. He is a keen musician. He is unsure where he contracted hepatitis C, although he believes he may have caught it accidentally from a sibling. He was diagnosed in 2006 by the National Blood Service. He undertook a course of combination treatment for 24 weeks in 2007 and attained SVR. He explained he did not return to work for five months post treatment due to on-going effects.

Freda was 53. She was diagnosed with hepatitis C in 1990 by the National Blood Service. She believes that she contracted hepatitis C during a blood transfusion given during the birth of one of her children in the 1970s. Freda did not discuss her hepatitis C with anyone until she was referred to a gastroenterologist. Freda was on treatment at interview but stopped at 28

weeks due to treatment failure and the severe treatment effects she experienced. Freda works in physical rehabilitation and continued to work throughout treatment, although she found this very difficult.

Kerry was 30 at the time of interview and was a single mum. She lived alone and described relying on support from her family in order to get through treatment. She was coming to the end of 24 weeks of treatment for hepatitis C at the time of interview and has since attained SVR. She has been actively involved in campaigning for greater awareness around hepatitis C. Kerry thinks that she contracted hepatitis C through sharing equipment for injecting drug use, although she stopped using drugs in 2005 when pregnant. Kerry lives with an existing mental health condition. Kerry is interested in music and has a degree in Politics.

Ken was 59. He was retired due to a range of health issues which he felt arose from 35 years of drug use. He had cleared hepatitis C five years prior to the interview (2005). He was diagnosed in 2003 at his local drug service. He had undertaken combination treatment successfully. He was a member of a local support group and described providing on-going support to people with hepatitis C. He lives with his partner. Ken felt it was very important to pass on his life experience to others. He volunteers for a local drug service and in a local prison.

JB was 55. He participated in the interview with his wife **Pixie** with whom he set up an online support group for people with hepatitis C. JB described contracting hepatitis C from experimenting with injecting drugs for a short period in the 1970s. JB was diagnosed by his GP in 2004/5. JB had been treated twice in two different geographical areas which highlighted differences in support. At the time of the interview JB had finished treatment for the second time and was waiting to see if he had attained SVR. He has since cleared the virus.

Pixie was in her 50s at the time of interview. She was married to **JB** and set up an online support group due to a lack of social support. She is active both in running this and raising wider awareness around hepatitis C. She contracted the virus in 1980 from a blood transfusion and was diagnosed in 2000. At the time there was no funding available in her area so she did not begin treatment until 2005. Pixie underwent treatment for 48 weeks and described experiencing no side effects. She attained SVR in 2007.

Carl participated in a group interview with **Andrew** and **Brad.** Carl was diagnosed 15 years prior to interview (late 1990s) after his liver function was tested before he went onto a medication. At the time of diagnosis, no treatment, information or support was available. Carl described experiencing no illness prior to beginning treatment and began treatment after entering recovery. He attained SVR and experienced post treatment effects for about 14 weeks.

Andrew also participated in the group interview with **Brad** and **Carl.** He was diagnosed with hepatitis C approximately 12-15 years ago. He was given the diagnosis whilst attending a substance misuse service with very little accompanying information, which he attributed to the time period. Andrew reported feeling no effects from the hepatitis C until he started treatment. He had completed treatment and attained SVR two years prior to interview, but described ongoing post-treatment effects.

Brad participated in the group interview with **Carl** and **Andrew.** He contracted both hepatitis C and HIV after being raped. He was diagnosed with hepatitis C much later than Andrew and Carl (mid-late 2000s). He finished treatment two years ago, at the time of the interview (2010), but explained that the experience felt very raw. He completed 48 weeks of treatment and experienced serious post treatment effects.

Richard was 60. He found out he had hepatitis C in 2000 after undergoing numerous investigations. He was diagnosed by a local drug service because he did not want colleagues

or his GP to know he was being tested. He thinks he contracted hepatitis C though injecting drug use in the 1970s/1980s. He underwent six months of mono interferon treatment but did not attain SVR. At this point he had cirrhosis of the liver and was put on the list for a liver transplant, which he had in 2004. He has since undergone a course of combination therapy, though this was also unsuccessful. Richard was also involved with his local support group and at the time of interview was researching the possibility of setting up a telephone support service for people with hepatitis C.

At the time of interview **Grace** was in her 40s and lived with her partner and teenage child. She thinks she caught hepatitis C around 20 years ago. Grace was not sure where she contracted it, but believes it may have been from a blood transfusion following childbirth or from a dentist. Grace was diagnosed in 2007 by a locum GP after seeking advice for a range of impairment effects for about two years. Grace gave up work and sold her own business, before she started treatment. Grace did treatment twice and at the time of interview had been on treatment for a year and a half. She has since attained SVR.

Daniel was diagnosed with hepatitis C in June 2009. At the time of interview he was waiting to see if he had cleared the virus after discontinuing the treatment due to an allergic reaction. He has a partner and a daughter. He is currently studying to become a therapist. He discovered he had hepatitis C after going 'for an MOT after getting clean and sober'. He has since attained SVR.

Holi was 46. She lives with her husband and has two adult daughters who she described as being very supportive during treatment. She discovered she had hepatitis C in 2008 but had been feeling unwell for about 20 years. Holi explained that she has never been in one of the 'risk groups' for hepatitis C, so can only speculate as to how she might have contracted it. She underwent 24 weeks of treatment and has attained SVR. Holi described severe

impairment effects during treatment including losing all of her hair. Holi worked as a therapist but reduced her hours on treatment.

Shaun lived with HIV and hepatitis C. At the time of interview he was coming to the end of a 24 week treatment having previously been treated for hepatitis C and cleared it. He was off work due to the effects of treatment.

Charlie lives with HIV and at the time of interview was clear of hepatitis C having completed 48 weeks of treatment. He has been HIV positive since 2000. Charlie cleared hepatitis C in 2009 following combination treatment. He works for a regional blood borne virus organisation which he felt was helpful in understanding how difficult the treatment was.

Ben also lived with hepatitis C and HIV. He had been through treatment twice for hepatitis C. Ben was diagnosed with hepatitis C during a routine appointment for HIV in 2003 and thinks it was transmitted sexually. He began the first course of treatment in 2004. He underwent treatment for 48 weeks and attained SVR at six months but found the virus was detectable again at eight months. He took a break and undertook treatment for a further 48 weeks in 2007 and sustained SVR in 2008. He described very different employer responses to his request for reasonable adjustments.

At the time of interview, **David** was living in a residential rehabilitation centre and in the early stages of 48 weeks of treatment. He has now attained SVR. He was diagnosed in prison in 2000, but was unable to access treatment until 2010 when he entered rehabilitation. He believes he contracted hepatitis C during a short period of injecting drug use. He described participating in the interview as an important part of his recovery. David described his family and friends as very important to him and worked hard to support those who were also undergoing treatment. He was training to become a counsellor and worked as a volunteer in a drug service.

Keith was 48 and had undertaken treatment twice (one 48 weeks one 72 weeks). He lived with his youngest daughter. He had experienced both impairment effects prior to diagnosis and experienced a range of debilitating treatment effects. He had attained SVR at the time of interview but still experienced post treatment effects and was unable to work - though prior to being made redundant his employer had made adjustments to enable him to work from home. Keith was diagnosed with hepatitis C after he was diagnosed with Diabetes.

Boab was 51. He lives in a small rural community with his wife and son. Boab contracted hepatitis C following a blood transfusion in the 1970s. He described repeatedly visiting his GP for a period of eight to ten years prior to diagnosis, eventually being diagnosed during a consultation for an additional impairment. Boab ceased treatment due to treatment failure, but reported severe impairment effects. Whilst he described initial relief at not having to continue with the treatment, he was concerned about his future health. Boab worked in a local factory and was the union representative.

Steve was 51 and to his knowledge had hepatitis C for 31 years. He was not sure how he contracted it but had experimented with injecting drugs in the 1970s. He was diagnosed in late 2000s after visiting his GP with a number of health issues. He had finished 24 weeks of treatment and at the time of interview was waiting to see if he had attained SVR. Steve described severe treatment and post treatment effects. He described stopping work prior to beginning treatment due to impairment effects. He was supported by his wife and children during treatment and had recently become a grandfather. Steve has since cleared the virus.

Chapter Two: Crafting hepatitis C realities in policy and social research

Introduction

This chapter introduces the hepatitis C social research literature. It begins by outlining prevalence rates, transmission routes and current understandings of disease progression and impairment effects.[2] The purpose of the literature review is to outline how hepatitis C and the realities of living with it, have been constituted and enacted in the literature to date, and to briefly explore some of the material consequences of this. Although academic research literature comprises the majority of the material reviewed, government policy and organisational reports are included where appropriate, for the insights they can provide regarding the UK context.

The main body of the literature review addresses participants' experiences of living with hepatitis C. These sections explore the themes of diagnosis, disclosure, support and information needs, knowledge and awareness, treatment experiences and developments, the role of professionals and the financial and employment implications.

The last section of the literature review, introduces the disability studies literature relevant to the thesis, highlighting the interconnection between cultural beliefs around disease and disability, stigma and disablism.

The structure of the thesis and the weaving of academic literature throughout the data chapters make the intra- active nature of the findings and the far reaching impact of living

---

[2] As will be explored below, I use the term 'impairment effects' from the work of Carol Thomas (2007; 136) which refers to 'restrictions of bodily activity and behaviour that are *directly attributable* to bodily variations designated 'impairments' rather than *those imposed upon people because* they have designated impairments (disablism)' (emphasis in original text).

with hepatitis C, visible. Thus some sections of the literature review are shorter than others and links to other chapters are appropriately signposted throughout.

The review mainly draws upon literature from Anglophone countries, including the UK, Republic of Ireland, Canada and the United States. Much of the social research literature is drawn from an Australian and New Zealand context, particularly from the National Centre of HIV and Social Research at the University of New South Wales, where social research interest in hepatitis C has been nurtured and expanded over the past decade. This significant body of social research has inspired and influenced my own work; contributing to a hepatitis C *hinterland* (Law, 2004) which opens up space for a discussion of issues beyond those currently focused on in academic literature and policy the UK, enacting hepatitis C as phenomena with far-reaching social and material consequences.

The dearth of social research

Research around hepatitis C has historically focused on clinical and medical aspects, including epidemiology (Shepard *et al.*, 2005; Aceijas and Rhodes, 2007; Nelson *et al.*, 2011) characteristics of the virus and its progression, (Freeman *et al.*, 2001; Forton *et al.*, 2001; Seeff, 2002) transmission routes (Macdonald *et al.*, 1996; McMenamin *et al.*, 2008; Aaron *et al.*, 2008; Doerrbacker *et al.*, 2011; Jafari *et al.*, 2012) treatment options and contra-indications (Heathcote and Main, 2005; McHutchinson *et al.*, 2009), including - as this thesis has been written - the increasing momentum of clinical trials[3] and the development of new treatments (Pockros, 2010; Kowdley *et al.*, 2013; Stedman, 2013). This clinical focus and the accompanying lack of research into the social aspects of living with hepatitis C (Hopwood

---

[3] Although it is important to note that some recent studies have combined both social and clinical aspects. For example, Maher *et al.* (2010a) who in seeking to understand motivations and barriers to participating in vaccine trials for people who inject drugs, point to the need for an understanding of social research in clinical trials from the start. Maher *et al.*,(2010b) also use the current emphasis on and privilege of biomedicine in order to reassert the importance of developing a safe and effective vaccine – emphasising the limited effectiveness of harm reduction initiatives in reducing hepatitis C infection rates.

and Southgate, 2003) from the perspective of those living with the illness, has been noted in the literature (see for example, Copeland, 2004; Crockett and Gifford, 2004; Conrad *et al.*, 2006; Butt *et al.*, 2008a; 2008b; Winter *et al.*, 2008; Harris, 2009a). There is a startling lack of attention to the experience of living with hepatitis C within the UK and the nuances and differences in policy response and services that this entails.

The thesis is informed by ideas arising from an emergent body of work (Fraser and valentine, 2008; Fraser, 2011; Fraser and Moore, 2011; Fraser and Seear, 2011; Fraser, 2012) which explores hepatitis C by drawing on insights from science and technology studies - explored in greater detail in chapter three and in the findings chapters. The thesis utilises this work to explore how hepatitis C is enacted and materialised when it is no longer assumed to be a fixed pre-existing entity, but is constituted as it comes into contact with other phenomena, shaped by social political and cultural forces (Fraser, 2011) and is understood as a socio-political entity as well as a medico-scientific one (Korner and Treloar, 2006: 16). The thesis also draws on insights from disability studies, (a brief introduction to which is provided below and elaborated on throughout the thesis) and explores aspects of recent developments in social policy in Britain and the impact this has on the lives of people with hepatitis C.

Although this may seem haphazard, it should be viewed as a materialisation of the wide ranging and varied impact of hepatitis C on the lives of participants in this study. In reviewing the literature, the crafting of hepatitis C realities (i.e. the current dominance of medical focus and medical treatment) is made visible and space is opened up for the new contributions to knowledge made by the findings chapters.

The basics of hepatitis C

Hepatitis C is a virus which, when enacted in medical terms, predominantly affects the liver (Foster, 2008). It is spread through blood to blood contact, was 'identified' in 1989 and has been shown to account for most cases previously referred to as 'non A non B hepatitis' (NANBH) (Department of Health (DH), 2002a). Infection can be roughly divided into six major strains (genotypes). In the UK the most common genotypes are one and three (Health Protection Agency, 2012). Genotype is important in determining length[4] of treatment (Thein and Dore, 2009).

The majority of studies (including social research) begin by describing the prevalence and incidence of hepatitis C locally and globally, [see Crofts *et al.*, (1997); Glacken *et al.*, (2001); Crockett and Gifford, (2004); Gifford *et al.*, (2003; 2005); Ehsani *et al.*, (2006); Brener and Treloar, (2009); Swan *et al.*, (2010) for examples] indicating how many members of the population are affected. The World Health Organisation estimates that 150 million people live with chronic hepatitis C worldwide[5], with three to four million infections occurring each year (WHO, 2012). Within the UK, estimates of infection range between 250,000 (DH, 2009) and 500,000 (RCGP, 2007) people. The most recent Health Protection Agency (HPA) (2012) figures suggest that, at present, there are 216,000 people living with hepatitis C in the UK. Fraser and Seear (2011) indicate that the use of statistics in this way 'scales up' the interest in hepatitis C and highlights it as a problem which needs to be addressed. While this is vital, they maintain that this primarily enacts it as a 'public health' issue rather than one which affects *people.* The implications of this are discussed further below and in chapter seven.

---

[4] Since April 2013 genotype has also been used to determine treatment type (i.e triple therapy for those with genotype one)
[5] Though global estimates also vary from 180 million to 123 million (Treloar *et al.*, 2010a).

As the dominant mode of infection with hepatitis C in the UK is the sharing of equipment used to inject drugs, there has been an understandable academic focus on injecting drug use and the people who practice it, with a view to prevention of infection or facilitation into treatment and support. Studies have explored sharing behaviours among drug users (Craine et al., 2004; Taylor et al., 2004; Treloar et al., 2008), effective harm reduction interventions, knowledge and perceptions of hepatitis C (Doab et al., 2005; Roy et al., 2007; O'Brien et al., 2008; Jost et al., 2010) and its treatment among people who use drugs (Munoz-Plaza et al., 2008; Treloar and Holt, 2008;Hellard et al., 2009; Wilson and Bryant, 2010). There has also been a focus on the knowledge and attitudes of health professionals and those who work with injecting drug users around hepatitis C (Brener et al., 2007; Richmond et al., 2007; Resnick et al., 2012). More recently qualitative social research has focused on barriers to treatment for people who use drugs (Swan et al., 2010; Harris et al., 2012a) and developing models to encourage access to treatment (Harris et al., 2012a; Islam et al., 2012,). The feasibility of and views around the integration of hepatitis C treatment into methadone maintenance therapy services (Novick and Kreek, 2008; Treloar and Fraser, 2009; Wilson et al., 2010) have also been an area of interest.

The research emphasis on people who use drugs is undoubtedly vital in helping to bring their needs and experiences into focus, and in harnessing their expertise in prevention (Taylor et al., 2004; Harris et al., 2012b; Harris and Rhodes, 2012a; Harris and Rhodes, 2012b; Harris et al., 2013), support (Sylvestre and Zweben, 2007; Brener et al., 2013a; Brener et al., 2013b) and treatment (Swan et al., 2010; Harris et al., 2012a). However, it also potentially marginalises the support needs of those who are not currently using drugs, who may have been living with it for a long time and who may currently be perceived to be well supported by current models (ACMD, 2009).

The course of hepatitis C infection

As mentioned above, hepatitis C is a virus spread through blood to blood contact with a person living with the virus. Globally, the main route of infection is iatrogenic, through unscreened blood, blood products and reuse of medical equipment which has been inadequately sterilised (Alter, 2006). Prior to 1992, before blood products were effectively screened, some UK recipients acquired hepatitis C in this way (DH, 2002a), including those who underwent surgery, caesarean births, received blood transfusions and blood products used in the treatment of haemophilia (Archer *et al.*, 2009). In response, some services have been developed to provide support to people, who contracted hepatitis C iatrogenically, notably compensation from the Skipton Fund and the development of the Caxton Foundation. There are campaign groups who maintain these responses are inadequate (see Taintedblood, 2013).

At present in western countries, transmission most commonly occurs through the sharing of equipment during past or present injecting drug use, including needles used for injecting and associated paraphernalia - spoons, filters, tourniquets, water, water filters and containers, surfaces and cookers (Hagan *et al.*, 2001; Doerrbecker *et al.*, 2011; Doerrbecker *et al.*, 2013). People injecting performance enhancing drugs may also be exposed to hepatitis C (McVeigh *et al.*, 2003; Day *et al.*, 2008; Larance *et al*, 2008). Evans-Brown *et al.* (2009) also note sharing of equipment for the injection of Melanotan I and II (used mainly to tan the skin.) Injecting is not the only way hepatitis C can be transmitted, as there is a theoretical risk of transmission via sharing equipment used to inhale drugs (Aaron *et al.*, 2008). There is also potential for the transmission of HIV and hepatitis C through sharing of crack smoking tools, particularly homemade ones as the raw materials of these often cause sores or blisters around or inside the mouth, increasing the possibility of exposure to blood (Leonard *et al.*, 2008). As this thesis was being written up, attention has also turned to the increasing visibility of gay men who inject crystal meth, mephedrone and 'G' in a sexual context (NAT, 2013).

Increasingly men and women of south Asian origin are enacted as a group of people who may be an elevated possibility of contracting hepatitis C and of it having a greater impact on their health. In particular, those originating from Pakistan, Bangladesh and India (Uddin *et al.*, 2010). Mann *et al.* (2008:425) found that 'ethnic minority populations[6] living in England were more likely than white populations' to be admitted to hospital with severe liver disease or to die from it. The authors conclude that there are multiple reasons for this, including higher prevalence in countries of origin, not identifying as needing a test, living with hepatitis C for a longer period, and difficulty accessing healthcare and support. Of concern are the substantial proportion of those testing positive for hepatitis C via an oral swab who refused to re-attend for confirmatory testing or engage in services, despite efforts to make this as accessible as possible (i.e. by funding taxis or providing home visits) (Mann *et al.*, 2008). The needs of the South Asian population are an area requiring further research.

Other possible routes of transmission include unsterile tattooing and piercing (Jafari *et al.*, 2010) and perinatal transmission (McMenamin *et al.*, 2008). This is increased if the mother also lives with HIV (DH, 2004). Sexual transmission among heterosexual couples is possible, but a recent study by Terrault *et al.* (2013) found that it was so infrequent that it was not necessary to change advice to people with hepatitis C, regarding sexual transmission.

Here, identifying routes of transmission is done for the sake of clarity. It is not my intention to create divisions between groups, or to suggest that the communities described above are singular and discrete. Indeed, this type of division or one dimensional representation is untenable (see Ellard, 2007). Yee *et al.* (2001) also found that many who were diagnosed with hepatitis C had experienced multiple opportunities for infection and concluded that it would be difficult to isolate how someone has contracted hepatitis C - in particular to separate out those who *had definitely* contracted it via injecting drug use. Despite this,

---

[6] People who identified as Pakistani, Bangladeshi, Indian Chinese, Other or Mixed heritage.

Grogan and Timmins (2010) note that injecting drug use has been used to inform (an admittedly limited) response in policy and service development. The focus on drug users has led to hepatitis C being confounded with drug use (Hopwood and Treloar, 2003) particularly injecting drug use (Harris, 2005). This association has serious social and material consequences for those living with hepatitis C.

The profile of hepatitis C

Despite the numbers of people living with hepatitis C in the UK, only 5% of between 200,000 and 500,000 people are believed to have been diagnosed (Frazer *et al.*, 2011b). Public and professional awareness and knowledge related to the virus has historically been low - both in the UK (Copeland, 2004; Rhodes Davis and Martin, 2004; APPGH, 2006) and across the globe (Treloar *et al.*, 2002; Van De Mortel, 2002; Van De Mortel 2003; Zickmund *et al.*, 2004; Gupta *et al.*, 2006). Hepatitis C is thus termed the 'silent epidemic' (Grow and Christopher, 2008).

Public awareness

Hepatitis C has been characterised by uncertainty and confusion since it was first 'identified', particularly around methods of transmission and the long term implications for health and wellbeing (Hopwood and Treloar, 2003). Existing literature shows confusion regarding the different types of hepatitis, transmission routes and treatment options, among those who used drugs. Ellard's participants (2007) described poor or partial understanding of hepatitis C. Davis and Rhodes (2004) found that people who used drugs made sense of hepatitis C in relation to HIV (returned to below) and a recent study by Treloar *et al.* (2011) found that misconceptions prevailed concerning the availability and eligibility for treatment.

Levels of knowledge among the general public have also been found to be poor. In 2002, a French street survey found that participants confused hepatitis C with HIV/AIDS and had poor levels of knowledge concerning the availability of vaccination and transmission via

casual contact (Munoz-Sastre *et al.*, 2002). A more recent survey commissioned by the Department of Health (Drugscope, 2009) found that a third of the people questioned in the UK were not aware of the major transmission routes for hepatitis C. The survey of 1500 people, found that one in four were unaware that it could be transmitted by sharing a needle, with four in ten unaware of its blood borne nature and one in eight believing it could be passed on through kissing. Crutzen and Goritz (2012) explored levels of knowledge around hepatitis A, B and C in The Netherlands and Germany, and found there was a dearth of practical knowledge in terms of prevention of transmission and vaccination. There is also evidence to suggest that despite concerted efforts in Australia, there is still work to do; Hopwood *et al.*, (2012) surveyed University students in Australia and found that although knowledge around transmission of viral hepatitis C was relatively high; students had poor knowledge regarding treatment options or vaccination.

Professional awareness

In the literature, professionals also show differing levels of awareness and expertise. Van de Mortel (2002; 2003), in her survey of Australian nurses, found that questions around transmission were incorrectly answered by most participants and the risk of infection was overestimated, leading to possible negative treatment of patients with hepatitis C. Dentists in Temple-Smith's (2006) study described feeling concerned about transmission, even if they were well informed and sometimes taking unnecessary precautions such as avoiding treating people with the virus or double gloving (see also Richmond *et al.*, 2007). Clearly there is some overlap here between knowledge and beliefs and discriminatory treatment.

Frazer *et al.* (2011b) in their survey of Irish nurses' knowledge, found it was much higher among nurses working in drug services, compared with those working in general nursing or practice nursing. Nurses working in substance use services were more likely to have attended an educational course on hepatitis C and exhibited higher levels of awareness

concerning vaccination availability and treatment options. Whilst this is perhaps not surprising, Frazer *et al.* (2011b) discuss the importance of extending education and support beyond substance use services and into more general settings, stating that professionals do, and will increasingly, come into contact with patients with hepatitis C .

Awareness campaigns

In England, the lack of awareness and knowledge has been connected to inadequate funding, provision and development of hepatitis C services (Copeland, 2004; APPGH, 2006; Agarwal *et al.*, 2007; Frazer *et al*, 2011b). The lethargic response to raising awareness has been attributed to the link between injecting drug use and hepatitis C, (Crofts *et al.*, 1997; Treloar *et al.*, 2002) as well as its historical position in relation to HIV and the long term ('less visible') nature of the effects of living with the virus. Ehsahni *et al.* (2006) have pointed to the limited political interest around people with hepatitis C. It may also be that awareness remains low for more insidious reasons, given that there is evidence to suggest that in the event of a concerted national effort, the amount of people coming forward may be too great for services to manage (Orgel *et al.*, 2005). There are already reports of services being overstretched with delays to beginning treatment (Agarwal, *et al.*, 2007; The Hepatitis C Trust, 2013c). Successive governments have failed to respond adequately to hepatitis C, including addressing serious structural problems, such as resource allocation and lack of awareness and policy direction (McKeown and Gibson, 2007). This is on-going, with the recent abandonment of the national liver disease strategy (LJWG, 2013) and increasing concerns around the costs of new drugs (Knox, 2013; Tucker, 2013).

Scotland is the only UK country to have begun to adequately address hepatitis C, allocating funding for capacity building of staff and education of professionals, as well as investment in developing services and strategies covering specific time periods in which to make progress (Scottish Government, 2008; Scottish Executive, 2006; Scottish Government, 2011).

However, the difficulties in raising awareness must be acknowledged. Hepatitis C affects a wide variety of people both within and outside of mainstream services (for example: drug services and GPs). Ellard (2007) points to the need for education to be delivered broadly and in a multitude of ways, particularly among those who may not perceive themselves to be at risk. In 2007, the All Party Parliamentary Group on Hepatology explored ways of raising awareness based on existing national public health campaigns. They concluded that campaigns need to be long term, maintain momentum and use a variety of media outlets. Indeed, the report concluded that the most effective campaigns were those developed by Cancer Research UK.

Smith *et al.* (2006), in their evaluation of an Australian mass media campaign, indicated that the use of television advertisements was particularly useful in facilitating calls to the local hepatitis C information centres[7]. The authors indicate that the campaign was particularly valuable in showing that hepatitis C is not just confined to one small segment of the population, and emphasised that increased funding from public health is required. Study participants reported increased knowledge with regard to transmission routes and a key finding was that the involvement of people with hepatitis C was necessary for changing attitudes and beliefs (also reported by Hopwood and Treloar, 2004). In an American study where participants of local support groups evaluated public service announcements about hepatitis C, Grow and Christopher (2008) found that stigma and structural barriers inhibited health promotion and awareness messages. Participants stated that to be effective, messages must be liked; they must feel new, relevant, encouraging and positive. Fear based campaigns have the potential to stigmatise and discourage people from being tested (see Slavin, 2006). Grow and Christopher (2008) indicate that structural barriers must be addressed, such as lack of information, or difficulties in accessing services.

---

[7] Though a key problem is that local information centres do not exist in the same way in the UK.

Increased education and awareness has continued to comprise a key recommendation across studies (Swan *et al.*, 2010). Treloar *et al.*, (2011) have emphasised that hepatitis C prevention lacks urgency, meaning that prevention and support services are politically vulnerable to funding cuts.

Living with hepatitis C

Ten years ago Hopwood and Southgate (2003; 251) called for an 'expanded sociocultural understanding of hepatitis C to account for the material effects of medicalisation, stigmatisation and discrimination and the sociocultural impact of treatment on the lives of people with hepatitis C.' Whilst progress has been made in Australia, qualitative exploration of people living with hepatitis C is lacking in the UK and is where this thesis provides important insights. The next section of the literature review explores the everyday experience of living with hepatitis C.

Diagnosis

Guidance from the National Institute for Clinical Excellence[8] (NICE) (2012c) estimates that 95,000 people had been diagnosed with hepatitis C in England by the end of 2011, which means a significant number remain undiagnosed. Increasing the number of people diagnosed with hepatitis C and raising awareness in order to promote testing and support has comprised a key element of UK policy (DH, 2002a, 2004; Scottish Executive, 2006; Department of Health, Social Services and Public Safety, 2007; The Scottish Government, 2008; Welsh Assembly Government, 2010; Scottish Government, 2011 HPA, 2012, NICE, 2012c).

---

[8] From 1st April 2013 NICE was renamed the National Institute for Health and Care Excellence, following the introduction of the Health and Social Care Act 2013.

Hepatitis C status is determined by an initial test to detect the presence of exposure antibodies in the blood. A confirmation blood test then determines whether the virus is currently present and replicating - and in what quantity (Klapper, 2009). Testing rates may be increased through the use of dried blood spot testing or oral swab testing, due to the speed and lack of need for venepuncture (White *et al.*, 2008). Efforts to increase testing both among people who use drugs and the general population, include dedicated drives in local communities (Uddin *et al.*, 2010; Readhead *et al.*, 2012) and the successful piloting of oral testing (with results available in 30 minutes). This is done in non-clinical settings by key workers in regular contact with people who attend substance use services (Evans *et al.*, 2012). Testing facilitated by peers is also described in the literature (Aitken *et al.*, 2002). As this thesis was being written up, calls have been made for rapid testing, particularly dried blood spot and point of care testing (Shivkumar *et al.*, 2012) to be made available in as many venues as possible, including primary care and drug services (LJWG, 2011) sexual health services, prisons and young offenders institutions (NICE, 2012c), and community pharmacies (Watson *et al.*, 2003; The Hepatitis C Trust, 2010a).

The experience of diagnosis is one of the more developed areas of social research in relation to hepatitis C, though the empirical literature exploring the experience of diagnosis centres around the early 2000s (Glacken *et al.*, 2001; Dunne and Quayle, 2001; Dunne and Quayle 2002; Hopwood and Treloar 2003; Davis and Rhodes, 2004; Hopwood and Treloar 2004). This opens up a space to explore more recent experiences of diagnosis, particularly in England.

The experience of diagnosis

The lack of awareness and the confusion attached to hepatitis C, has meant that diagnosis is frequently described as difficult or unexpected (Harris, 2009b). Participants reported feeling shock, disbelief, fear and anxiety about the future (Glacken *et al.*, 2001; Tompkins *et al.*, 2005; Sgorbini *et al.*, 2009; Stewart *et al.*, 2012). In Pakistan, Gill *et al.* (2005) found

participants described the diagnosis as more stressful than divorce, moving house or a loss of income. 16% (15 participants) of the sample reported anxiety severe enough to warrant a referral to psychological support. Faye and Irurita (2003) described this is terms of being 'contaminated or condemned' and similar feelings were reported by participants in Fraser and Treloar's (2006) study (six of 38 participants) who used the words 'dirty' and 'totally contaminated' to describe their feelings.

Others have emphasised the contextual nature of diagnosis. Sutton and Treloar (2007) found that reactions to diagnosis among 36 people living with hepatitis C in Australia ranged from having no real impact to being a life changing event. Some felt that it was an inevitable part of being an injecting drug user (consistent with Rhodes Davis and Martin's (2004) study in the UK), or of little consequence, either because they had grown up with it or it had no visible effects.

In Harris's (2009b) qualitative exploration of diagnosis, her sample was almost evenly split between those who described it as 'devastating' and those who felt it was 'no big deal'. Harris (2009b) states diagnosis is understood and intertwined with bodily, structural and cultural responses[9].

Preparation for diagnosis

Fry and Bates (2012), in their exploration of the experience of diagnosis in Australia, found that it was experienced as more difficult if preparation for the diagnosis or the delivery of the results were insensitive or inappropriate to participant needs. The need for clear pre and post-test information during a hepatitis C test has been repeatedly emphasised, and guidance has been enhanced over the years to incorporate tailored information appropriate to literacy levels, culture and need (Department of Health, 2004; Royal College of GPs 2007;

---

[9] This reminds me of Oliver's (1990) observations that impairment does not carry intrinsic meaning or negativity, but depends on social contexts or community responses.

NICE, 2012c). NICE (2012c) emphasises the need for clear explanation of infection implications and transmission routes, treatment options and exploration of support networks, as well as adequate explanation of the testing process and gathering informed consent. Results should be provided by the same person who delivered the test in a face to face consultation. Written information should be provided, along with referral to further support. The guidance produced by the RCGP (2007) elaborates on the types of information which should be provided both pre and post-test, extending to the provision of emotional support, on-going counselling and/or mental health support.

However, the experience of diagnosis has frequently been described in the literature as poor and in need of urgent improvement. Hopwood and Treloar (2003, 2004) in their exploration of diagnosis using both surveys (504 responses) and in depth interviews (19), found that the majority of participants were given their diagnosis of hepatitis C by a doctor, but that one third (123) of the sample felt that they had had no explanation of what the diagnosis meant and only 27.8% (116/417) felt that they had been provided with all the information they needed. 137 (32.8%) participants diagnosed between 1989 and 2001 had received *no information* regarding conventional or alternative treatments, counselling or referral to further information or support services; the year of diagnosis did not affect the amount of support provided.

This has been echoed in the work of Gifford *et al.* (2005) who found that few of the men who completed their questionnaire (308) reported receiving either pre or post-test discussion (although this data was collected in 2000). Gifford *et al.* (2005) also found that few members of the sample were provided with referral to a specialist or liver clinic (30%), and only 26% were referred to a support group. Pre and post-test counselling was also rare for women in the female arm of the study (Gifford *et al.*, 2003). Only 17% of the sample received pre-test

counselling and 4% post-test. The likelihood of receiving post-test counselling was associated with a later diagnosis.

In the UK, Davis and Rhodes (2004) described participants being diagnosed in a way which devalued and trivialised hepatitis C, and experienced 'blasé' responses from workers who did not acknowledge the seriousness and the impact on the person's life. A similar finding was also reported by Tompkins *et al.* (2005) in their study of the experience among homeless people in the UK. Harris (2009b) describes how this kind of response from professionals, can reinforce the belief that hepatitis C diagnosis is unimportant and nothing to be concerned about - affecting engagement with services and support as well as personal beliefs about self-worth - see below.

As outlined above, the lack of information and referral to support or specialists, raised specific issues around telling others about the infection, which the next section focuses on.

Disclosure to others

There is no legal requirement to disclose hepatitis C positive status in the UK, other than if employment involves a blood to blood contact element[10]. Despite this, disclosure constitutes a serious issue for people living with hepatitis C and is often a precursor to poor treatment and discrimination (Hopwood and Treloar, 2003; Conrad *et al.*, 2006). The decision to disclose often involves the weighing up of costs and benefits, opening up the possibility of accessing support but also risking negative reactions from others. In this thesis the process of disclosure is examined using both hepatitis C literature and literature from disability studies.

---

[10] The complexities around the issues of transmission and 'infectiousness' are enacted in the recent modernisation of the rules allowing HIV positive healthcare workers to carry out dental and surgical procedures which they had previously been barred from (DH, 2013) – despite no evidence of anyone ever contracting HIV from a healthcare worker in the UK. Less than a month later, in September 2013, the Aneurin Bevan Health Board in Wales announced that a 'look back' exercise has been launched after a retired healthcare worker who treated patients in Wales between 1984-2003, was diagnosed with hepatitis C. Two patients have subsequently been diagnosed with hepatitis C.

The vague and 'asymptomatic' nature of hepatitis C related illness, and the accompanying lack of visibility, has been recognised as providing people living with hepatitis C with a choice about whether or not to disclose their status (Fry and Bates, 2012).

Participants in Hopwood and Treloar's (2004) research maintained that they disclosed because they felt it was the 'right thing', part of being in a mutually respectful relationship with a health care professional. Conrad *et al*. (2006) found participants disclosed to promote trust or because they felt obligated to, though they often received poor treatment as a result. Hopwood *et al*. (2010) described participants feeling judged or pressured to disclose in healthcare settings, particularly when infection control precautions were not universally applied by health care staff. Other participants in the same study described having their hepatitis C status disclosed to someone else without their consent. This negative treatment proved to be counterproductive. Both Hopwood and Treloar (2004) and Hopwood *et al*. (2010) found a number of participants reported that they were less likely to disclose in the future, due to fear of negative reactions, which in turn acted as a barrier to receiving care and treatment.

Similarly, Blasiole *et al*. (2006) found that one fifth of the people interviewed did not disclose to anyone in order to avoid negative reactions and Schaefer *et al*. (2005) found that 25% of 103 people with hepatitis C surveyed, preferred not to disclose due to fear of being rejected or treated negatively. Participants in Sgorbini *et al's.,* (2009) study stated that they preferred to keep their status to themselves, as they were concerned they would be questioned about how it was acquired.

To avoid being viewed negatively, Conrad *et al*.'s (2006) participants developed strategies for disclosing their status. Those who had contracted hepatitis C iatrogenically, accompanied the disclosure of status with an explanation. These participants reportedly found it easier to disclose. However, the association of hepatitis C with injecting drug use, and the tendency to

overestimate the risk of potential infection, meant that negative reactions and experiences were not necessarily avoided.

In their exploration of how people with hepatitis C tell others about their status, Hopwood *et al.*,(2006) described four main strategies: non-disclosure (not telling anyone), strategic disclosure (disclosing only to those who are trusted), substitute disclosure (disclosing 'liver disease' or something similar) and open disclosure. Substitute disclosure in particular was helpful in explaining the visible impact on participant health in interactions with others, without the possibility of experiencing negative reactions.

Treatment for Hepatitis C

The previous sections provided an introduction to hepatitis C and engaged with diagnosis and disclosure literature. The next part of the review addresses the main response to hepatitis C; medical treatment. There is currently no vaccine for hepatitis C, though these are currently being developed and trialled (Halliday *et al.*, 2011). At the time data was generated, the recommended treatment for all genotypes of hepatitis C was a combination of Interferon[11] (injected once per week) with twice daily oral Ribavirin[12] (NICE, 2006). Combination therapy has a sustained virological response (SVR) rates of 50% and 80% depending on genotype and medical literature has pointed to the value of treatment even without SVR, as treatment can inhibit the progress of the virus (Gow and Mutimer, 2001). For those with genotype 2 or 3, hepatitis C treatment lasts for 24 weeks. For people living with genotype one, 48 weeks of treatment are recommended. Patients can be said to have

---

[11] Interferons are viral proteins which occur in the body and work to stop viruses from replicating and stimulate immune response. Pegylated interferon are chemically modified versions of interferon which increase the amount of time the interferon is effective within the body, requiring only one injection per week (Sgorbini *et al.*, 2009).

[12] Ribavirin is not fully understood, but when used in combination with interferon as oral anti-viral medication, it increases treatment effectiveness (Sgorbini *et al.*, 2009).

'cleared the virus' if they achieve a sustained viral response rate 24 weeks following the end of treatment (NICE, 2006).

In the existing literature, the effectiveness of treatment responses shift in line with the specific realities being enacted. For example, Grogan and Timmins (2010: 2869) indicate that hepatitis C 'treatment success rates are high', where Murphy (2011) and Fraser and Seear (2011) point to the 'limited' effectiveness of treatment. Here hepatitis C treatment *becomes* different things depending on the reality being enacted; in Grogan and Timmins' (2010) study to shore up the role of the hepatitis C specialist nurse and the need for increased services, and in Fraser and Seear's case (2011), to point to the dominant response of medicine.

Here hepatitis C treatment as 'multiple' (Mol, 2002, Law, 2004) is made visible. Clearly I too have participated in enacting a specific reality for the purposes of this literature review and this thesis, and in doing so, have paid attention to the realities enacted and the political and material consequences - discussed further in chapter three and throughout.

At present, both in the UK and globally, treatment uptake is low (Fry and Bates, 2012; Harris *et al.*, 2013). Recent reports from the Health Protection Agency (2012) state that only 3% of those with hepatitis C in the UK are currently accessing treatment, in spite of the recommendations from NICE (2006) that drug use should not act as a barrier to treatment. Thus for many, hepatitis C is experienced as a long term condition.

This makes the sample of participants in this research (all of whom underwent treatment) well placed to understand the impact of treatment, as well as the everyday experience of living with the virus. Participants reported no (longer participating in) injecting drug use, were housed, maintained regular contact with health professionals and adhered to treatment. They would thus appear to be well served by the current system. The findings contained within this thesis suggest that this is not the case.

As is explored in greater depth in chapter seven, hepatitis C treatment has been documented as extremely difficult to tolerate and described as being worse than living with hepatitis C (Jenner and Scott, 2008). Emphasis is made within the literature of the variable and unpredictable nature of impairment effects and side effects (Fraenkel *et al.*, 2006; Hopwood *et al.*, 2006; Treloar and Sutton, 2007; Harris *et al.*, 2012a).

Existing qualitative literature describes a significant and diverse range of experiences of treatment, and indicates that treatment effects have a significant impact on everyday life – physically, psychologically and socially (Hopwood *et al.*, 2006; Sgorbini *et al.*, 2009). Participants in Fraenkel *et al.*'s study (2006) indicated that the difficulties they experienced on treatment, both in severity and unpredictability of effects (severe cognitive impairment, difficulties in eating and insomnia), meant they felt underprepared to manage it. Further to this, the lack of information concerning side effects made it difficult for them to seek support. Some were able to develop a routine on treatment, others referred to the unpredictability of the side effects which made it difficult to manage work and social commitments (Sgorbini *et al.*, 2009).

Professionals interviewed as part of an Australian study into participant support needs, indicated that needs on treatment varied from week to week, with some participants requiring intensive support and a weekly check in with the specialist nurse, whilst others required far less (Hopwood *et al.*, 2006). The support and information needs of participants in this study and the implications are addressed in chapter seven.

In addressing the effects of the treatment, participants reported relying on a combination of medical support, such as ancillary medicines (Hopwood and Treloar, 2005; Hopwood *et al.*, 2006) or self-management. Hopwood and Treloar (2005) found participants developed coping strategies which were outside the realm of medicine, such as organising childcare or giving up work, though clearly this depends on having the financial resources to be able to

do so. Swan *et al.* (2010), in a Northern Irish study, indicated that participants required practical forms of support, such as childcare provision and help to facilitate work and study. Close relationships with family and friends were acknowledged both as a vital source of support (Hopwood *et al.*, 2006) and a key factor in pursuing treatment (McNally *et al.*, 2004, Wilson *et al.*,2010), but were often placed under extreme pressure whilst participants lived with the virus or undertook treatment. Participants described feeling that they had to shield family members from worry or felt guilty that they could not participate in family life to the same degree (Dunne and Quayle, 2001; Sgorbini *et al.*, 2009).

New treatments; new enactments of hepatitis C

The time period during which this thesis was written proved to be one of particularly fertile development of hepatitis C treatments. In April 2012, two direct acting antivirals, Bocepravir and Telapravir (hereafter referred to as DAAs), were approved by NICE (2012a; 2012b), after a decade of only one form of treatment. These direct acting antiviral agents are taken in combination with Ribavirin and Interferon (referred to as triple therapy) for those with genotype one. Bocepravir and Telapravir whilst providing increased cure rates for people with genotype one, do have side effects which compound those occurring in combination therapy. Other direct acting antivirals are currently in late stage trials, including interferon-free combinations, which may reduce both side effects and treatment duration. Some treatments are for specific genotypes whilst others are intended for people with all genotypes of hepatitis C (Stedman, 2013). Studies have an increasingly optimistic tone (for example, Kowdley *et al.*, 2013), although given that some studies with interferon showed that combination treatment was approximately 20% less effective in real life settings than in clinical trials (Kramer *et al.*, 2012), and phase three trials can involve highly selected subsets of patients, some caution is necessary. A fuller explanation of the different combinations and

their effectiveness and impact is beyond the scope of this thesis, particularly given the rapid changes – but is clearly an area for further research.

At present this major focus on new drugs and the focus on increasing effectiveness enact hepatitis C and its treatments in specific ways. For example, Chung (2011) describes the present as a 'watershed moment' and 'treatment revolution'. Others refer to a 'new era' of treatment (Jensen *et al.*, 2011) and the 'final nail in the coffin' for hepatitis C (Manns and Cornberg, 2013). This is part of the rhetoric around scientific progress explored by Fraser and Seear (2011) and the heroics of medicine, which overlook the difficulties in terms of access to treatment.

In addition, newer treatments are likely to be more expensive (Rice, 2011), raising issues for already stretched hospital budgets (Swan, 2013). This issue takes on additional importance given a recent report which found that usage of even NICE approved medication within the NHS was one of the lowest in Europe[13] (Stephens, 2012); raising questions about the consequences that re-organisation of and cuts to, the NHS will have for new treatment. Further, Rice (2011) estimates that it will be five years before interferon and ribavirin free treatments reach the hospitals as they still need to be tested among diverse groups. Here, new hepatitis C treatments will intra-act with political and social conditions to enact and materialise the experience of living with hepatitis C in new ways.

It is also important to note that with the focus on increasing effectiveness, the approval of new treatments with potentially reduced side effects (interferon free treatments) and shorter treatment duration, there is a danger that hepatitis C will be seen as increasingly transient or (even more) unimportant. Living with hepatitis C may be increasingly enacted as temporary, overlooking issues such as access to treatment, the needs of those for whom treatment does not work, and of those for whom hepatitis C exacerbates other

---

[13] For impairments including hepatitis C, intractable Asthma and Eczema, as well as therapy for specific forms of cancer - a significant finding in the context of the discussion in chapter six.

impairments/disablism. In addition, it marginalises the need for help for those on treatment *at the moment*, and potentially negates against taking action to provide support.

Dominance of a medical response

It has been recognised that living with hepatitis C poses a range of issues across social, reproductive, physical, psychological and emotional areas, requiring international and interdisciplinary research (Banwell *et al.*, 2005; Stewart *et al.*, 2012). Despite this, medicine has provided the overwhelming response to hepatitis C.

In qualitative interviews with Australian Hospital consultants, Teague *et al.* (1999) found that views on the support needs of people with hepatitis C were varied. Although some consultants were open to working with support groups and hepatitis C councils, they were unclear about the aim and function of these groups. Others described a reluctance to refer to support services, not understanding why anything other than medical support would be required. Whilst these findings could be attributed to the timing of this study (it being one of the earliest qualitative investigations), there is evidence that this focus on medicine at the expense of other aspects persists.

Critiques come from both within and outside medicine. Nursing scholars Paterson *et al.* (2006) note that support offered to those living with hepatitis C centres on inhibiting the progression of virus and liver disease alone, rather than exploring other dimensions of experience (see also Sgorbini *et al.*, 2009). Participants reported being given advice which fitted poorly with the context of their own lives (for example, being advised to take bed rest when they were the sole wage earner in their household) - with one participant stating that the consultant 'only cares about my liver' (p.217). Here I am reminded of an observation made in Oliver (1990), who indicates that medicine is indeed important and helpful, but that 'the problem…is that medical people tend to see all difficulties from the perspective of

proposed treatments for a patient without recognising that the individual has to weigh up whether treatment fits the overall economy of their life' (Brisenden 1986, cited in Oliver, 1990: 5).

In a rare UK based study, nurse researchers Grundy and Beeching (2004) lend support to the observation that the UK medical system concentrates on medical aspects of experiences during appointments at the expense of wider issues, constituting and re-constituting the power of medicine.

Similar findings have been reported by New Zealand Sociologist Harris (2005), who herself lived with hepatitis C, indicated that if participants could not tolerate treatment, or did not wish to undertake it, there was very little that could be offered. Others have since described only a partial fit between what medical markers (i.e. liver function tests, viral loads) indicate about participant illness and the forms of support they need (Sutton and Treloar, 2007), and this is particularly the case with regard to post treatment (Paterson *et al.*, 2006) - discussed in chapter eight. Most recently, Harris *et al.* (2012a) has highlighted the medical focus, noting that of 44 of 53 EU countries who responded to a survey for World Hepatitis Day, 68% reported a care pathway – though for many, this only consisted of referral to a specialist or hospital.

Hepworth and Krug (1999) indicate that in times of uncertainty, medicalisation can be important in helping people make sense of their lives and their illness (cf. Jenner and Scott, 2008). Wendell (1996:123, 2006) notes that medicine has a cognitive authority to define 'valid' impairments. This means that they come to understand it in particular ways and which potentially marginalises their experiences (what Wendell refers to as 'epistemic invalidation'), as well as cultural and social implications (and the accompanying support) (Hopwood and Southgate, 2003). Jenner and Scott (2008) note the certainty offered by medicine in existing literature (which their findings refute). As discussed in chapters seven

and eight, for participants in this study, treatment offered more uncertainty even when SVR was obtained.

Whilst medical knowledge is important, it is not the only basis on which individuals act. Aspects of life affected by hepatitis C include work, family, relationships, friends and participants' understanding of themselves, and there are increasing calls for models of support to account for this (Harris, 2005; Sutton and Treloar, 2007; Murphy and Fitzpatrick, 2011). This thesis makes an important contribution in exploring the experiences of living with hepatitis C and treatment in the UK, and looking both at and beyond medicine to see which other forms of support are necessary.

Professional Support

In the UK, the key role of professionals in supporting and treating those who have, or may contract, hepatitis C has been acknowledged in all action plans (DH, 2004; Scottish Executive, 2006; Department of Health, Social Services and Public Safety, 2007; The Scottish Government, 2008; Welsh Assembly Government, 2010; Scottish Government, 2011). In the UK, treatment is commonly delivered by a specialist hepatologist or gastroenterologist alongside a specialist nurse in a large hospital (Tait *et al.*, 2010). Patients attend weekly and then monthly appointments with the specialist nurse, and maintain contact until six months post treatment.

Ehsani *et al.* (2006) in their interviews with 14 key stakeholders of liver clinics in Victoria indicated that specialist hepatology nurses are crucial in improving treatment uptake and maintaining people on treatment. In the first study which explored patient perceptions of specialist nurses, Grogan and Timmins (2010) surveyed 106 patients in the Republic of Ireland, six months after treatment, concerning the care and support they had received. Whilst overall the cohort surveyed were very satisfied with their care, the authors

maintained that those with genotype one required greater support, including referral to support groups, help to manage side effects and provision of individually tailored support - though they do not make clear how this might look.

Interestingly, the authors link the need for increased support among those with genotype one, to method of transmission (from blood products) rather than the increased duration of treatment (48 weeks). This enacts those with hepatitis C contracted through blood products as requiring greater support and marginalises the impact of treatment for everyone. No referral is made in the study to multi-disciplinary support, and though Grogan and Timmins (2010) make reference to the need for psychological care, no specific forms are described.

The need for multi-disciplinary support in addressing the needs for those living with hepatitis C is acknowledged in UK policy. Welsh and Scottish Action Plans (Scottish Executive, 2006; Scottish Government 2008; Welsh Assembly Government, 2010; Scottish Government, 2011) outline how effective treatment provision requires collaboration between different agencies including primary care, social services, mental health, alcohol and other drug services, support groups and criminal justice agencies. They refer to clearly defined pathways of care decided at the local level, in order to make treatment accessible, minimise nonattendance and encourage adherence and completion.

The need for a multi-disciplinary response has also been described elsewhere, with Janke *et al*. (2008) indicating that 'wherever possible clinicians should seek to work with multidisciplinary teams or mental health care providers' (p. 499). In their study exploring pre-treatment preparation, Hopwood and Treloar (2007) describe treatment being managed within a multidisciplinary network, including specialists, nurses, psychiatrists and social workers. Sternhell *et al*. (2012) describe the successes of a multidisciplinary integrated support service for people living with hepatitis C and HIV who require mental health support in Australia. The service comprises of a clinical psychologist, psychiatrist and a clinical nurse

consultant, as well as an administrator, and the service liaises with the person's GP which reduces adverse events for patients. The need for professional support from counselling services has also been noted, as has the inconsistency in availability of services depending on where a person lives (Hopwood and Treloar, 2005).

Nursing scholar Jacqui Richmond (2008), writing in an Australian context, indicates that optimal care for people with hepatitis C involves a range of professionals, including: hepatologist, specialist nurses, GPs, counsellors, complementary and alternative therapists and pharmacists. Other professionals referred to by Ehsani *et al.* (2006) include drug and alcohol services, psychiatrists, social work staff and interpreters. Yet they also indicate that funding and resources are an issue for services - which at the time were delivered on an ad hoc basis. Stewart *et al.* (2012) also recognise funding constraints in provision of support and indicate that this might be remedied by provision of internet support services and by the expansion of existing hepatitis C services in Australia. The problem within the UK (particularly England) is that the same infrastructure of support does not exist. Sgorbini *et al.*'s (2009) participants suggested that due to the connection between hepatitis C and injecting drug use, there was far less support than if a person had a different chronic illness. The connection between negative beliefs and support provision is explored in greater depth in chapters six, seven and nine.

The emphasis on multi-disciplinary support here is not intended to 'scale up' (Fraser and Seear, 2011) responses to hepatitis C in a way which pathologises those living with the virus - not all people with hepatitis C will need access to a wide range of services, or indeed will require formal support. As Treloar *et al.* (2011: 400) state, 'assuming people of a disadvantaged group are deprived and debilitated, can do more harm than good. When working with people who inject drugs, it is important to recognise the impact that housing employment and social networks have on access to healthcare services. It is equally

important to recognise that for some, access to healthcare services is all they need and attempts to connect them to welfare services are misguided'.

Social Work support

The previous sections have explored the documented social issues and implications of living with hepatitis C (Crockett and Gifford, 2004), and the accompanying need for support. One particularly underexplored form of support for people with hepatitis C is that of social work, making it an important element of the thesis, revisited in chapter seven.

The absence of literature which explores in depth the role of social work in supporting people with hepatitis C has been noted (Paylor and Orgel, 2004; Paylor and Mack, 2010; Moulton, 2011). This is surprising given that explicit recognition of social work and social care in addressing hepatitis C is also present in policy and guidance. Both the Department of Health's (2002a;2004) Hepatitis C Strategy and Action Plan for England made reference to the provision of support and information, facilitating testing and support to children and families, and even the provision of Direct Payments to enable the provision of care, including a case study of a specialist hepatitis C social work role. In recent years, the Archer Inquiry (2009) into the needs of those who acquired hepatitis C from blood and blood products indicated that there may be a need for substantial input from social work including support for carers, access to financial support and homecare.

In spite of the clear recognition of the role of social workers, there is scant evidence that, this discussion and recommendations have been meaningfully engaged with in England (as the thesis explores). In 2004, Paylor and Orgel pointed to the need for social work to 'wake up' to hepatitis C and more recently, Mack (2007) and Paylor and Mack (2010) outlined the junctures at which social workers could raise the issue of, or become involved in, supporting people with hepatitis C.

The potential reasons for social work's limited engagement are numerous. It may be explained in significant part by the increasingly constrained resource and policy environments in which social workers are expected to function (Galvani, 2007) and even purposeful marginalisation of the issue, given the anticipated costs, both economically and in terms of social workers' time (Orgel et al., 2005). It may also be explained by social work's limited engagement with substance use in the UK, given that sharing injecting drug use equipment is a main route of transmission. People who use drugs require support from a range of services, including social work (Neale, 2008). Their needs cut across the range of social work teams and may be one of a number of interlinked issues (Keene, 2001). Despite this, there is a severe lack of specialised education on undergraduate, postgraduate and post qualifying education in social work (Galvani and Hughes, 2010, see also Natale et al., 2010). This means social workers lack knowledge and understanding about the effects of hepatitis C and the client groups it affects. This lack of attention to substance use (and hepatitis C) on the social work curriculum reinforces the perception of substance use (and blood borne viruses) as health issues, and sends a message about how concerned and involved social workers are expected to be (Galvani and Hughes, 2010).

In a recent mixed methods study involving surveys and focus groups with social workers from both children's and adult services, a key finding was that those working with adults (older people and disabled people in particular) felt uncomfortable or found it difficult to ask about substance use, and as a result rarely or never asked about it. This is important as it simultaneously reduces the opportunity to have a discussion about hepatitis C and other BBVs. Though social workers in children's services did feel that asking about substance use was in their remit, this often only occurred when the social worker perceived it was impacting on the parent's ability to fulfil social roles or caring responsibilities, when harm may have already occurred. Thus hepatitis C may go unnoticed and unsupported. Galvani et al. (2013) point out that talking about substance use maximises the opportunity to address it

and provide support. This is equally applicable to talking about hepatitis C. The lack of guidance exploring the role of social workers in relation to hepatitis C (a notable exception being Paylor, 2010) may mean that social workers are unsure when to raise the possibility of a test, the kinds of support and information they can provide or how to support people through treatment.

Although the two viruses have different social and material implications, given the dearth of available literature, it has been useful to extrapolate some findings from the HIV social work literature here. Social work has played a key role in prevention support and care of people with HIV over the last three decades globally (Natale *et al.*, 2010), and is involved in addressing a range of issues pertaining to diagnosis, treatment and everyday life with HIV. However, UK based social work academic Clarke (2012) also notes that disease progression and successes related to HIV are measured in medical terms, which may lead to the social circumstances being overlooked. Clarke (2012) emphasises the vital place of HIV on the social work curriculum, given that people affected by HIV may also be affected by a wide range of issues including drug use, loss and bereavement, migration and criminal justice - although she does not mention disability issues, an important omission in the context of this thesis. Clarke (2012) maintains that social workers should be equipped with knowledge around transmission and disease progression, treatment, loss, and pre and post-test counselling for HIV. She concludes by emphasising the need for expansion of this basic information onto social work degrees across the country. These findings could equally be applied to hepatitis C.

To date, only one in-depth empirical study explicitly exploring the role of social work for those with hepatitis C has been undertaken. Moulton (2011) interviewed 10 of the 15 specialist social workers attached to hepatitis C treatment centres in New South Wales, Australia, regarding their perspectives on the support needs of people on treatment, as well

as the skills, values and experiences required of the workers. Moulton (2011) found that client needs centred on information and support following diagnosis, identifying personal strengths and resources, support to access drug and alcohol services and to access and complete treatment. This study was from the perspectives of specialist social workers and this thesis makes an original and important contribution in exploring the extent of social work support available to the participants, as well as identifying the kinds of support required and the potential barriers to social work involvement (see chapter seven).

As was noted above, living with hepatitis C can have a serious impact on everyday life. Groessl *et al.* (2008) found that participants in their study had specific concerns about disclosing to family members and preserving relationships. This is paradoxically a time when people are most likely to require support, but may feel most isolated having absorbed wider negative assumptions around hepatitis C. This isolation is likely to be exacerbated (Janke *et al.*, 2008) by other life circumstances, including financial strain (as explored in chapter nine, changes to ESA and DLA may increase isolation) previous drug use, involvement in the prison system and recent introduction of the under occupancy penalty may mean moving to different areas resulting in uprooted social networks, making social work involvement particularly timely.

Hepatitis C and peer expertise

Given that hepatitis C can impact negatively on social networks (Sgorbini *et al.*, 2009) and given the lack of formal services, there is a need for forms of support which utilise information and expertise from sources other than professionals, notably, support groups and peer support services. The role of peer support for people living with hepatitis C is increasingly recognised (Harris, 2005; Treloar and Abelson, 2005; Grogan and Timmins 2010; Stewart *et al.*, 2012). Peer support can represent an important addition and challenge to the dominance of the medical discourse. The particular knowledge and expertise of peers in

relation to hepatitis C is noted by Treloar *et al*'s. (2010a) study of participation in prospective vaccine trials for hepatitis C. Participants indicated that where health professionals knew about hepatitis C from books and academic information, peers had an embodied form of knowledge that came from living with the virus (see also Treloar *et al.*, 2011). Although it is important to note that the experiences of peers and people with hepatitis C are not homogenous (Treloar *et al.*, 2010b), and peer education methods and modes need to accommodate different learning styles and experiences.

The privileging of peer perspective functions as a message to others that they are worthy of good treatment rather than being seen as a 'threat' to public health (Hopwood and Treloar, 2003). Hopwood and Treloar (2003) found that peer support groups served a number of purposes, from providing up to date information, to sharing strategies for dealing with the effects of hepatitis C in everyday life. Participants indicated that the emotional support they attained from meeting others with hepatitis C, and being listened to, was also vital (see Galindo *et al.*, 2007, and Harris, 2005).

The specific knowledge and experience of peers who *do not* have hepatitis C has also been recognised as important in light of still developing hepatitis C knowledge, specifically among injecting drug users, who after a long injecting career are still free from hepatitis C. Mateu-Gelabert *et al.* (2007) refer to an international study ('The Staying Safe Project'), concerning the risk protection strategies employed by people who inject drugs. In the Australian arm of the study, Harris *et al.* (2012b) found the strategies that protected injectors were not directly related to hepatitis C or harm reduction messages, but rather were concerned with maintaining social (friendships, family relationships) and structural (housing) resources, managing withdrawal and maintaining appearance. For example, using new needles to avoid scarring which simultaneously avoided sharing, and living in a stable home which meant that

participants were able to endure withdrawal to wait to inject in a safer environment (see also Rhodes and Harris 2012b).

Peer support has been used successfully to encourage engagement with services among people who use drugs. Aitken *et al.* (2002) described the successes of a trained peer in delivering hepatitis C testing and counselling to clients visiting a needle exchange in Australia. Sylvestre and Zweben (2007) describe an integrated peer based service in the US to encourage people using drugs to engage with hepatitis C support. Here, support groups are led by those who have recently completed treatment, in collaboration with a member of the medical staff. The group supports peers with a wide range of issues, from treatment effects to housing and transport and has resulted in increased engagement testing and treatment. Galindo *et al.*, (2007) writing in their capacity as peer educators for the above project, indicate that peers are vital for bridging the gap between people with hepatitis C and the medical system, given that people with hepatitis C may have had negative experiences with the health care system in the past.

Norman *et al.* (2008) describes the integration of support into a 'one stop shop' for people attending a drug service who undertake treatment for hepatitis C. A peer worker employed by the organisation acts as an empathetic and experienced listener, as well as being able to provide support such as arranging alternative therapies, providing transport and support at hospital appointments. However, lack of funding is identified as a major concern, as well as the need for a professional framework (see also Treloar *et al.*, 2012) for peers, given that they felt they were not trusted by the medical professionals. A framework would also provide clear boundaries to the role, given its labour intensive nature and the complex needs of those supported.

More recently, the role of peers has been incorporated into self-management programmes. Groessl (2008; 2011) in their development of such a programme for people with hepatitis C

have included specific sessions where peers who have done treatment participate in discussions and answer questions. There is evidence to suggest that peers are also influential in treatment decisions: Munoz-Plaza (2008) found that peers were often the main source of information when deciding whether to initiate treatment. Although peers can be instrumental in encouraging individuals to access treatment (Galindo, 2007) they can also represent a source of anxiety or negative information (Munoz-Plaza *et al.*, 2008). Swan *et al.*'s (2010) participants described hearing horror stories from peers regarding treatment which acted as a deterrent to treatment initiation. Even when respondents were being supported by a doctor, input from their peers meant they still expressed reticence about receiving treatment. The role of peers is returned to in chapter seven.

The impact on finances and employment

Qualitative research relating to the impact of living with hepatitis C on employment and finances is scarce and, as such, constitutes a key gap in the literature. The focus on employment and finances (specifically welfare benefits) is particularly timely, given that the thesis has taken shape in a global economic recession, and as major reforms of the welfare benefits system and the NHS, and deep cuts to services have been announced. This thesis is, therefore, situated at an important point in time; generating data in the early days of reform has meant it is possible to provide a point of comparison and to engage in discussion of how some aspects of reform might affect those living with hepatitis C.

Hepatitis C and employment

Both qualitative and quantitative studies have stated that the emotional and physical dimensions of illness, treatment side effects and their wide ranging and unpredictable nature (Conrad *et al.*, 2006) can affect participation in the workplace (Coughlan *et al.*, 2002; Crockett and Gifford, 2004; Blasiole *et al.*, 2006). A recent Australian study described participants'

difficulties in sustaining their careers and ambitions. They attribute this to hepatitis C related fatigue which they state both exacerbated other symptoms and altered their daily routines and tasks (Fry and Bates, 2012). The study found that participants reduced their hours from full to part time, or stopped altogether, as part of what they termed 'self-care' (p.470). It highlights that people with hepatitis C face the dilemma between needing to work for financial and personal reasons but not always being able to do so (Swan *et al.*, 2010). As a result this may mean that people with hepatitis C seek financial support elsewhere (discussed further below). Platt and Gifford (2003), in the only qualitative study to focus solely on employment experiences, found that in addition to the financial benefits, work was an important marker of self-worth, enabled participants to feel part of their community, and provided structure to manage the effects of living with hepatitis C (findings mirrored by Hopwood *et al.*, 2006). The authors found that the loss of employment had a serious impact on participant self-confidence and wellbeing (see also Glacken *et al.*, 2001). Additionally, a US study found that employment (even part time) was associated with greater access to information and support in relation to hepatitis C (Zucker, 2006).

However, in a comprehensive inquiry into the discrimination faced by people with hepatitis C in New South Wales Australia in 2001 submissions to the inquiry indicated that employment was the most common site of discrimination, after healthcare settings, and that discrimination often followed disclosure in the workplace (ADBNSW, 2001). For participants in Crockett and Gifford's (2004) study, a fear of negative consequences meant they hid their status from employers, thus creating difficulties in explaining the need for time off for regular hospital attendance (see also Hopwood *et al.*, 2006), potentially impacting on their ability to maintain appointments and therefore affecting their health (Swan *et al.*, 2010). Hopwood *et al.*, (2010) found that very few people had disclosed their hepatitis C status to their boss or work colleagues, 16.5% (83/504) and 17.3% (87/504) of participants respectively, due to concerns about their reactions. Although some did describe feeling obligated to tell their colleagues

(see also Platt and Gifford, 2003). Other studies described how participants withheld their status in the workplace as they were concerned they would lose their jobs or would not be considered for the position at all (Butt *et al.*, 2008b; Moore, 2009).

Discriminatory workplace procedures have also been described in the literature, including being subjected to invasive questions concerning the method of transmission (Conrad *et al.*, 2006) or assumptions related to participants' (perceived) status as someone who used drugs (ADBNSW, 2001). In a US context, Moore (2009) found that occupational health examinations were also used as a site of discrimination, enacting hepatitis C as highly contagious. Moore's (2009) study is one of the few which makes explicit reference to the possibility of protection afforded to people with hepatitis C at work through legislation (in this case the Americans with Disabilities Act) and the ADBNSW (2001) in an Australian context refers to coverage of people with hepatitis C under the Anti-Discrimination Act 1991 and the Disability Discrimination Act 1992.

In the UK, the recent Scottish BBV and sexual health framework (Scottish Executive, 2011:24) acknowledges that people living with *HIV* may face financial hardship and that these financial difficulties can impact on their ability to live well. It refers to the need to support both those who were diagnosed before effective therapy became available and those who are living with more recent HIV, including support to work for as 'long as they can and wish to'. The framework points to the importance of providing information to both employer and employee on the effects of HIV on working life, including confidentiality, avoiding stigma and discrimination and obligations under equalities legislation - although similar guidance is not provided in relation to hepatitis C. This apparent lack of acknowledgement that hepatitis C can affect employment further emphasises the importance of the contributions of the thesis in this area.

Attention to the qualitative experiences of employment for people with hepatitis C is particularly important given that the findings in some quantitative literature could have highly disabling consequences. Two studies[14] concluded that side effects of combination treatment led to decreased productivity in the workplace and the need to work shorter hours (McHutchinson, *et al.*, 2001; Perillo *et al.*, 2004). In 2010, Su *et al.*'s analysis of employment records maintained on a human resources database found that those with hepatitis C (who were not on treatment) were less productive at work - though it is not clear what this means - and had more time off sick, both short and long term. Although the authors acknowledge that this could act as a source of stress and anxiety for the workers, no reference is made to the obligations of employers under legislation or to the possibility of adjustments that could be made to facilitate and maintain employment. Given the authors' affiliations with pharmaceutical and health assessment human resources organisations, these studies contribute to a disabling hinterland, where hepatitis C is constituted as an individual problem to be managed, and where people with hepatitis C are seen as a burden to employers. This has potentially very serious material consequences in terms of the employment of people with hepatitis C.

Hepatitis C and social security benefits

The financial implications of living with hepatitis C and the experiences of claiming social security benefits are underexplored in existing literature. Studies which do refer to participants receiving welfare benefits do so mainly as part of the demographic information (Balfour *et al.*, 2004; Crockett and Gifford, 2004; McNally, 2004; Banwell *et al.*, 2005; Sternhell *et al.*, 2012), but do not explore the process or the implications of this in great depth. Welfare benefits are an important and timely topic for people with hepatitis C, and were raised spontaneously by participants. This thesis makes an important contribution in

---

[14] The research teams included medical staff, pharmaceutical researchers, as well as those from companies who measure health outcomes.

exploring participants' experience of welfare benefits in the UK, notably Employment and Support Allowance and Disability Living Allowance, and the interconnection between (former) drug use, hidden impairment, discourses and attitudes related to welfare benefits, chronic illness and disabling barriers.

Due to limited engagement with hepatitis C to date, useful insights can be gained from HIV literature. In a recent Australian study, McAlister *et al.* (2012) surveyed 335 people living with HIV and found that financial stress affected treatment adherence for a small, but significant, number. 65 (19.6%) found it very difficult to adhere to treatment due to the financial impact. 49 (14.6%) stated that they had delayed buying medication due to pharmacy costs and 30 (9%) had ceased treatment due to cost. A further 19 (5.7%) felt that it was difficult to attend appointments due to travel costs. In spite of this, only a small proportion has been asked by their care teams about the difficulties they faced in meeting financial needs. McAlister *et al.* (2012) emphasise that people should be asked about this routinely as part of appointments.

Owen and Catalan (2012), in their interviews with British men about the process of ageing with HIV, found that moral as well as financial concerns existed, specifically anxiety and shame regarding 'benefit' and 'state dependency'. Those diagnosed prior to the development of HAART[15] were more likely to receive disability benefits, but expressed concerns that they were caught in a 'benefits trap'. They described feeling stigmatised and marginalised for claiming financial support. This moral dimension of claiming benefits is timely given the current 'scrounger' rhetoric (Garthwaite, 2011) in the media, and the perceived immorality associated with drug use (Harris, 2009a). Receipt of government support (or not) and the intrinsic links between hepatitis C, drug use and its' 'self-inflicted' nature, are explored in greater depth in chapter nine.

---

[15] Highly Active Anti Retroviral Therapy

Cultural representations of disease

Within existing literature, hepatitis C is frequently compared with HIV (Treloar, 2002; Copeland, 2004; Davis and Rhodes, 2004; Davis *et al.*, 2004; Korner and Treloar, 2006; Treloar and Rhodes, 2009; Harris, 2009b; Swan *et al.*, 2010; Farrell and Comisky, 2012). This is often suggested as a reason for the lack of political engagement with hepatitis C (Treloar and Rhodes, 2009), or used to contextualise the provision of funding and support. For example, Copeland (2004) indicates that despite hepatitis C affecting greater numbers of people than HIV, the profile of HIV remains much higher than hepatitis C. While Korner and Treloar (2006) maintain that people with HIV and hepatitis C face similar social issues - both illnesses are uncertain, both treatments require commitment and can have difficult side effects. Hepatitis C is perceived as the 'poor relation' of HIV, existing in its shadow. Hepatitis C was enacted as a 'problem' only after a high level of media coverage and public health awareness raising in the 1980s around HIV -accompanied by 'information fatigue'(Slavin, 2006, Treloar *et al.*, 2011). A similar level of media interest has never existed for hepatitis C, in part because hepatitis C has not had the same impact, with men and women dying suddenly and visibly. Nor is there the same level of concern about hepatitis C spreading to the general population (Pisani, 2009). In addition, hepatitis C and injecting drug use are frequently conflated (Harris, 2005) which positions hepatitis C as something that happens to 'other' people.

Further, hepatitis C was historically referred to as 'non A non B hepatitis' before it was named hepatitis C in 1989, which Harris (2009b) indicates contributed to its constitution as trivial. It is made sense of in relation to other more established forms of hepatitis, understood as what it is *not,* rather than what it is. Harris' (2009b) participants indicate that this meant they found it difficult to take seriously. This is augmented with the common

practice of provision of hepatitis C test results alongside results for HIV, which implicitly creates a hierarchy where hepatitis C is marginalised.

Treloar *et al.* (2002) maintain that hepatitis C has not received the same level of concern regarding policy input as HIV due to the association with injecting drug use, and the perception by health bureaucracy of people who inject drugs as disorganised and not constitutive of a community in the way the gay community was perceived during the HIV epidemic. Treloar *et al.* (2002) (see also Butt *et al.*, 2008a) maintain that this slow Government response amounts to systemic discrimination against people with hepatitis C and that negative perceptions of hepatitis C as a 'drug users disease' have impeded adequate funding.

More recently, hepatitis C has been discussed alongside other forms of hepatitis for example, World Hepatitis Day (WHO, 2012), or other blood borne viruses as in Scotland's Sexual Health and BBV Framework (Scottish Government, 2011). This works to focus attention on the range and intra-action of BBVs and the need for a response. It lends further support to the position that hepatitis C and HIV do not exist as fixed entities but are enacted differently (with material implications) depending on how and who constitutes them.

Stigma, discrimination and using disability studies to explore hepatitis C

The connection between hepatitis C and stigma is well documented in the literature (Crofts *et al.*, 1997; ADBNSW, 2001; Van De Mortel, 2002; 2003; Hopwood and Southgate, 2003; Zickmund *et al.*, 2003; Grundy and Beeching, 2004; Golden et al., 2006; Treloar *et al.*, 2006; Zacks *et al.*, 2006; Moore, 2009). Indeed, it is described as a central element of the experience of living with hepatitis C (Hopwood and Southgate, 2003; Zacks *et al.*, 2006), leading Richmond *et al.* (2004) to refer to hepatitis C as two illnesses - living with the virus and its effects, and living with the stigma.

Existing literature has explored stigmatising responses and experiences in a number of settings, notably responses of family and friends (Zickmund *et al.*, 2003; Fraser and Treloar, 2006; Moore, 2009). The literature in this field reports overestimation of transmission risk (Zickmund *et al.*, 2003) which impacted negatively on personal interactions and relationships (Groessl, 2008). People reported being deterred from playing with child relatives, being told they could not use the bathroom and being deprived of physical contact (Zickmund *et al.*, 2003, Crofts *et al.*, 1997), thus further isolating people with hepatitis C and leading to reduced support networks (Blasiole *et al.*, 2006; Moore, 2008; McCreaddie *et al.*, 2011).

Stigmatising responses are also documented within institutional settings, particularly healthcare, given that status is most frequently disclosed here (see ADBNSW, 2001; Habib and Adorjany, 2003; Hopwood and Treloar, 2003). Participants reported healthcare staff judging them negatively, using universal precautions to stigmatise and shame them, refusing to treat them, or treating them only at particular times, such as the end of the day (ADBNSW, 2001; Temple Smith *et al.*, 2006; Moore, 2008). Negative treatment by healthcare workers potentially becomes a cyclical process where people with hepatitis C who have been treated negatively, anticipate poor treatment and respond defensively - thus inhibiting a respectful and helpful relationship (Paterson *et al.*, 2007). Other incidences of discriminatory treatment documented by the ADBNSW (2001) (see also Crofts *et al.*, 1997) explored stigma in the context of funeral services (refusal to allow viewings or embalm, storage or burial of bodies in unnecessary ways), employment (involuntary disclosure and subsequent poor treatment), or welfare organisations (segregation from others).

Stigma is most frequently attributed to perceptions of injecting drug use. As a result those with hepatitis C are enacted as irresponsible, morally deficient and to blame for their infection (Richmond *et al.*, 2004; Paterson *et al.*, 2007; Moore, 2008). Other studies have suggested that people who use drugs are understood as dangerous, deceitful (concerned

only with obtaining drugs), ultimately to be avoided (Hunt and Derricott, 2001; Paterson *et al.*, 2007; Peckover and Chidlaw, 2007; Lloyd, 2010) and thus, those with hepatitis C are constituted as less 'deserving' of support (revisited in chapter nine).

Those who continue to inject drugs report more incidences of discrimination and are more likely to experience negative assumptions (Paterson *et al.*, 2007; Day *et al.*, 2008; Foster, 2008), with Hopwood and Treloar (2004) noting that they received less support following diagnosis, were less likely to be referred to, or initiate treatment, or were treated reluctantly. For those who did not contract hepatitis C via drug use, there is evidence that for some, the assumption of drug use persisted (Gifford *et al.*, 2005; Conrad *et al.*, 2006), forcing them to make the transmission route clear, or even to lie about it. Other studies have suggested that negative treatment is not only related to drug use. Women in particular described poor treatment (Crofts *et al.*, 1997), including being advised to terminate pregnancies (Gifford *et al.*, 2003) or made to feel that they were unfit parents. This feeds existing perceptions of women who use drugs and/or have hepatitis C as deviant and as unfit mothers (Zickmund *et al.*, 2003; Ettore, 2007) and enacts them, and the lives of their (potential) children, as having little value. Lesbian and bisexual women also reported receiving less support from services (Banwell *et al.*, 2005).

Other literature has referred to 'self-stigma' where people with hepatitis C have absorbed negative views, shame or incorrect beliefs about themselves and about hepatitis C (Waller, 2004; Zacks *et al.*, 2006), accepting or expecting poor treatment (Crockett and Gifford, 2004). Other studies reported participants being afraid to disclose because of fear of negative reactions or the potential to damage social relationships. Zacks *et al.* (2006) indicated that 'self-stigma' was not necessarily related to mode of transmission, whilst Moore (2009) found that those who had contracted hepatitis C via needle stick or transfusion reported more positive interactions.

Elsewhere, participants described 'feeling contagious' or being labelled as contagious (Moore, 2009) and, as such, being subjected to humiliating treatment. Others reported not necessarily *experiencing* stigma but fearing it in interactions which both lead to, and was augmented by, concealment of their hepatitis C status. These actual or anticipated experiences of stigma and discrimination had a direct impact on participants' experiences of seeking help and support on treatment, as well as on their feelings of self-worth, confidence and self-esteem (Habib and Adorjany, 2003; Temple smith *et al.*, 2004; Jenkinson *et al.*, 2008). The issue of self-stigma is returned to under internalised oppression below.

Shortcomings of stigma literature

However, there has been an acknowledgement that much of the existing stigma literature focuses on interactions between individuals, thus enacting stigma as an individual trait, or indeed blaming individuals (i.e. healthcare practitioners) for their behaviour (Paterson *et al.*, 2007), with insufficient attention to the structural aspects which contribute to the maintenance of stigma and discrimination (Rhodes *et al.*, 2004; Paterson *et al.*, 2013; Hopwood *et al.*, 2006). Paterson *et al.* (2013) point to the need to look to the wider social and structural context which co-constitutes these negative views and works to maintain them (see Parker and Aggleton, 2003). For example, policies determining who is eligible for treatment, money spent on treatments (Stephens, 2012), service responses (or lack thereof). Harris *et al.* (2013) highlight how the hospital environment facilitates or impedes access to treatment for people who inject drugs, via inflexible appointment systems, conflicting schedules and the layout and distance to the hospital. Paterson *et al.* (2013) explore how policies, practices and rules within the hospital restrict access and support for people who use drugs. The authors found that patients were introduced as 'drug users', before detailing why they had been admitted, were flagged as 'infectious', or noted as drug seeking in a log book and made to answer questions in public spaces, which was perceived as threatening

and invasive. The highlighting of structural barriers faced by people who use drugs (and have hepatitis C) in accessing treatment and support is vital, and this opens up a niche to explore the experience of structural disablism faced by people with hepatitis C which is discussed in greater depth below and in chapter five.

Within the existing literature, the forces contributing to the development and maintenance of the negative status of those with hepatitis C include: the illegal nature of injecting drug use (Harris 2009a), the controversies and potential lack of support for harm reduction methods, such as needle exchanges (Crofts *et al.*, 1997), and, more recently, safer injecting facilities (Strathdee and Pollini, 2007; Hathaway and Tousaw, 2008). In addition, the transmissible nature of hepatitis C further marginalises the virus via fear of contagion, illness and death (Richmond *et al.*, 2004).

In an important recent piece of work, Harris (2009a) shifted from descriptions of instances of stigma, to focusing on the processes and beliefs which constitute and contribute to stigma in the context of hepatitis C, specifically the association with injecting, perceptions of contagion and beliefs about chronic illness. She indicates that the act of injecting disturbs the strongly held perception of the body as a clean closed vessel. In injecting, the person breaches the boundaries of the body at points of their own making, drawing out and reintroducing bodily fluids which may be perceived as polluting. This, together with the (often incorrect or exaggerated) perceptions of the infectiousness of the virus and the unwillingness to engage with chronic illness (which may not be immediately visible, may fluctuate and ultimately challenge linear notions of 'getting well') constitutes hepatitis C related stigma. Similar sentiments are echoed by Barnes (1997) when he states that fears related to disability are connected to that which is considered abnormal or abject (revisited below).

Theories of stigma

Parker and Aggleton (2003) note that the concept of stigma is frequently used but often poorly defined. They draw attention to widespread use of the notion of stigma as a 'mark of disgrace' with limited further explanation. Perhaps the most famous of stigma theories is Goffman's (1963) 'Stigma; notes on the management of a spoiled identity'. Goffman (1963) describes how stigma originated in Ancient Greece as bodily sign to denote that a person had done something morally wrong. Over time, stigma has come to be understood as being produced in interactions where individuals with specific (negatively perceived) attributes are marked out as different in comparison with what Goffman (1963) terms 'normals.' Goffman (1963) is concerned with the interaction between stigmatised and 'normal' people, and the 'management' of this interaction undertaken by the stigmatised person. Goffman's (1963) theory has been shown to be helpful in exploring interactions between disabled and non-disabled people (Keith, 1996) and his work on creditable and discreditable attributes, and 'passing', is particularly important and is examined in chapter six.

However, Goffman (1963) has been subject to criticism concerning his focus on individual interactions at the expense of structural conditions and processes that facilitate stigma, and for treating stigma as a single event or attribute rather than a contingent shifting process which is not inevitable (see Parker and Aggleton, 2003; Reeve, 2004; Harris, 2009a). Further to this, others maintain Goffman's (1963) use of 'stigma' serves to shift the attention from those who create the problem on to those who appear to signify it, and maintains the underlying perception that those considered stigmatised are 'not quite human' (see Bogdan and Taylor, 1989).

Oliver (1990) maintains that stigma as a concept is inherently individualist and points to the need to pay attention to discrimination and oppression instead. Similar views are echoed by Sayce (1998), writing in the mental health field. Whilst I agree with the need to explore the experiences of people with hepatitis C using a framework of discrimination and oppression,

in paying attention to the wider social context, stigma remains important and useful to this discussion, not least because it was so frequently referred to by participants and forms an important component of existing hepatitis C literature.

Here it is important to reiterate the words of Finkelstein (1980:29) 'not everyone, of course, uses the term "stigma" in the same way or consistently. In very many cases "stigma" is used in the same sense as "prejudice".

A note on the usage of terms

Within this thesis, the concepts of stigma, prejudice and disablism are entangled and messy and subsequently, their usage is slippery. It is important to emphasise that this is not due to poor understanding of the terms, but for a number of reasons. Participants favoured the term stigma within their accounts, rather than prejudice or discrimination. This may be because it is more frequently used, both within society and within hepatitis C literature, where other terms (in particular disablism) are used in more academic arenas. It may also be because participants had potentially absorbed the negative views around hepatitis C as an 'individual' issue.

However, there are significant commonalities between stigma and prejudice which contributes to their entanglement. Phelan et al. (2008) in their analysis of the similarities and differences between stigma and prejudice, point out that bodies of literature on these concepts mingle together and indeed 'borrow' from each other. Such 'borrowing' took place during the course of this research as I came to realize what participants (and indeed the literature) termed stigma might more accurately and usefully be termed disablism or prejudice.

As explored above, stigma is most frequently understood as an individual mark or characteristic which is perceived to be socially or morally unacceptable. Goffman (1963)

maintains that the stigmatized person becomes reduced in the eyes of others; not quite a full person. Thus the focus of stigma is the individual themselves. They are the one with the 'problem' that needs to be solved, much like the individual model of disability.

Prejudices refer to negative ideas and judgments held about individuals or groups of people. Prejudice is most commonly applied to groups (i.e. race and ethnicity) (Phelan et al., 2008). Prejudice is different from stigma in that it shifts the focus from the individual to the person holding the views. They are the ones who hold prejudices. Disabled activist Jenny Morris (1991) makes explicit reference to prejudice in her exploration of the negative views of non-disabled people about what life as a disabled person is like. Examples of prejudice include the perception that being disabled is tragic or that disabled people strive for normality or cure above all else.

Pyscho-emotional disablism (Reeve, 2008) flows from Morris' (1991) work by recognising that the negative messages and values (prejudices) held in society about what it means to be a disabled person (or indeed a person with hepatitis C) circulate and are absorbed and reabsorbed by both wider society and disabled people. These prejudices can become internalized with negative consequences for the person's wellbeing (explored in greater depth below).

It is here that links with disablism are made. The absorption of prejudice are termed by Reeve (2008) as pyscho-emotional disablism. In using the term disablism, rather than stigma which has a focus on the individual or prejudice (which focuses on the person holding the views), this oppression becomes a distinctly political concept which shares commonalities with oppressions, such as (hetero) sexism and racism, which are recognised within wider society and can be challenged with collective action. The focus is shifted to the wider structures in society which contribute to the creation and maintenance of oppression. Harris (2010) maintains that stigma and discrimination, though inter-related, are not the

same thing and that the concept of stigma captures assumptions, and values in a way that discrimination does not. Reeve (2008) maintains that Goffman (1963) insightfully describes the intricacies of interaction between stigmatised and non-stigmatised people, including the negative feelings associated with the stigma and the way that these are absorbed by the person. Scambler and Hopkins (1986) differentiate between concepts of 'felt' and 'enacted' stigma which translate to the *expectation of* stigma and *the actual experience* of it. They maintain that it is often the 'felt' stigma which is more damaging and indeed, within the research, participants described being concerned that they would experience negative treatment much more than incidences where it actually occurred. So, this differentiation is important. However, the tone of Scambler and Hopkins' (1986) work still enacts those interviewed as deviant, without paying attention to wider structural and contextual forces, though Scambler later acknowledges this (see Scambler, 2004). Barnes (2012) critiques Scambler's work as 'inward looking', taking insufficient account of the work already done in this area by disability studies scholars. Thus, stigma as a concept continues to be used throughout the thesis. I have made particular efforts to define my use of the word stigma where necessary, and to maintain its usage both by participants and in existing literature. However, I have chosen to use the term 'oppression' as a distinctly political decision, focused on the impact of wider structures rather than individuals. The remaining section of the literature review introduces the important insights drawn from disability studies for the purpose of this thesis.

A brief introduction to disability studies

In line with the theoretical perspective outlined in chapter three, the intertwined and intra-active nature of hepatitis C, disablement, illness/impairment, drug use, medicine, and cultural and political forces should be kept in mind. The exploration of the literature begins

with a brief outline of the constitution and treatment of disabled people in western history. This is explicitly linked to chapters seven, eight and nine, and the discussions of *pharmakos* and access to financial support. Next, the decision to use the 'extended social relational model of disability and impairment' is clarified, and the concept of psycho-emotional disablism, as introduced by Thomas (1999; 2007) and expanded on by Reeve (2002; 2004; 2008; 2012a) (addressed further in chapters five, six, and nine), is explained. Some key forms of psycho-emotional disablism are introduced. Finally the place of disability studies in adding to discussions around hepatitis C is briefly explored.

Historical enactments and materialisations of impairment and disablism

Within UK disability studies, disability is understood as the oppression of those who live with impairments that are visible or indicate that the individual is in some way 'different'. In exploring the roots of disabled people's oppression, Barnes (1997) outlines the historical treatment of those with impairments. He maintains that contemporary attitudes have their roots in Greek and Roman times (see also Stiker, 1999), where great emphasis was placed on physical strength and achieving bodily ideals. Greek Gods exiled those with impairments, so on earth, many of those[16] with visible impairments were murdered at birth, left to die or became objects of ridicule. They were used as *pharmakos* (scapegoats) providing 'communities of Antiquity with the opportunity to project their transgressions onto those who - by virtue of their physical or intellectual difference - existed on the margins' (Hughes, 2012:19). The discussion of *pharmakos* and the intertwined nature of disability, medicine, hepatitis C and drug use is taken up again in chapter seven. Within Judeo-Christian beliefs, impairments were also seen as divine punishment for past wrongdoing (Shakespeare, 1996; Barnes, 2012). Given that Barnes (1997) indicates that Judaeo-Christian beliefs are the

---

[16] Barnes (1997) indicates that there was clearly some resistance to this given that disabled people have been present throughout history.

foundation for current moral values, this may contribute to perceptions of 'deserving' and 'undeserving' in relation to drug use and people with hepatitis C.

Disability studies scholars (Finkelstein, 1980; Oliver, 1990; Gleeson, 1999 in Thomas, 2007) later trace the advent of industrialisation in the cementing of exclusion of disabled people[17]. Where those with impairments had previously made contributions via agriculture or small scale industry, the shifting of modes of production to factories meant they were excluded, owing to patterns of work and inaccessible locations (Oliver, 1990). This led to the determination of those who could not work as problematic and they were subsequently segregated in institutions, such as asylums and workhouses.

At this time, it quickly became apparent that workhouses required a system of determining who could be defined as 'unable to work' and under the Poor Law Amendment Act (1834), the workhouse test and the principle of less eligibility were introduced. Oliver (1990) does make it clear that not all disabled people went to the workhouse, many remained with their families. However, disabled people who lived in families that no longer felt they could support them tended to be moved into institutions. Oliver (1990) indicates that this was important in enacting impairment as shameful and in drawing divisions between those perceived as 'deserving' or 'undeserving' of support from the state. This is explored in greater depth in chapter nine.

Key to determining who was found fit for work were doctors. Stone's (1986) exploration of social policy in three countries (America, Britain and Germany) traced the development of systems for those unable to work and how the decisions around who is (not) fit for work are determined through systems of power – notably medicine (Marks, 1999; Lupton, 2003; Borsay, 2005; Beauchamp-Pryor, 2011). Finkelstein (1980) also discusses how this led to the

---

[17] Though Borsay (2012) does caution against oversimplifying the factors enacting disabled people's exclusion here.

development of a wide range of health and social care professionals, cementing the medical response.

During the 20th century and arguably persisting to date, the dominant understanding of disability in the west is one of personal tragedy and disaster, reflecting wider societal beliefs that it is something to be managed or addressed by the individual (Oliver, 1990; Beauchamp-Pryor, 2011; Oliver, Sapey and Thomas, 2012), and treated and cured wherever possible (Crow, 1996). Challenges or barriers faced by the person are perceived as a *direct result* of their impairment (Thomas, 1999).

These ideas about disabled people and the 'cause' of disability began to be challenged in the 1960s and 1970s by the collective action of grass roots movements of disabled people, who shared experiences with other oppressed groups, and united against the paternalistic medical and charitable organisations that claimed to speak for them (Roulstone *et al.*, 2012; Campbell 1997). In 1968, Vic Finkelstein, a disabled psychologist, met Paul Hunt, a disabled man who had rejected life in an institution. Discussion between the two led to a fundamental change in the interpretation of 'disability' which was understood as 'a social relationship between a person with an impairment, and the social environment in which they live, rather than a personal (medical) possession' (Finkelstein, 2005: 2). Together with a group of other disabled people, Hunt and Finkelstein formed the Union of the Physically Impaired Against Segregation (UPIAS), and the Fundamental Principles of Disability were developed in 1976. The principles clearly separated impairment and disability: Impairment was understood as biological, a functional difference, and recognised as 'lacking all or part of a limb or having a defective limb or mechanism of the body'. Disability was understood as a social phenomenon and defined as: 'Something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from society. Disabled people are therefore an oppressed group' (UPIAS, 1976:4).

Mike Oliver then formulated the social model of disability as a means of aiding understanding among social workers and other professionals (Oliver, 1990; Finkelstein, 1996). Oliver (1990) suggested that the individual model (of which medicine was a key component) situated disability as a personal problem to be individually managed or treated; within this model, the *cause* of disability was a functional problem or 'abnormality' of impairment. The social model of disability rejects these principles, situating disability firmly within society; the 'problem' of disability lies in the barriers and oppression that disabled people face in daily life, including access to education, employment and services, physical barriers in the structural environment and oppressive professional practices.

Since then, although the social model has been critiqued, it has remained the vital starting point, without which disability studies would not exist (Barnes, 2012). Indeed, Thomas (1999: 26) maintains that within disability studies, the 'social model has created the space which makes everything else possible'.

The limitations of the social model have been recognised, notably for the purpose of this thesis, by disabled feminist writers, including Morris (1991), French (2003) Crow (1996) and Thomas (2004), who critique the model's focus on structural barriers, indicating that it has prioritised structural exclusion and disablement without taking adequate account of impairment, relegating it to the realm of 'personal trouble'. Thus, many of the difficulties which can be attributed to impairment and impairment effects are effectively silenced and marginalised. However, it is important to note that the social model has never ruled out the importance of the experience of impairment: Oliver (1990, 1996) indicated it was not something he was concerned with and that it is more pragmatic and potentially 'easier' to address structural barriers, where clear solutions and areas of work exist (Reeve, 2004).

Thomas (2004:40) maintains that 'the exclusions that constitute disability should include those which work along psychological and emotional pathways' and that 'oppression

operates on the inside as well as on the outside'. Furthermore, Thomas (1999; 2007) and Reeve (2012) have emphasised that impairment is inextricably bound up with the kinds of disablism people experience. Up to this point, impairment has remained in the realm of the private in order to clearly sever the link between impairment and disability, for fear this would represent a step back to the belief that impairment causes disability. However, Reeve (2012) staunchly maintains that impairment is not the cause of disability, but that there are dimensions of disability and disablism which remain under addressed because of a reluctance to engage with emotional and personal dimensions.

Psycho-emotional disablism

The recent work of two female disability studies scholars in particular, Carol Thomas and Donna Reeve, will be drawn upon. Thomas (1999; 2007) developed the extended social relational definition of disability, initially formulated in her work, *Female forms* (Thomas, 1999). This definition was later refined to include the term disablism (Reeve, 2012a) in order to explicitly imbue the oppression faced by disabled people with the same weight as those who experience racism (hetero)sexism and ageism (see also Abberley, 1987; Taylor, 2004):

> 'Disablism is a form of social oppression involving the social imposition of restriction of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing' (Thomas. 2007: 73).

This is the definition that I work from and that Reeve (2008; 2012a) has developed and explored in her work on the experience of psycho-emotional disablism. Both Thomas (1999; 2007) and Reeve (2008; 2012a) have highlighted the different forms of disablism. Structural disablism relates to the barriers such as inaccessible environments or processes, physical and social exclusion and discrimination 'which is implied by the social model' (Reeve, 2012a:79).

The other form of disablism covered by the definition, provided by Thomas, are those barriers which impact on wellbeing:

'Social barriers place restrictions on what disabled people can do, but psycho-emotional barriers place restrictions on who they can be, shaping inner worlds sense of self and social behaviours' (Thomas, 2007:72).

This recognises that oppression can operate at both public and private levels (though these are not easily separated). Reeve (2002) gives examples of being stared at, or made to feel ashamed. These emotional aspects can make disabled people feel invaluable, invalid, stressed and ashamed, excluding them as effectively as any structural barrier might (Reeve, 2004).

In exploring the experience of disablism both psycho-emotionally and structurally, Reeve (2008; 2012a) has responded to calls to include the body in theorising about impairment and disability, and to retrieve the experience of impairment from the margins (Hughes and Paterson, 1997; Paterson and Hughes 1999). Harris (2009a; 2009b; 2010) has similarly called for the recognition of the body in experiences of hepatitis C and it is at this point of overlap that this thesis is positioned.

This approach to impairment and disablism is commensurate with the theoretical position outlined in chapter three and the accompanying discussion about the messiness of hepatitis C. Disability studies scholars have indicated that impairment and disability are socially constructed, not existing as prior or fixed, but brought into being via particular social cultural, political and historical forces, practices and understandings.

Abberley (1987) has noted how some impairments are more prevalent in specific parts of the world, due to the distribution of resources. In the same way, hepatitis C infection (often attributed solely to individual behaviour) results from social and structural forces, including

access to information, clean equipment, and government funding for blood products (see Archer *et al.*, 2009) and services.

Further to this, impairment and disability are contingent, varying depending on time, place and understanding; a person might be disabled in one workplace, or may be impaired on some days and not others, and cultural understandings of illness/impairment may differ over time (i.e. understandings of HIV, ME). Mol (2002) has shown how the common impairment Atherosclerosis *becomes* different things, for example in an X-ray or an MRI or in a conversation with a friend (this is explored in chapter three). Recognising the contingency of realities and impairments in this way challenges the dominance of medicine.

Reeve (2012a) indicates that impairment and disability are not easily separated (not to be confused with the argument that impairment *causes* disability), but that impairment, impairment effects and disablism are intertwined. The kind of impairment someone has influences the kinds of disablism they experience. This is especially the case for hepatitis C.

For the purpose of this thesis, hepatitis C is treated as a chronic illness[18] (Paterson *et al.*, 2006) and thus as a category of impairment (Thomas, 2007). Wendell (2001) has emphasised the need to pay greater attention to the experience of chronic illness, (see also Gibson and Lindberg, 2007) and this thesis adds to a body of work within disability studies which has begun to address chronic illness (see for example, Wendell, 1996; Wendell 2001; Carrie and Chan, 2008; de Wolfe 2012). Closely intertwined with this are de Wolfe's (2002) comments on the division between illness and disability. De Wolfe (2002) indicates that she had previously thought of herself not as 'disabled' but as 'ill' and she did not feel that she could define herself as disabled. Whilst the disability movement has worked to emphasise that it is possible to be healthy and disabled, eliminating illness from discussions of disability shifts

---

[18] Defined as being long term, fluctuating, difficult to treat, not following a conventional illness trajectory (symptoms –diagnosis – treatment - recovery) and not necessarily visible (see Lightman *et al.*, 2009).

the boundaries of exclusion, meaning people who are chronically sick remain the sole responsibility of medicine. De Wolfe (2002) maintains that a firm division between the two cannot be maintained and similar sentiments are expressed by Harris (2010) who describes health and illness as a continuum.

Direct psycho-emotional disablism

Donna Reeve (2002; 2006; 2008; 2012a) differentiates and names specific forms of psycho-emotional disablism. She distinguishes between direct and indirect psycho-emotional disablism. Indirect psycho-emotional disablism arises from intra-action with experiences of structural disablism, whereas direct psycho-emotional disablism arises from being made to feel bad about oneself via the actions of others, for example, thoughtless comments or actions.

Internalised oppression

Internalised oppression is one specific form of direct psycho-emotional disablism, as Morris (1991:19) states:

'One of the biggest problems are the underlying messages which we receive every day of our lives from the non-disabled world that surrounds us and become our way of thinking about ourselves.'

Internalised oppression occurs as a result of poor treatment within society (Mason, 1990). Negative views (prejudices) in relation to impairment and disability are absorbed, ultimately affecting what the person feels and thinks about themselves (Reeve, 2012a), and these can be difficult to challenge given the limited positive cultural representation or understanding of disability. Whilst Reeve (2004) has emphasised that internalised oppression is not inevitable and can be resisted, this clearly depends both on personal

biography and support, as well as professional input, which works to challenge and break down these internalised views.

As will be explored throughout the thesis, the experience of internalised oppression is highly relevant to the experience of hepatitis C. Negative assumptions related to drug use and people who use drugs, along with perceptions of contagion and infectivity, and self-infliction, intra-act with wider perceptions concerning chronic illness and eligibility for support and can have a direct impact on both what people with hepatitis C *can be* and also the services they are able to access. This is explored throughout the findings chapters.

Indirect psycho-emotional disablism

Indirect psycho-emotional disablism arises from experiences of structural disablism - i.e. not being able to access buildings. Imrie (2002) maintains these spaces separate out disabled and non-disabled people and as a result, send messages that disabled people are not welcome (Morris, 1991) or are indeed, out of place (Kitchin, 1998). Buildings and structures carry with them about the people who (are expected to) use them, for example, that people with hepatitis C have no access needs or need to be hidden away (explored further in chapter five), potentially inhibiting engagement with services (cf. Harris *et al*, 2012a).

Reeve (2008; 2012a) maintains that psycho-emotional disablism is more difficult to address than structural disablism because it operates informally, though for people with hepatitis C, recognising this experience as disablism may be an important first step. Reeve (2004) also acknowledges that the extension of the social model to incorporate psycho-emotional aspects potentially weakens its campaigning power, given that it is difficult to incorporate something that is complex, intangible and difficult to quantify (cf. de Wolfe, 2012). However, as this thesis shows, psycho-emotional disablism is a widespread phenomenon that exists for

hepatitis C and naming it as a form of disablism potentially increases campaigning power in other ways, for example: encouraging reflection on media and public health messages and flagging up disablist beliefs manifested in service responses.

This chapter has reviewed existing social research literature in relation to hepatitis C, exploring in-depth aspects of the experience of living with the virus to which this thesis contributes. Specific gaps in the literature have been identified. The latter part of the chapter introduced disability studies for the purpose of the thesis, explaining the decision to draw on the extended social relational model of disability and the concept of psycho-emotional disablism. The next chapter explores the theoretical position taken throughout the PhD process.

Chapter Three: 'Getting messy', theoretical underpinnings

Introduction

This chapter explains and explores the ontological and epistemological shift which occurred during fieldwork and the implications this has for the thesis (in both form and content), and for understanding and responding to hepatitis C. This shift can be briefly described as one which acknowledges the messy and contingent nature of the research process and the world (Law, 2004). The chapter and thesis draw on the work of John Law (2004; 2006; 2009; Law *et al.*, 2011), specifically his work on mess and the active role of methods in co-constituting reality. In addition, this thesis draws on Karen Barad's (1998; 2003) concept of agential realism, which recognises the inseparable, intra-active and co-constitutive nature of the agencies of observation and the thing that is being observed, and Anne Marie Mol's (2002) work on multiplicity and ontological politics, which suggests that realities are multiple and, thus, bringing realities into being is a political act. These works will be discussed in greater depth later in the chapter. They have recently been used to explore the politics and constitution of hepatitis C by Australian Sociologist Suzanne Fraser (Fraser, 2009; 2010; 2011; 2012; Fraser and Seear, 2011). This developing body of work, emerging in published format as I wrote and thought about this thesis, both informed and inspired my own thinking[19].

My work differs from that which has gone before, given that a central tenet of the approach outlined by Law (2004; see also Mol, 2002 and Barad, 2003) is that knowledge is always partial and contingent - and the politics and enactments of hepatitis C shift and materialise, based on local intra-actions with phenomena such as bodies, policies and systems of support. Interviews have been conducted with UK residents at a time of political and economic upheaval which has had, and will continue to have, significant consequences for

---

[19] It is part of the 'hinterland' (Law, 2004) on which this study draws: the work and relations which accumulate and bundle together to shore up understandings and realities in particular ways.

people with hepatitis C, enacting the virus and materialising participant experiences in specific ways. Attention is paid throughout the thesis to enactments of hepatitis C and implications currently under addressed in the hepatitis C social research literature, for example, the experience of treatment and post treatment, seeking welfare benefits, support and experiences of disablism.

This chapter proved to be extremely challenging to write given (as will be discussed) the inseparable nature of methods, data and writing (Richardson, 1994; Smart, 2009), the ever expanding reach of the discussion, the difficulty of drawing a boundary around this chapter and chapter four[20], and the contingent nature of the writing and re-writing process. In order to make this chapter accessible and enjoyable for the reader, it stays close to my experience of doing the research and uses examples from the data.

What is presented in the thesis is necessarily partial. It is not my intention to provide *an overview* of the research experience, instead, it is intended as a *walk* (Mol and Law, 2002; see also Fraser and Seear, 2011) through some of the messiness of the experience and the issues raised throughout the research process. The walk, introduced by DeCertau (1983) and utilised by Mol and Law (2002), differs from the overview in that instead of attempting to take a broad and sweeping view overall, it is a way of covering a small amount of ground whilst immersed in what is happening locally and specifically. Through walks it is possible to encounter things that are interesting, intricate, and unexpected. In walks, these things can exist alongside each other without trying to capture a whole picture (Mol and Law, 2002). 'Walking' is a pertinent metaphor given that I frequently travelled on foot during fieldwork (see chapter four), and walks - both during fieldwork and in writing the chapters - also involve stumbles, detours, getting lost and forging new paths.

---

[20] To a certain degree this is a false divide; in order to enhance readability, chapter four concentrates on the practicalities of the method, whereas chapter three explores in greater depth the philosophical underpinnings and understandings. I have tried as much as possible to avoid repetition between these chapters whilst simultaneously attempting to make clear the intertwining and co-constitutive nature of the content.

In the spirit of the advice given by Criminologist Martina Feilzer (2009), the chapter (and indeed thesis) aims to 'tell a good story' (p.480); to articulate in an engaging, accessible and honest way, the difficulties and challenges I faced in the course of this work. Feilzer (2009) maintains that discussions such as these are important in stimulating debate and in contributing to policy responses (see the recommendations in appendix one).

Thus, the chapter walks the twisting and messy nature of the fieldwork addressing how this complex, frequently difficult and uncomfortable process, co-produced the reality and the phenomena being studied, paving the way for new understandings. It introduces the changes which occurred throughout the research process and outlines how and why the eventual decision was made to focus the thesis on the accounts of people with hepatitis C. It first addresses how research accounts are commonly presented as linear and ordered, with clear outcomes, which during the fieldwork, generated a sense that I was 'doing it wrong'. The chapter then moves on to a theoretical discussion of the concept of mess, the change in ontological and epistemological understanding and how the world itself is complex, diffuse and vague (Law, 2004). Furthermore, I will explain why mess is a useful concept in discussing the experiences of hepatitis C. Here space is made for talking about the theoretical and political aspects involved in discussing mess – including the implications and consequences of understanding the world and hepatitis C as messy and fluid, and the responsibility this entails for the researcher[21].

The messy realities of fieldwork

The shift to exploring mess initially emerged from a sense of anxiety around my research practices. The research began with the intention of generating accounts from two participant

---

[21] Although to some degree I am providing an overview in this paragraph and clearly some overviews are necessary for the sake of clarity and engagement. Law's (2004) observation that complexity has to involve some simplification, in order to hold something still long enough to explain it, is pertinent here.

groups - people who (had) lived with hepatitis C and professionals working in the field[22]. I planned to interview people with hepatitis C about their experiences and use these as a basis to guide both the interview schedule and the professional sample. I set out with the intention to interview 15 people with hepatitis C and 15 related professionals. During the interviews with people who had hepatitis C, it became clear that support had been required (though as this thesis explores, not necessarily provided) from a much wider sample of professionals than initially anticipated. As well as liver specialists, hepatitis C specialist nurses, harm reduction and other drugs services staff (reported in the literature: Teague *et al.*, 1999; Ehsahni *et al.*, 2006; Brener *et al.*, 2007; Janke *et al.*, 2008; Grogan and Timmins, 2010; Stewart *et al.*, 2012), participants also described contact with, or requiring support and information from, social work teams (working with disabled people, in mental health, with older adults and children and families), the Department for Work and Pensions (DWP) and welfare benefits advisory staff, GPs, housing services and professionals from the funeral service industry. The role of these professionals in supporting those with hepatitis C is rarely reported, especially in the UK, although the responses of governmental organisations and the funeral industry have been reported in an Australian context, (Crofts *et al.*,1997; ADBNSW, 2001; Hopwood and Treloar, (2003).

Thus, I, rather ambitiously for a single researcher with limited time, established contact with a wide range of professionals (with ethical approval from research sites and local organisations), intending to interview a range of them and aiming to embrace the experience and document the complexity of what occurred in the field (Becker 1966; Holloway and Biley, 2010). This activity can be seen as an attempt to gain an overview of the experience of living and working with hepatitis C, indicative of my understanding, at that time, that it was

---

[22] It is important to note that the experiences of living and working with hepatitis C are not necessarily separable – another complexity which will be revisited throughout the thesis.

possible to 'capture' the experiences to develop a fuller picture. As will be explored, my views on this have altered in the course of this work.

I found that generating data from professionals was complex: those who were involved with hepatitis C (i.e. liver specialists, hepatitis C specialist nurses) were happy to talk formally about their experiences in a recorded interview, but speaking to other professionals who did not perceive themselves to be directly connected to hepatitis C (social workers, alcohol support services, Job Centre staff, welfare benefits advisors) was more difficult and required flexibility. Data generation (where it occurred) was often informal and swift - 10 minute discussions in staff meetings, 'straw polls' in open plan offices, informal discussions and snatched telephone conversations[23].

In these situations I followed the advice of Buchanan *et al.* (1988) who suggest that when doing research in organisations, a researcher must do what they can, when they can. When a social work manager invited me to conduct a 'straw poll' of his staff in an open plan office concerning their work (or apparent lack thereof) with people with hepatitis C, although I had initially anticipated returning at a later date (i.e. a staff meeting) to speak with the staff more formally (and with a digital recorder!) I took this as the only opportunity I would get owing to pressures of work on the team and the distance travelled on my part[24]. Another team of social workers allowed me a short time period in a staff meeting (even though I offered to provide some training and information on hepatitis C in return for a larger amount of time)

---

[23] Others, such as housing services, gave greater time and requested information and training around hepatitis C. This raised specific methodological issues. Data was generated alongside information provision. Here there was a conflict between wanting to promote greater awareness of hepatitis C and wanting to generate data for the thesis. This is just one of many messy strands it has been impossible to explore more fully.

[24] Following cuts and reorganisation of services, some of these teams have been reformed. This has implications for dissemination of the findings in that they will be both disseminated more widely among the participants across teams, but that the findings potentially have a lesser impact another materialisation of the messy context of the thesis.

which necessarily limited the data generated[25]. However, the sense of messiness was *more* than negotiating methodological issues and research practicalities, the phenomena of hepatitis C felt difficult to grasp.

An example of this can be seen in the way professional narratives shifted from talking about hepatitis C to discussions of HIV, hepatitis A and B, and even alcohol related hepatitis [similar to Law and Singleton (2005) - see below]. In these interactions, hepatitis C shifted in and out of focus, connected to, but not the same as other diseases. In short, hepatitis C could no longer be understood in isolation or as a clearly bounded object (see Barad, 2003 and below).

For example, on a team of social workers who worked with learning disabled adults, when asked about hepatitis C, one participant shifted the focus of the conversation to describe being vaccinated for hepatitis B in a previous occupation and the experience of one service user in relation to treatment for hepatitis B. Another participant described the negative treatment of one service user in institutional care related to her HIV positive status. This particular interaction was interjected by one other worker who commented *'wouldn't the nurses down the hall know more about this[26]?'*

To a degree, this echoes Davis and Rhodes' (2004) findings, that given the partial nature of their knowledge, participants made sense of hepatitis C in the context of diseases they felt they knew more about but it was more than this. A similar phenomenon was visible in participant accounts, suggesting that the shifting was not solely a matter of degree of knowledge about hepatitis C on the part of the professionals, as some literature has

---

[25] Clearly this raises some methodological issues, notably around the collection of consent in ad-hoc situations (this was collected verbally and no identifying information from the participants was obtained, only their position in the team). A full and robust discussion of the methodological issues raised in these situations are beyond the scope of this thesis.

[26] This shows that hepatitis C is marginalised in favour of diseases that the professionals perceived were better understood enacting it as something beyond their remit, as a health issue as discussed in chapter 2 and chapter 7.

suggested (van de Mortel, 2002, 2003; Paylor and Orgel, 2004). Interviews generated much messier accounts than I was prepared for. Participants living with hepatitis C also talked about HIV, cancer, housing and other existing impairments, as well as recovery and financial issues which were related to, but not the same as (Law and Singleton, 2005) hepatitis C, as this extended extract from David shows:

'Hep C has been one my biggest consequences of my active addiction in that physically it has taken this year of treatment out of me. Emotionally and physically, it has given me all this pain for all these years of living in denial and hiding it from people and it has given me a lot of pain, but it is only a consequence.... There are other consequences of mine, the other is that I do only get to see my son every couple of weeks watching football, another consequence is that I didn't get to watch him grow up... Hep C will always be, like I am hoping now it will be an experience, the treatment, that I will be able to pass on my experience to others just to tell them 'look don't leave it as long as I did, you don't have to'. In 5 years' time will it [having hepatitis C] be more socially acceptable? I don't know. I do believe the only chance it's got that the people who do go through treatment and get successful outcomes, that they don't just piss off to their normal everyday lives and forget where it was they come from because by doing that, they are forgetting what they was like when they needed someone to talk to... someone who had gone through it and got [understood] it. I am grateful that I am in recovery with other recovering addicts who have completed this treatment eight years ago and still want to help people...because they still remember what it was like for them and they want to give something back and I believe that is part of my part of my purpose in the fellowships and be[ing] in my workplace, to let people know and hopefully there will be more kind of support and there will be more agencies and there most definitely, hopefully be more education'.

Here in a recorded interview, the shifting, complex and multiple phenomena of hepatitis C is made visible. As David describes the implications of living with hepatitis C, each thought builds on the next with no clear separation between concepts, the experience of hepatitis C is inextricably bound up with other aspects of his life. Here, it is possible to see how hepatitis C is enacted (comes into being) differently in different places what Mol (2002) refers to as 'multiplicity'. Hepatitis C is variously enacted as a serious physical impairment requiring difficult medical treatment, and as an experience which has had impact on his emotional wellbeing, relationships and sense of self. Then it shifts. It is peripheral in his narrative as *'only a consequence'* – one of many he negotiates daily – and then enacted as an important reminder of his recovery, and as a point of identification and support with others who have done treatment, as well as a future opportunity for him to support others.

Importantly, it shows that the experience of hepatitis C is not fixed and therefore not totalising or inherently oppressive, but depends on the practices and relationships which bring it into being – explored under ontological politics (Mol, 1999) below. David explicitly links his own experiences and treatment as an individual to wider social structures (support education, service availability and treatment policy), resisting individualising oppression.

David's interview and the way hepatitis C moved about in it and seeped into other areas, facilitated an ethically (and politically) important moment in the research what Guillemin and Gillam (2004: 262) describe as 'the difficult, often subtle and usually unpredictable things that arise in the practice of doing research' this required reflexivity and prompted me to discuss this issue in greater depth with my supervisors.

Getting messy and making sense

In 2010, ten months into collecting data around personal and professional perspectives on hepatitis C, I had followed up multiple threads and been drawn down multiple avenues of

research, where hepatitis C appeared to shift and change (rather than become better understood or more clear) and was difficult to grasp or link together between one interview and the next. Some of the issues explored in interviews with people with hepatitis C, overlapped and connected with professional accounts (for example, the importance of access to treatment), whereas others were marginalised or not discussed at all (Law and Singleton, 2005) (for example, the need for social work support or post treatment experience) the implications and consequences of which are discussed throughout the thesis.

I no longer had a clear idea what I was exploring, what I had found or how it could be written, resulting in a deep sense of failure (Mellor, 2001). I was signposted to Law's (2004; 2006) work after discussing the anxiety and mess of the research process with my supervisors. We discussed how to some degree research fieldwork is messy and contingent (see also Duff, 2012 and chapter four), but this felt like more than the pitfalls of doing research in organisations, rather, the reality of living or working with hepatitis C was difficult to understand, accounts did not always neatly fit together, were difficult and inconsistent. Reading Law's (2004) *After Method; mess in social science research* provided the recognition (and relief![27]) that the research process and findings were messy, because most of the time the world is messy and accounts of it often 'distort it into clarity' (Law, 2004:2).

Producing misleading hygienic accounts

The sense of messiness and the thesis being difficult to hold still, was reinforced in interactions with other postgraduates and academics who appeared to explain their research topic with relative ease. I, generating and analysing data and drafting chapters, had real

---

[27] Like Guttorm (2012) I experienced an emotional, as well as an intellectual, connection with texts which is not something frequently included in research accounts, but is part of the complexity of the research process.

difficulty explaining what my thesis was about. It is possible that this can be attributed, in part, to the shifting and learning involved in the PhD process (Ferguson and Thomas–MacLean, 2012), but it was also heavily influenced by research accounts which appeared to set out with a research question in mind, *conduct* interviews or *carry out* methods and then come back and write it all up (cf. Smart, 2010).

A number of scholars in varying disciplines [see for example, Cameron (2007) in physiotherapy, Mellor (1998; 2001) and Cook (1998; 2009) in educational research and Thomas-MacLean (2012) in drama], have drawn attention to the dissonance between the realities of fieldwork and the accounts of it what Silverman (1985:4 in Buchanan *et al.,* 1988) refers to as a 'reconstructed logic'. They posit that the omission or removal of difficulties in accounts,[28] equates to a loss for academic scholarship including the contribution to knowledge that accounts of failed research can make concerning the avoidance of future potential harm (Cameron, 2007), or the role of these accounts in providing support to those experiencing something similar in the future, together with the creative opportunities that messy experiences provide (Mellor, 2001). Others have problematised the expectation that research should be a linear, clean and tidy process with clear outcomes, stipulating that detours and changes of direction in research can result in valuable outcomes for those the research is for (Ferguson and Thomas-MacLean, 2012).

Thus, it is not that the research process *is not* messy or difficult - but that this *may be concealed* in accounts. That is, the work that produces these accounts and the consequences this has for enactment and materialisation of hepatitis C experiences is removed what Law (2004:41) refers to as the 'fluidities, leakages and entanglements of the hinterland of research….the, missing seven eighths of the iceberg involved in method', (see also Fraser and valentine, 2008) explored further below.

---

[28] Another kind of silence - this is discussed in chapter six.

Accounts (both written and verbal) of intense, messy, difficult fieldwork and the resulting (or co-existing) struggle to understand, or painful changes in consciousness (see Stanley and Wise, 1979; Reeve, 2012a) are relatively scarce. In particular, I identified with Cook (1998) who referred to the sense of shame and guilt her untidy work generated. Both Cook (1998) and Law (2004; 2006; Law *et al.,* 2011) indicate that this is actually part of the process of generating new knowledge and forging new understandings.

There is some overlap here between the concerns raised above and Law's (2004) call to move away from accounts of method that are concerned with 'hygienic' research, following instructions (constraints) around how methods are supposed to be done, to produce clean, tidy and justifiable findings. Though Law's (2004) understanding of mess diverges from some of the above accounts, in that messiness is not treated *as part of a stage in the process to eventual clarity and resolution*. Rather, Law (2004) indicates that we need to recognise and accommodate messiness, because the world is multiple, difficult and active, and to ignore this would amount to asking reality to adjust itself to fit with our accounts (Law and Singleton, 2005).

A note of caution and explanation

It is important to note that I am not using the concept of mess as a means of sidestepping difficult questions about my work (Singleton, 1996), or suggesting that we abandon existing methodological texts. This is not what Law (2004) suggests and as can be seen in chapter four this is not at all what I did. Instead, Law (2004; 2006) suggests that we need understandings of mess and method which are broader, more generous, which recognise the role methods play in creating realities and the limit of conventional methods. Thus, I have explored the role that methods played in enacting specific realities and used the notion of mess to explore how hepatitis C is enacted in and through the experiences of people with it.

This, in turn, is intertwined with and helped produce my thesis, pushing me to think about hepatitis C in new ways (Fraser and Seear, 2011).

At this point, I need to be clear about what I mean by mess, not as a means of creating a fixed definition, but in order to make what follows accessible and understandable. Thus avoiding falling into a trap identified by Fraser and Moore (2008) (who use the example of the 'chaotic' in literature concerning people who use drugs) whereby the lack of definition around a term, means that it becomes totalising, potentially oppressive and further contributes to embedded assumptions around the term. This is especially the case in discussing mess, which is often perceived as something negative which should be avoided, contained or at least hidden from direct view (LaCom, 2007).

There are also some important connections here between the notion of messiness in research as something negative[29] which needs to cleaned up, with enactments and representations of hepatitis C (and bodies with it[30]) as infectious, abject (Harris, 2009a) and potentially dangerous and leaky (LaCom, 2007; Shildrick and Price, 1999; Lenton et al., 2011).

Harris (2009a) uses the concept of the abject in exploring the constitution of hepatitis C stigma, related to fears about contagion and the breach of bodily boundaries. Kristeva's (1982) words on the abject are particularly pertinent to the concept of mess discussed here the abject is 'that which disturbs identity, system, order and which does not respect boundaries, positions, rules – the in-between, the ambiguous' (Kristeva, 1982: 4). The abject is described as that we wish to thrust aside, but never fully can, given that borders are illusory. In the same way, it is impossible to thrust away messiness in research, like the intra-

---

[29] Used as a put down for those obsessed with making things tidy, an observation of Lucy Suchman in Law (2006).

[30] See also Imogen Tyler's (2008; 2010) discussion of the bodies of 'chavs' as excessive and beyond control.

action of hepatitis C and injecting drug use (Harris, 2009a), even as this concept disturbs our perceptions of the world as definite and pre-existing and of objects as definite and clearly bounded.

Both messiness in research and bodies with hepatitis C are subject to moralising discourses (see Fraser, 2004; Harris, 2010) concerning the need for containment or concealment. This is reinforced when we consider that blood is often enacted as a pollutant (Douglas, 1966) which represents contagion or negativity (Sanabria, 2009), and that blood flows, leaks and seeps (Shildrick and Price, 1999; Fraser and valentine, 2006)[31] beyond constructed boundaries. Fraser and Treloar (2006) found that this was enacted in the implicit structuring of some health promotion information based on binary understandings of the body with hepatitis C (i.e. open/closed, clean/contaminated, healthy/ill[32]) with the body represented as a clean, closed fortress). Participants in their study frequently internalised these binaries and representations resulting in a sense of 'total contamination' (their bodily boundaries had been breached). Fraser and Treloar (2006) suggest these binaries need to be disrupted in order to address (and avoid perpetuating) oppression, and alternative models should be proposed which recognise bodies as simultaneously open and closed (things enter and leave the body daily) and unstable and fixed (as with chronic illness). In the same way, I too wish to disrupt the tidy/messy dualism (along with other binaries[33]).

Within this thesis, the term mess is used to describe that which does not fit into existing frameworks, which disturbs boundaries and neatness and is frequently marginalised. It is

---

[31] However, the multiple nature of blood as creative and active is discussed below (Fraser and valentine, 2006).

[32] Fraser and Treloar (2006) maintain that another binary, that of 'having/not having hepatitis C' is also present. As will be discussed in chapters seven and eight, this is not clearly delineated. Although use of these binaries is perhaps medical, they do not provide sufficient insight into what it means to live with hepatitis C every day.

[33] In chapter seven the concept of *pharmakon* is used to describe the experience of treatment - disturbing binaries.

also that which is vague, fluid, and ephemeral, and difficult to make sense of (see Law, 2004). 'Messy' issues are those which are not easily addressed or 'fixed.'

Law's (2004) approach was chosen because it treats messiness as an end it itself rather than a state which is passed through to achieve clarity, given that clarity may be the result of distortion and oversimplification. The concept of mess as Law (2004) uses it was also highly relevant given that bodies with hepatitis C have the potential to be 'messy'. First, because as people who are chronically ill they do not fit into clearly defined categories (healthy or ill) or processes. Their everyday lives and experiences are nonlinear and characterised by shift and change[34]. Second, bodies with hepatitis C are messy given that impairment effects (and treatment and post treatment effects) fluctuate. Further, as explored above, the blood borne nature of hepatitis C and the perception of hepatitis C as contagious (Harris, 2009) add a potentially physically 'messy' element. Third, hepatitis C is (and has the potential to become) 'messy' given that, as the thesis shows, it is currently under addressed. There are no 'quick fixes' and it crosses professional boundaries (medicine, social work, community services e.g. department for work and pensions, housing). Criticisms levelled by Stanley and Wise (1993) (see also Law, 2004) concerning clean, ideal accounts of research, are paralleled

---

[34] The focus on non linearity and continuous and abrupt change might also be seen to have much in common with complexity theory; a meta theory which draws from a number of disciplines, including physics, computer science, maths and biology. This has increasingly been used within social work (Stevens and Cox, 2008; Stevens and Hassett, 2012), particularly in child protection and mental health contexts. Complexity theory offers a means of understanding complex and adaptive systems which constantly shift and change and which self-organise to produce effects which cannot be predicted (Stevens and Cox, 2008). A key feature of complexity is non linearity (Stevens and Hassett, 2012), which maintains that intended interventions are not always effective because the components of the system are not systematic or consecutive (A + B=C). In a linear model, hepatitis C testing and diagnosis should result in support and help for the person being diagnosed, but as is explored in chapter five this is not necessarily the case. In my view, complexity theory has much to offer those working in the hepatitis C field, for example, in aiding understanding of working effectively with people who use drugs or who are homeless , as complexity theory focuses on the whole system (the individual, their family and friends, the environment, the organisation context, the practitioners working with them) and explicitly rejects narrow thinking or oversimplification. As such, this is an area for further research. The work of Law (2004) was favoured in this thesis because of the explicit attention and recognition given to research methods in his work (which is where I began to realise the applicability of the concept of mess) and because I wished to focus on individual accounts rather than the systems in which hepatitis C care and support are delivered. .

in Kuppers' (2006) and Turner's (2007) criticisms of the sterile idealised bodies exhibited in Von Hagen's 'Korperwelten' (Body Worlds) exhibition. Both criticise the concealment of the process of crafting and maintaining the bodies in the exhibition[35] and the sense of removal from the messiness of living tissue. Kuppers (2006) in particular critiques the exhibition's promotion and re-enactment of the ideal, closed, dry, non-disabled and (mainly) male body. Kuppers (2006) and Turner (2007) also note that the cleanliness and closure is not maintainable; the bodies 'leak[36]'to make visible the processes which brought them into being. Kuppers (2006) points to the need for messier, more fluid, changing and affecting engagement with bodies (and diseases), such as Shimon Attie's exhibition about living with diabetes, 'White Nights Sugar Dreams', which combines personal stories of the experience of diabetes with video installations of changing landscapes. It does not present idealised bodies or conceal the process of production. Similar to my research, it 'started out as a project about Diabetes [hepatitis C] and goes somewhere else with it.' Thus the account of my own research (and the 'object' of study) is not provided in a clean and sanitised way. The process of production is acknowledged as an active constituent in the fieldwork and the thesis; the messiness of the accounts 'leak' and seep through these and multiplicity is enacted.

Law's argument

Law (2004; 2006) critiques methodological normativity: the understanding that research carried out according to specific rules will necessarily lead to solid, clear findings and that research which does not conform to these rules (or produces results that do not fit) are marginalised or denounced as failure. This has been recognised by a number of scholars, for example, Gould (2006), writing in the field of mental health social work, levels similar

---

[35] Kuppers (2006) also notes that the metal scaffold used to augment the positioning of one exhibit is airbrushed in promotional material, giving the impression that exhibits maintains their positions unaided
[36] Mould is present on one exhibit and scalpel marks are visible on others.

criticisms at the dominance of randomised control trials (RCTs) in determining the evidence base for mental health[37]. Similarly, criminologist Alex Stevens (2011) describes how powerful groups (including governments and policy makers) decide what counts as 'worthy evidence', and use it to shore up ideological assumptions surrounding illegal drug use (e.g. that it is inherently damaging and users must be punished or treated). Evidence which does not support these assumptions is ignored. This means that dominant groups and forms of knowledge maintain power and control, and thus have material consequences for those affected by decisions (i.e. impacts on policy).

These observations challenge conventional understandings of method as a technical endeavour, the employment of a set of tools designed to capture a social world (Law *et al.,* 2011) and a social reality which is assumed to be fairly definite and amenable to being understood through a set of specific processes (Law, 2004). Law (2004) asks what method would look like if we no longer understood the world and reality to be definite, that instead of passive tools we understood that methods actually actively work to bring specific realities into being.

 In making his argument, Law (2004) states that much research is based on a set of what he terms 'Euro-American assumptions', that the world is assumed to be independent (of our attempts to know it), anterior (exists before our attempts to know it), definite (bounded, clear, graspable) and singular (that is the world that exists is a singular material one). Law (2004) works to challenge these assumptions, positing that the world can actually be understood as vague, multiple, fluid and indefinite (Duff, 2012). Further to this, these processes have their own agency, active and evolving methods participate in producing active and evolving realties. Because the world is shifting and multiple, it is not possible to capture anything entirely; objects and experiences are brought into being in ways which are

---

[37] For a fuller exploration of the alternative non-hierarchical knowledge framework he proposes, see Gould (2006).

necessarily contingent, partial, and dependent on the methods being used and on the assumptions underpinning them.

Law (2004) uses the concept of 'method assemblage' in exploring the vague, fluid and multiple nature of the world. Encompassing the broader, shifting concept of method, he argues: 'Assemblage is a process of bundling, and recursive self-assembling where elements are not fixed in shape' (Law, 2004: 24.)   Thus, these methods and the realities expand outwards, shifting and changing with that which they come into contact. They necessarily exclude some things as they bring others into being, some which we are aware of (manifest absence) and others which we are not (otherness). The forms that this method assemblage took is explored in chapter four.

This has much in common with (and indeed draws on) Barad's (1998:3) concept of agential realism which she defines as an: 'epistemological and ontological framework which understands science [and other phenomena] as material-discursive practices which are productive rather than descriptive'. Barad (2003) draws on Neils Bohr's rejection of Newton's assumption, positing that objects cannot be understood as independent, clearly bounded and possessing independent properties, rather Barad (2003; 1998) argues for ontologically primitive relations (which she terms phenomena) which do not pre-exist but are co-constituted in intra-action with other phenomena. Thus, the term phenomena is used to describe 'objects' such as hepatitis C, 'treatment', 'stigma' relations and emotions, recognising the continually intra-active nature of the constitution of reality (see Fraser and valentine, 2006). Barad (2003) also challenges the separation between that which is being observed and the process and means of observation. Barad has been explicit in terms of the implications and applicability her work has for that outside science. In recognising that apparatus are active in bringing some realities into being and thereby marginalising others this has important political implications and consequences.

A key aspect of Barad's (1998; 2003) work is that we need to be concerned with *matter*. She maintains this has been marginalised by an appeal to language within the social sciences, but matter contributes to the creation of realities. Moser (2008:99) using Law (2004b) describes how the term *matter* can be understood to mean 'of importance', as matter-ing (i.e. in constant motion, enacted and re-enacted in various practices) and that they are 'matter-real not reduced to discourse or culture'. Similar critiques of post structuralism concerning the emphasis on language and the absence of the body, have been addressed by Hughes and Paterson (1997; Paterson and Hughes, 1999), Reeve (2004; 2012a) and Harris (2010) who call for the body to be brought back in to discussions and use phenomenology (the study of the body being in the world) to facilitate this. Though I have not explicitly drawn on phenomenology [for an example of this in relation to hepatitis C see Harris, (2009b)], I have paid specific attention to the materiality of the body, how it is brought into being in and through practices and relations, and the importance of embodied experiences in the data.

Focusing on people with hepatitis C

The experience of shifting ontological and epistemological perspective, recognising the world as vague and messy, has been uncomfortable and very difficult at times. As the understandings and writings of mess expanded, this enacted new issues and problems that I was required to think through. Previous frameworks for understanding the world were no longer sufficient (Cook, 2009). This thinking through required attention to detail and rigorous exploration, which could only be explored on a smaller scale. Mol and Law (2002:3) point to the smoothing process that occurs in the making of an academic piece, that even though these texts discuss objects and events that may be unusual, unexpected or difficult, the tone is 'almost always calm' and gentle. In this final edited draft, I too have participated in a

smoothing process[38], necessarily excluding some realities in including others. A degree of simplification has occurred. Mol and Law (2002) indicate that this is unavoidable and is actually necessary to explore the richness of the mess (see also Fraser, 2010: 232). One such simplification was the decision to focus only on the data generated from those living with hepatitis C, rather than also trying to focus on the professional accounts.

During fieldwork and writing to make sense (the second and third year of the PhD), there was a noticeable concentration in my writing on the data generated with those living with hepatitis C. Early chapters which took shape focused on the comparison participants made between cancer and hepatitis C, the experience of social security benefits and the experience of treatment and post treatment. Whilst the insights professionals offered were valuable, I felt that there was far more to be said at the time of writing by those living with hepatitis C. These experiences were complex and deserved in depth and focused attention.

Law (2004) is clear that it is not simply a matter *of choice* over which reality to bring into being, but that realties are enacted and depend on a hinterland. The hinterland is a constantly expanding bundle of relations, knowledge and practices which are usually made invisible during the research process, but which carry with them a weight and authority in dictating what is important in research.[39] In this case the hinterland included previous social research which explored the experience of living with hepatitis C, the dearth of such research within the UK (indeed the exclusion of specific enactments of reality), the enactment and materialisation of hepatitis C as a low priority for funding and support, and the increasing push towards medical treatments. Thus, in the third year of my PhD, as draft

---

[38] Although it has not been my intention to smooth out all the edges or to hide the mess, I have also attempted to relate the anxiety and slow progress generated.

[39] This makes me think of a quote from Plumb (2001:873), reproduced in Banwell *et al.,* (2005:341), concerning the dearth of research around women who have sex with women: 'without funding we cannot do research, without research we cannot be published in medical journals, without being published in medical journals we cannot convince medical professionals that a health need exists and without convincing them that a health need exists we cannot get finding for research prevention or programmes'.

chapters were written and the thesis began to be formed and shaped, I made the decision to focus only on the accounts of people with hepatitis C.

The move to focus the thesis on the accounts of those living with hepatitis C should not be taken as one which attempts to avoid exploring messy issues in professional accounts, or indeed draw a boundary around the accounts to contain them, rather, it was important to recognise that it would be impossible to address in depth (and satisfactorily) the nuances of both personal and professional accounts. The decision to focus solely on participant accounts was also a political one. In privileging the realities of those living with hepatitis C and focusing on issues which they had raised as important, this afforded specific attention to realities often marginalised or othered in the literature. This in turn contributes to making these realities *more real* (Law, 2004) and to a hinterland which recognises that living with hepatitis C requires social and emotional support, and that people with hepatitis C experience disablism. This is not to say that I will not be returning to interviews with professionals in the future, but this task requires care, time and adequate space, and as such is beyond the scope of this research.

The applicability of the concept of mess in exploring hepatitis C.

As described above, Law (2004; 2006; 2009) argues against the notion of pre-existing, fixed notions of realties and of objects (Barad, 1998; 2003). These positions have been used to explore hepatitis C by Fraser (2011). Fraser draws on Duffin's (2004a) assertions that hepatitis C, rather than being unearthed fully formed (frequently referred to as being 'discovered' or 'identified' in 1989), has been actively constructed over the last 20 years and is still very much under construction, socially, politically, culturally and medically. Fraser (2011) is explicit in her assertions that hepatitis C does not pre-exist the populations it

affects, but is enacted and materialised in specific practices[40]. I have followed Fraser (2010) in 'denaturalising' hepatitis C,[41] exploring how it is enacted by people with it (and myself) in interviews, in intra-action with the responses of services, welfare benefits application processes and treatment experiences. These enactments and intra-actions depend on, a hinterland, which the thesis and interviews draw upon and feeds back into, contributing to new enactments and re-enactments of hepatitis C and of treatment and the material, social and political consequences.

Law (2004) states that the world is in flux and that stability may only be possible for very short periods (see also Barad, 2003) indeed, this is visible with the use of the word 'enact' in the thesis. Enactment is a contingent, continual process, always already happening. The time period during which I participated in fieldwork and wrote the thesis, means it is particularly pertinent to talk about messiness and flux. At the time of writing, major reforms of social security benefits and the NHS are taking place (DH, 2010; Royston, 2012) and public services are being cut or reformed. This is part of a hinterland of political and economic action which will enact and materialise hepatitis C in multiple ways. For example, historical (and recent) enactments of welfare benefit claimants as undeserving (see Borsay, 2005; Garthwaite, 2011; Garthwaite *et al.*, 2013) intra-act with the conflation of injecting drug use and hepatitis C (Harris, 2005). This, together with an increasingly restrictive benefits application system and public information provided by some hepatitis C organisations; enacts hepatitis C as an illness experience which does not warrant financial support. This, in turn has serious consequences for people with hepatitis C. The experience of applying for welfare benefits

---

[40] A strikingly similar point has also been made by Disability Studies scholar Oliver (1990:58) in relation to normative speech, who indicates that pathologising individuals is part of an ideological commitment to shifting responsibility onto the individual and creating a role for Speech and Language professionals.

[41] This is not to say that hepatitis C does not have very real consequences. Law (2004) himself describes a commitment to 'primitive out thereness' - that we participate in a real reality. Similarly Treichler (1999) and Fraser and Seear (2011) emphasise the role of theory in contributing to urgent and positive change for people with blood borne viruses. This also involves employing 'mindfulness and reflexivity (Warin, 2011), as explored below.

and the way that this process produces people with hepatitis C and hepatitis C is explored in chapter nine. In addition newer treatments have developed during the writing of this thesis (NICE, 2012a; 2012b), which will enact hepatitis C and the bodies of people with hepatitis C in new ways.

The concept of multiplicity is also useful here, developed by Dutch philosopher Annemarie Mol (2002) and later used by Law (2004) in outlining his messy ontology. Mol (2002) explores how the disease atherosclerosis [42] is brought into being in various hospital departments; for example, under a microscope, in an operating theatre and in a consultation with a patient. In each of these environments, atherosclerosis is *enacted* differently, becoming different things for different people (Duffin, 2004b). This is not the same as saying that the disease is a fixed object upon which there are many different perspectives, but rather that the object itself is brought into being through specific practices in the hospital which produces different objects. Mol explores how some of these objects overlap, or are brought together (for example, in negotiations between doctors or in administrative processes), whilst others which do not, are rationalised away. In the thesis, I too explore how hepatitis C can be enacted differently in different places, i.e. in accounts made by people with hepatitis C, in work capability assessments, in blood tests, in appointments with consultants. Some of these enactments hang together or overlap with other enactments [for example, the hepatitis C (treatment) enacted by Keith in his conversation with the housing department overlaps with the hepatitis C (treatment) enacted by his consultant – see chapter seven], but not with others (for example, the post treatment effects reported by participants diverge from the post treatment protocol in the hepatitis C clinics). Here it is possible to see that different hepatitis Cs exist.

---

[42] Conventionally understood as a build-up of plaques in arteries which occur mainly in the legs. Impairment effects include pain and difficulty walking.

Mol (2002) uses an unwieldy concept to describe how these objects are not the same thing, but not entirely separable either - 'more than one less than many'. This involves a decision about what to bring into being. As Fraser (2010:233) observes, if realities are being made and remade in the process of intra-action, the unsettled nature of knowledge about hepatitis C infection and treatment, means decisions about what to bring into being are highly important.

Revisiting the messy fieldwork process

Now that I have outlined and explored the shift in understanding, I return to the examples from the data to explore how messy methods can be re-understood in light of Law's argument, and how this contributed to the co-constitution of the thesis. Or, as Watts (2012:36) states: 'the method was as much an effect of my fieldwork as my evidence'. As was described above, the fieldwork process was more complex, the sample much broader, the methods were shaped by organisational priorities (but also understandings of hepatitis C – see below) and interviews covered topics that I had not readily anticipated. In addition, participant illness, geographical location and my own views about hepatitis C shaped the method.

Both Charmaz (2004) and Law (2004) discuss how methods shape, and are shaped by, the circumstances and the phenomenon being explored. Harraway (1988) states there is a need to make room for the unexpected and also ultimately recognise that we are not 'in charge' of what happens in the world. As I engaged more with Law (2004), I recognised that I could not simply capture what was 'out there' and that hepatitis C was a phenomenon enacted in ways which overlapped, diverged and connected.

Charmaz (2004) discusses embracing the ambiguity and bewilderment in the research project, and the opportunity this presents, to gain an understanding of the phenomenon as a

result. For example, although the decision was made to discuss the personal perspectives of hepatitis C throughout the rest of the thesis, it was not a simple matter of separating professional and personal perspectives. Apart from the overlap that occurred for some participants, in that they worked in a substance use or blood borne virus service, the realities enacted in personal interviews made present the extensive reach of hepatitis C in terms of professions that are well placed to take a more active role. These professional interviews, in turn, also shaped personal interviews.

Charlie's interview (and subsequent publicising of my research within his network) led to the recruitment of two additional participants who were co-infected with HIV and hepatitis C, an important aspect of the research which may not have been made present if I had not been open to travelling with the flow of the project. This is an example of how methods necessarily make some things present, others knowingly absent [for example, the experience of hepatitis C among transgendered people also discussed by Charlie (Deacon *et al.,* 2013)] and others unknowingly absent (othered) (Law, 2004).

The data generated during a swift participation in a staff meeting, or the unanticipated generation of accounts with embalmers or men with HIV, might be seen by conventional understandings as a poor or failed method. However, the shift to understanding the multiple and shifting nature of hepatitis C, and the role of methods in enacting it, meant that I began to see the method as fluid and hepatitis C as a fluid object. In describing the maintenance of a clean water pump in Zimbabwe, Mol and deLaet (2000) found that although the pump was delivered to different communities in a standardised form, over time it was adapted by particular communities, using unconventional parts (i.e. not from the manufacturer) which the residents had adjusted to fit the purpose. Similarly, over time, my method and the realities I explored were adjusted, extending to explore a wider range of professionals and to explore enactments of hepatitis C beyond those made in medicine. If I had only maintained

the focus on the professional sample as anticipated (and which is predominantly reported in the literature), and not made adjustments to accommodate the messiness of hepatitis C in participant interviews, this would have smoothed out (and thus reproduced) the experience of hepatitis C as solely a medical issue and repressed those aspects which were vague and difficult to address. Here, Mol and deLaet's (2000) observations that it is the fluid and responsive nature of the object which makes it strong are particularly pertinent. The fluid and shifting nature of the method meant that I came to see how hepatitis was enacted and re-enacted by participants in different ways, making the research robust and opening up possibilities and opportunity for change. I acknowledged that I could not maintain control over the project if it was to be of most use to readers/participants. This approach also highlighted that hepatitis C has a much wider impact on a person's life than is currently enacted and materialised in policy responses.

In making efforts to explore that which is often made absent or 'othered', I have explored how hepatitis C is enacted by and materialised in the bodies of participants who reported not using illicit drugs, a group whose hepatitis C realities, and the significance of hepatitis C in their lives, are frequently 'othered' through policy and media responses which promote access to treatment and little else. I have also explored the social and emotional experience of treatment, given that current policy responses enact barriers to treatment as the biggest issue, whilst the need for support on treatment (or after) is marginalised. Moore and Measham (2012) in their work around the production of the 'drug' and 'drug problem' GHB/GBL (or 'G'), discuss how researchers contribute to the production of meaning of phenomena based on the participants who are interviewed (i.e. 'recreational' G users, or here, people who were no longer injecting drugs), the questions asked and the places in which interviews are conducted. This works to make specific enactments of hepatitis C - and the way in which treatment materialises in the bodies of those with hepatitis C - more visible. In seeking to combat the silence around hepatitis C within England, I have enacted

and performed specific hepatitis Cs, shaping what it is and how it is understood, especially regarding aspects which are more frequently marginalised.

As outlined above, hepatitis C was difficult to make sense of, between one interview and the next. These experiences were vindicated (and indeed stabilised and made more real) when reading Law and Singleton's (2005) experiences of exploring 'alcoholic liver disease'. Like Law and Singleton (2005), I found that pathways to and through diagnosis were fluid and multiple and which contributed to the making of hepatitis C in specific and particular ways. In addition, it was difficult to map one trajectory onto another. Some trajectories were not co-ordinated. For example, the trajectory of treatment did not (and does not) co-ordinate with trajectories for welfare benefits such as Disability Living Allowance (or Personal Independence Payment).

As with Law and Singleton (2005), it is possible that services for people with hepatitis C would be improved with better organisation and co-ordination between services[43]. However, poor organisation of services is only part of the issue, hepatitis C and the structures surrounding it are fluid and non-coherent and so, imposing order necessarily oversimplifies the experience. Hepatitis C must be understood in a context of multiplicity and non-coherence.

The writing process; making and cleaning up mess

This section addresses the process, practice and role of writing in co-constituting the thesis and enacting specific realities. It first addresses the important role that writing occupied for the duration of the PhD, and the forms and functions of this writing. The chapter moves on to discussing writing as a political activity (Mol, 2002; Law, 2004) bringing into being some

---

[43] Though some of the lack of co-ordination for people with hepatitis C may serve a political purpose, increasingly, restrictive PIP mean that the social and support needs of people with hepatitis C are even further marginalised – see chapter nine.

realities, excluding and 'othering' others. To bring the section to a close, I raise some questions which I have been forced to think through around the limitations of the written word in enacting and materialising mess and accounts of hepatitis C.

Writing has been key in constituting the thesis at every stage. The writing process was messy, multiple and not adequately captured by the term 'writing up' which, as Smart (2010) indicates, suggests a kind of hygiene and an approach devoid of creativity. For me, writing was a form of research (Mellor, 1998; Minkin, 1997) intertwined with fieldwork and reading a means of inquiry, used in a very similar way to Richardson (1994:517) who states that she writes 'in order to think, to find out more about a topic or myself and to travel in the thinking that writing produces'.

This writing took a number of forms, I *wrote around* topics I wanted to try out or make sense of, not all of which made it into the final thesis other times I wrote *through* difficulties, to make sense, to construct a chapter or to take a point as far as I could. I wrote *down* in order start somewhere, to have something on the page, or to get it out of my head. Writing *up*[44] came much later when final chapters and edits were being ground out and refined.

Forms of writing included: notes in my research diary, transcription, annotations on transcripts and articles, scrawled post-it's on trains and buses, keywords or observations on a bedside notepad, as well as working drafts, conference papers, presentations to professionals and documents for PhD requirements, plans and ideas[45]. In addition, I made room for multiple interpretations (and multiple realities) using the comments function in Microsoft Word to record my thoughts or reflections, links I made with other chapters, or to question my own observations during the writing and re-writing process. Minkin (1997: 172-

---

[44] In Lakoff and Johnson's (1988) discussion of the orientational metaphors 'up' and 'down', 'up' is frequently used with the implication of positivity, success and progress, whereas 'down' is frequently used to denote negativity, states of unhappiness, subordination and loss. Thus, 'writing up' implies a progress, a sense of control over the PhD, which I would argue against.
[45] Part of the method assemblage (Law, 2004).

175) makes a similar point in talking about writing, he says: 'movements back and forth will often depend on the way the mind engages and connects with the data as well as how the data the data is accumulated...chance can produce new associations and new productive connections'. In the interests of presenting an account which includes multiplicity, I have included these, where possible, in the final product. I have not pursued a singular account but made room for multiple enactments. The 'cut and paste functions' in Microsoft Word enabled saving, moving to other documents (and chapters), drafting and redrafting. This also meant that multiple enactments of the thesis reality could exist alongside each other at the same time, facilitating the thinking through of the consequences (e.g. the comparisons participants made with cancer and the challenges to it). Here, writing allowed and maintained my focus on multiplicity of thought and interpretation (Law, 2004), and highlights how the process of writing was just as important as the final product in enacting messy realities.

Conventional accounts of writing emphasise the gradual move towards clarity, sense making and singularity (Minkin, 1997). In earlier drafts I found myself using phrases like 'as the research moved forward' or 'as the research progressed', which imposed a framework of progress and obscured the back, forth and circular movement of chapters[46]. This was particularly evident in earlier versions of this chapter where new mess was made with each draft. As mentioned above, not all of the writing was enjoyable, this process has been anxiety producing, tedious and difficult to keep going. Writing as a process of discovery (Minkin, 1997) meant I was forced to think through new and difficult concepts (like mess!) which were sometimes uncomfortable as the ground shifted (and indeed continues to shift) beneath my feet. I had to consistently remind myself of Cook's (1998) observations about the skill, time (and I would add, patience) in enacting mess. This echoes and intra-acts with

---

[46] Cf. Mol and Law (2002) suggest that research and writing might be viewed as tidal, rather than linear. Tidal movement makes space for ebb and flow, swirling and being caught in currents.

the comment from one participant, Pixie (revisited in chapter seven), about the impossibility of a 'quick fix' in developing support for people with hepatitis C. Obscuring or removing the messiness and difficulties of writing in order to make writing (and thinking!) swifter and easier[47], would create and re-enact silence around the difficulties for people with hepatitis C and contribute to enactments of hepatitis C which were limited and further removed from participant experience.

Continuing to write also enabled me to remain engaged with the PhD. When the messy nature of the fieldwork meant that it was difficult to see a way through, or when previous understandings were shifting, writing was a way of establishing and maintaining a connection with the data and the thesis (Mellor, 2001; Woodby *et al.*, 2012), and it is possible to see the development of the thought process on earlier drafts. Writing was also an embodied process[48] which I used to establish whether a point or draft felt 'right' or not - this is not easily translated onto the page but feels both ephemeral and at the same time searing (Mason, 2011). Key findings and working drafts were developed, understood and refined through reflexive engagement with feelings of discomfort, pain and positivity (the 'yes!' moments), as well as flashes of inspiration and identification (Law, 2004). These engagements helped me to make sense of 'ethically important moments in research' (Guillemin and Gillam, 2008) and to negotiate the contingency of the research and writing process (Whiteman, 2010) which further shaped the thesis.

Reflexivity in writing was important in understanding and reflecting on what kinds of realities I was crafting (Law, 2004): what was being made present, what was being made absent and

---

[47] Although this would have involved 'considerable violence to the data' (Smart, 2010:4) in making it fit.

[48] In addition as explored by Crooks *et al.*, (2012), my own impaired body and the need to make adjustment to my workspace shaped the production of my work in terms of what and how I wrote. On days when impairment related pain was well managed, writing on my laptop was much more focused. Days when pain was not as well managed (or indeed where impairment effects were exacerbated by sitting at the laptop) often forced me to return to handwritten notes and drafts. Here, the space afforded by being away from the laptop meant that writing-related stumbling blocks were often overcome.

what was being othered or repressed (Law, 2004). Writing is an inherently political activity (see Mol, 2002; Law, 2004; Moore and Measham 2012), as explored above. In recognising this, I have paid attention to the multiple natures of interpretations, making space for that which does not fit or is usually excluded. For example, the time period between diagnosis and receipt of formal support (chapter five), discussions of cancer and HIV (chapter six), treatment and post treatment experiences (chapters seven and eight), and the difficulties and non-coherences around accessing social support and applying for welfare benefits (chapter nine).

The intra-active nature of writing means that it is not just a uni-directional process of putting words on a page, but the act of doing this sparks thought and discussion and alters ideas and realities. As Barad (2003) indicates, realities cannot be brought into being through processes which are solely social – in this way the electronic document, being cut and pasted and commented on, 'kicked back' (Barad, 1998:116) and became an active participant in the constitution of the thesis. The comments function meant I was able to make links and connections between chapters, which augmented and supported my use of Reeve's (2002; 2004; 2008; 2012a) concept of psycho-emotional disablism. A draft chapter on the symbolic nature of blood (space constraints and the specific direction of the thesis means that this has been necessarily made absent) augmented the fieldwork and the object of study as messy. The first draft of what eventually became chapter six also incorporated discussion around post treatment effects which, over time, in struggling to draft and redraft, I realised was a far bigger issue that needed to be explored in a standalone chapter.

One of the most important points that Law (2004) (and others, see Barad 1998; Mol, 2002) make concerning the role of methods is the possibility that reality can be remade - realities can always be another way. Law (2004) maintains that this crafting of specific realities requires a researcher to take responsibility. If realities can be another way, then there is a

need to pay attention to what a 'good' reality might be, and what the implications and consequences might be (see also Fraser, 2010). In keeping with Law's (2004) philosophy, no general answers can be provided, and can only be decided specifically and locally, clearly this depends on the hinterland of my own disciplinary commitments. For example, my commitment to challenging the oppression of disabled people and to developing an improved response to hepatitis C in the UK. Law (2004) suggests that *politics* is one form of good which we can pay attention to in enacting realities. Realities and method assemblages that are crafted, can contribute to better social (and non-social) arrangements, amplifying particular patterns and thus, enacting some realities as more real than others. Within the thesis I have tried to work in ways which contribute to improved social arrangements for people with hepatitis C, making realities which materialise the social and emotional realities of living with hepatitis C, as well as the medical ones.

However, Moore and Measham (2012) highlight the limits of the researcher's ability to enact particular realities. They discuss the generative potential for research maintaining that its agentic qualities mean that the researcher is not always in control of the realities that are enacted, in the reading and use of published data. This, therefore, has the potential to compound, as well as challenge, inequalities and the making of disease experience in particular ways.

This final section explores the limitations of writing in making the vague, fuzzy and ephemeral (Law, 2004) known. Just as Moore (2008) indicates that it is difficult to translate the embodied experience of pleasure onto the page, Law (2004) also questions whether that which is vague and messy can be translated onto the page, given that writing about non-coherence necessarily produces some kind of order. Law (2004) does make some suggestions about the forms this might take, for example, the presentation of objects or poetry which do not depend on a reality which is independent, pre-existing, definite or

singular [49]. The use of poetry and other forms of writing is explored, and used, by Guttorm (2012) in her discussion of the development of a conference paper. Guttorm (2012) states that once she acknowledged mess, she found it impossible to return to the definiteness of a conventional research account.

Paradoxically for me, although the process of writing has made room for mess, my own political commitment that the thesis be of use, necessarily requires a coherent, accessible and engaging final product, which might appear to be at odds with mess. In addressing and justifying this, I focused on Law's (2004) observation described above, that enacting good realities depend on reflexivity and political decisions. In crafting a written account, I have a final thesis which conforms to what Law terms 'common sense realism', partly out of necessity to receive the PhD (because of the hinterland that academic scholarship is built on - indeed Law (2004) himself indicates that this is difficult to avoid), but also in order to be of use to practitioners who may read the thesis (or parts of it), and to give credence and make visible in an academic arena those areas of participants' lives which may not have been made visible before. However, I have also paid attention to what is not being said and what emerged in the spaces between participant accounts. For example, in asking participants about their experiences of services and their treatment by professionals, they spoke about feeling undeserving of welfare benefits (chapter nine) and also of the meaning of the dingy nature of services they attended (see chapter five).

One of the messiest examples of living with hepatitis C was from the participant who later withdrew from my study. This withdrawal has meant that it is not possible to include data from this particular participant and points to a larger issue concerning the difficulties and constraints involved in making mess visible and reporting on it. For this participant, the experience was (literally) messy in that it was very difficult to make sense of and had intra-

---

[49] American writer and academic Michelle Leavitt has used poetry to explore aspects of her own experience of living with hepatitis C - see Leavitt (2011).

acted with many other life experiences to the point where it became clear it was unethical to include them. The exclusion of her difficult, but important, story has actively shaped the thesis, with consequences for the discussion around the impact of treatment and the need for support from mental health services. This highlights the way that mess is often concealed or unreported. Indeed, it is potentially too messy for ethical review processes, requiring negotiation of, and attention to, contingency throughout (see Whiteman, 2010) and the development of 'ethics in practice' (Guillemin and Gilliam, 2004), as is explored in chapter four. I have tried to ensure that the participant's effort in recounting these difficult experiences was not in vain, by exploring some of the messiness involved in the interview process (rather than content) in chapter four.

Making recommendations

The move to understanding the shifting and continually intra-acting nature of hepatitis C has raised specific questions and ethical dilemmas about how to bring the thesis (indeed the chapters!) to a close, and how to balance the need to make recommendations for practice, policy and further research without also falling back into viewing hepatitis C as singular and fixed. It has been necessary to acknowledge that providing a neat, clean end to the thesis has involved a degree of obfuscation, silencing some of the complex realities of living with hepatitis C. Acknowledging the shifting and vague nature of reality and the need to provide some starting points for improvements to practice and policy, has involved a 'delicate balancing act' (Warin, 2011: 807) between the theoretical and philosophical commitments which make such recommendations possible in the first place, and the need to honour the contributions of participants (Etherington, 2007) who wish to see change in the way people with hepatitis C are supported. It is not my intention to draw a division between these two things, in addressing this issue, I argue (following Warin, 2011) that it was necessary to

reflect on the reasons for engaging in the research and in doing so, I realised that recommendations, whilst involving a degree of fixity, can also acknowledge the ambiguous and shifting phenomena of hepatitis C and indeed, this should form part of the recommendations. Therefore the recommendations in appendix one are included with a recognition that they are intended to be taken forward and built on to create new enactments and materialisations of hepatitis C.

This chapter has explored and outlined the shift in ontological and epistemological understanding that occurred through and within the process of fieldwork. Given that a key point within the chapter concerned the active role of methods in bringing realities into being, chapter four now explores these methods in more detail.

Chapter Four: 'Getting messy', the realities of fieldwork

Introduction

This chapter describes the twists and turns of the research process, exploring in depth the messy and complex practicalities I faced during fieldwork. It should be read alongside chapter three, with which it is closely intertwined. As explained in chapter one, the decision concerning the ordering of (what became) chapters three and four was not an easy one, given that I wished to remain faithful to the co-constitutive nature of the phenomena of hepatitis C, the methods used and the accounts generated. It was through the research process that the 'messiness' became apparent and shaped the epistemological and ontological position (Braun and Clarke, 2006), and the reader should remain mindful of this.

The first section of this chapter outlines aspects of methodology which underpinned the study from the outset. It details personal and professional experiences and attributes which shaped the research process, design and goals. The rationale for using qualitative methods is provided. The second section addresses the practicalities of the research process, detailing the development of the research design, application for NHS and Lancaster University ethical approval, sampling and recruitment strategies, including how the cultural position of hepatitis C and the current responses to it in the UK were enacted in these strategies. I then move on to discuss the research interviews, the need for flexibility in interview mode and the generation of participant accounts.

Later, I explore some pertinent issues which arose during the fieldwork process, including the realities of 'informed consent', the challenges in recruiting from a connected community (i.e. support groups and online forums), and the role and responsibilities of the researcher during fieldwork. The chapter ends with an exploration of the analysis process and how early

dissemination shaped the findings, before closing with a discussion of the limitations of this study.

This chapter makes new and important contributions in a number of areas. It adds to the emerging body of work around hepatitis C which recognises the co-constitutive role of the method in enacting specific realities of living with hepatitis C. It explores some of the methodological issues which arose from working with people who have hepatitis C, which have not been documented to date (for example, recruiting from a pool of people who know each other and the effects of treatment on the consent process). Further to this, existing qualitative research with people who have hepatitis C has favoured face to face interviews. I show that interviews can also be conducted using other mediums (MSN and telephone) and that these modes enact different realities of living with the virus. The chapter (and indeed the thesis) has the explicit aim of talking honestly and transparently about the difficulties faced, and how rather than being seen as moments of failure or poor practice, these difficulties were indicative of the complex and fluid nature of hepatitis C.

The use of qualitative interviews with people with hepatitis C

Qualitative methods aimed at generating accounts of participants' meanings, interpretations and experiences (Mason, 2002) were chosen from the outset. Hepatitis C has historically been marginalised, both globally and within the UK (especially in England where most of the participants lived), and Korner and Treloar (2006) highlight how people with hepatitis C have frequently been included as subjects in clinical trials, rather than as people with support needs. Harris (2009a; 2010) similarly describes how those who use drugs are frequently

referred to as 'IDU', obscuring their personhood. Thus it felt important to utilise methods where greater emphasis was given to the perspective of participants[50].

Further to this, Conrad *et al.* (2006) maintain that the complexity of living with hepatitis C is lost (or rather, enacted in an even more partial way) through quality of life measurements reinforcing the need for a flexible and accommodating method. The commitment to including the perspectives of people with hepatitis C has become increasingly important, given the rapid developments in treatment (see chapter two and chapter seven). Here hepatitis C becomes something to be cured rather than an experience which impacts on a person's life. It is important to emphasise here than I am not aiming to naively 'give voice' to participants (explored in greater depth below), but to provide and open up further space for accounts which make visible the complexity of living with hepatitis C.

Rationale for qualitative research

Mason (2002:1) maintains that qualitative inquiry requires researchers to be engaged on emotional, physical, practical and intellectual levels, and that the biography of the researcher plays an important part in shaping the research design. Here my background in social work was important in developing the position I took towards the research participants, notably that expertise arises from living in and through particular experiences (Beresford and Croft, 2001). Thus the experience of hepatitis C was given a place of 'epistemic privilege' in the research (see Shah 2006; Stanley and Wise, 1993).

As described above, the perspectives of people with hepatitis C have historically been marginalised, so it was particularly important for me to pay attention to power relations in the interview process and create an environment where the interview became an exchange of views, rather than one person questioning another (Burgess, 1984). Though I indicated

---

[50] Though this is not to imply that the researcher does not play a central role in shaping these accounts – discussed below.

from the outset that, like Harris (2010), I aimed to combat the silences and silencing that operates around hepatitis C, this does not mean that I uncritically subscribe to the claim to 'give voice' to the participants in this study (see James, 2007; Ashby, 2011) indeed, participants described numerous ways in which they were using their own voice to raise the profile of hepatitis C, including responding to consultations on the national liver strategy, writing to their MPs about the difficulties faced on treatment, talking about hepatitis C within services, working with services to develop improved responses and setting up support themselves. Thus, the research is just one area where their views were being given. Furthermore, the 'one off' nature of the interviews meant that very partial realities were enacted, when their bodies, feelings and experiences shift, other partial realities may come into being; as Richard stated *'there might be other things that might occur to me another day.'*

Whilst the sample did also include those who were less vocal about their hepatitis C experiences (indeed I was only one of a handful of people some participants had told), it is important to note that participant voices are necessarily qualified by the researcher. The choices in selecting quotations (choosing and editing which voice to present), in interpreting and developing themes, and the writing, did not involve the participants directly (Braun and Clarke, 2006), recognising that the interpretations are my own, and that my voice is important too (Ashby, 2011). However, in working from the positions I did (see below), I was carrying out the research with the key aim of combatting oppression (Vernon, 1997) faced by people with hepatitis C.

During the research process, I made specific efforts to address power relations including letting participants choose the location and mode of the interview, travelling to them, giving them control over switching the recorder on and off, and making it clear that I was aware of their expertise in relation to hepatitis C. I was mindful of Oakley's (1981) observations that

interviews are best based on non-hierarchical relationships, when the interviewer is prepared to share their own experiences and respond honestly and meaningfully to questions. During the interviews I shared details of my interest in hepatitis C, my professional background, my home life and my impairment when appropriate. This was important in establishing rapport and reciprocity (Elmir *et al.*, 2011), showing an appreciation for the stories they had shared with me and (hopefully) negating any sense that I was 'mining' (Kitchin, 2000) their experiences. I also did my best to answer questions. These included [as Oakley (1981) defines] questions about the research, the outputs and requests for information (though there were limits here - see below). I also answered personal questions, including one which stayed with me for a long time:

Grace: 'Do you feel I am contagious? When you mix with us?

Heather: No! I really don't -and I mean that honestly.

Grace: Is that because of what you've read or because of what you haven't read? (Chuckling)

Heather: Probably because I have spent a lot of time - as a student you're taught to find stuff that's... rigorous and solid information - I've got a fairly good idea of how (hepatitis C) is spread and there isn't really that opportunity there. And I don't think it's helpful, certainly not for me to think of it in that way. I don't think of people with hep C as contagious.

Grace: Are you okay mixing with people with AIDS?

Heather: Yeah

Grace: Do you know something I don't have a problem mixing with people with AIDS, I never have and I don't know anyone who has it but I've always thought I wouldn't have a problem with it'.

By asking whether I thought she was contagious, Grace requests personal reassurance and explores my values and motivations. This strengthened my assertion that multiple interpretations are possible. However, Grace quickly moved to talking about people with hepatitis C in general. I remember feeling unsure about how to answer this question at the time, it felt important to try and address some of the negative feelings around hepatitis C that Grace had, particularly around how 'contagious' hepatitis C is and, indeed, that having hepatitis C at all, should be inherently bad. At the same time, I was reluctant to be so vociferous that Grace felt her views were dismissed, potentially contributing to further oppression, or guilt, and damaging rapport. On reflection, I am uncomfortable with the links I first made around transmission, which enacted hepatitis C, predominantly as 'possibly infectious'. However, this observation and the reflection on it, intra-acted with and has informed the findings chapters. This also motivated me to reflect on the pervasiveness of internalised oppression (Mason, 2001; Reeve, 2008) and negative views experienced by people with hepatitis C . When Grace moves on to discussing people with AIDS, she appears to be both seeking my approval in developing rapport and is simultaneously enacting a hierarchy of disease – see chapter six.

Influences and identities I brought to the research

Milner (2007) states that all researchers should reflect on their position in relation to participants. There has been vast literature around the issue of the researcher sharing the experiences of the people they are interviewing or working with (see for example: Fatimilhein and Coleman,1999; Allman *et al.*, 2007). Within disability studies there has been much discussion about the role of non-disabled researchers in disability research (see for

example: Drake, 1997; Branfield, 1998; Duckett, 1998). My negative hepatitis C status proved to be a source of significant anxiety for me in the planning stages of the research, in that I would be considered an 'outsider' and therefore less suited to researching such a sensitive issue. Whilst there were some incidences where participants indicated that my hepatitis C negative status negated understanding on an experiential and embodied level, others referred to the importance (and unusualness) of someone who does not have the virus being interested in it, or the value of having a different perspective (Holloway and Biley, 2010). Furthermore, the complexity of hepatitis C experience and the multitude of contextual factors which impact on participant understandings (i.e. age, gender, life experience, and treatment experience) would not have been minimised in the event that I too, had hepatitis C.

I worked from the position that identities and traits are fluid and unstable rather than essential categories, and I occupied a range of different positions which were understood differently by participants (Halse and Honey, 2007). The privileging of hepatitis C status potentially overlooks the multiple and cross cutting characteristics shared (or not) between researcher and participant. Brown and Boardman (2011) indicate that different facets of their identities came to the fore during the research process. Similarly, my identity as a woman, disabled person, research student, social worker, advocate, and partner all made appearances during the research process and helped me to support participants, whilst my experiences of living in a different geographical area, my age, gender and my sexual orientation may have inhibited some areas of discussion (Takeda, 2012). As Measham and Moore (2006:19) note, 'insider and outsider status is partial, flexible negotiated with a range of positive and negative implications for the research process.'

As both Shah (2006) and Brown and Boardman (2011) have recently indicated, research is always shaped by the researchers experience, my own experience of impairment and

disablism also brought a shared experience of oppression, which then connected the experiences of people with hepatitis C with other disabled people.

Shah (2006) maintains that a researcher can bring ontological privilege (see also Goodley and Tregaskis, 2005) including the use of empathy which helps to understand and identify both similarities and differences. Warin (2011) emphasises the importance of interrogating the feelings of similarity (the 'me too' moments), so that blind spots are not created or overlooked. Thus, I became wary that I could *over identify* commonalities between myself (and other disabled people) and those with hepatitis C. I made reflexive efforts to explore the differences between people with hepatitis C and (other) disabled people. Some participants' rejection of a disabled identity and the ways in which people with hepatitis C may not fit easily, are reflected on in chapter nine.

My previous experience as a social worker (and my on-going commitment to social work) meant that I maintained sensitivity to the role social workers can play in supporting those with hepatitis C. However, it also engendered strong feelings during and especially post, interview. Reading through notes and transcribing interviews, I was repeatedly struck by feelings of frustration concerning the lack of support offered to people with hepatitis C, which increased throughout analysis, where a role for social work support was clear.

My age and my female gender may have also impacted on the research particularly in establishing open and supportive relationships. My age (mid-twenties at the time of interview) coupled with my status as a student may potentially have deterred some participants from taking part, in terms of feeling I was 'just a student' (see Sampson and Thomas, 2003). I took steps to guard against this, for example, by introducing myself as a 'postgraduate researcher' (see also Garthwaite, 2009). My status as a student may have helped me to gain access to some participants, for example, Daniel was currently engaged in further education and Kerry and Laurie indicated a willingness to take part because they too

had also completed research based dissertations. Some of the participants indicated that I was about the same age as their children and this may have helped them to feel more comfortable and balanced out some of the power differences.

My female gender may have been helpful in some ways, participants may have felt it was easier to share details with a woman [given the stereotypical positioning of women as caring and good listeners (Padfield and Procter, 1996)] but it may also have meant that participants shared more than they meant to (Finch, 1993) indeed, some asked for aspects to be removed from their transcripts. My gender may also have inhibited some areas of discussion, for example, in relation to sexual relationships. Whilst some of the female participants discussed this with me, it was less common among men. In addition, with the participants who lived with both HIV and hepatitis C, there may have been some areas of discussion that I may not have had easy access to, given the one-off nature of the interview.

My own 'personal qualities' played a significant part in the progress and route of the research and eventual formulation of this thesis (Punch, 1994). There is little existing literature about the way that the research is shaped by the researcher's own (shifting) traits, but my passionate interest in the experience of living with hepatitis C, flexibility and openness to following the flow of research in unexpected directions were integral in exploring and enacting the complex and multiple experience. It was important for me to be receptive to the phenomena of hepatitis C, to engage with as many accounts as possible and with as many facets as possible. This curiosity and passion sustained me through difficult periods and the untidiness and openness meant that I followed up on things that a more structured PhD may not have allowed.

In doing so, reflexivity was key, defined here as the continual exercise of 'stepping back' from the research to critically examine the researcher's position, in relation to the research and participants. It is described by Hertz (1997: viii) as an intense examination of 'what I

know and how I know it,' an on-going conversation, whilst existing in the present moment. The feelings and observations which arose from this process were noted in my research diary, post interview notes and using the comments function when drafting in Microsoft Word. These observations shaped and, in turn, were shaped by, engagement with the research process and thus became a form of data (Crooks *et al.*, 2012; Takeda, 2012). As will be discussed below, openly exploring and explaining my position and the ways in which the findings and the thesis came into being are used to exhibit rigour within the research (see Koch and Harrington, 1998; Jootun *et al.*, 2009).

Gaining ethical approval

I initially intended to advertise the research in local hepatitis C clinics, and drug and blood borne virus services, in order to make contact with people with hepatitis C and professionals involved in their care, although I was not asking services to play any part in the recruitment of participants because of the potential threat to anonymity. As I anticipated that staff interviews would take place on work premises, I was required to obtain ethical approval from the local NHS Research Ethics Committee (REC) and individual sites via local Research and Development offices.

This involved completing a lengthy online application process known as the 'Integrated Research Application System' (IRAS). IRAS is intended to be a comprehensive system for applying for the permissions and approvals for health and social care research in the UK, in one single electronic application (IRAS, 2010). Completing the application and awaiting approval proved to be a long and labour intensive process, taking 12 months from beginning the application to gaining REC approval, which brought with it both benefits and challenges[51]. The ethical approval process started only 8 weeks after beginning my PhD,

---

[51] Here NHS Ethical Approval is pharmakon (Derrida, 1981). A concept explored in greater depth in chapter seven.

which was helpful in encouraging me to systematically think through the research project from beginning to end, including ethical issues I thought I might face. This process required fixity and clarity, potentially inhibiting creativity in research design. Ethical approval processes such as this have been criticised by social researchers who maintain that the process does not lend itself to the flexible and shifting nature of qualitative fieldwork, and that risks posed to participants in biomedical research (for whom the process was initially designed) are very different (see Dyer and Demerit, 2009). This process also obscures the complexities inherent in fieldwork which cannot be systematically addressed in applications, explored below.

Others maintain these lengthy ethical approval processes, far from encouraging researchers to reflect on their project, become a 'hurdle' to clear or are intended for institutions to protect themselves rather than providing protection to participants (Hammersley, 2006; McDonagh et al., 2007; Alderson and Morrow, 2011). Further, as Winlow and Hall (2012: 412) suggest, there is the potential for ethical commitments to be replaced 'by a world weary cynical process deprived of the real substance which would make the process real and valuable'.

As I outline below, the ethical issues I faced in the field were on-going and contingent (Whiteman, 2010) and could not be addressed through a one off process (Halse and Honey, 2007). Indeed there is a difference between what Guillemin and Gillam (2004) term 'procedural ethics' (discussed by ethics boards) and 'ethics in practice' (the unpredictable issues which arise in everyday fieldwork). I thus employed the advice of Halse and Honey (2007) and Guillemin and Gillam (2004) to engage reflexively with the research process, place respect for persons at the centre and to pay attention to ethically important moments arising in the course of research.

I applied at the same time to Lancaster University Research Ethics Committee (UREC), receiving approval in 2009. Thus I was able to make contact with local support groups not attached to NHS services and also with online forums. The lengthy nature of the NHS approval meant that I actually recruited 13 participants with UREC approval and a further 8 after obtaining NHS clearance. This shaped my research in that I moved away from recruiting in formal services, the implications of which are explored below.

Sampling and recruitment

Due to the 'silent' nature of hepatitis C (explored in greater depth in the data chapters) people living with it are neither physically nor culturally visible (see Suarez and Shindo, 2008) and can be marginalised, meaning recruitment strategies needed to be sensitive and careful. The recruitment strategies themselves were also bound up with and constrained by, the lack of dedicated formal support services, and the post code lottery which exists in the UK. This meant some participants were more easily accessed than others and thus, the experiences of hepatitis C included in this study were enacted in particular ways.

I was keen to access a range of people living with hepatitis C, both those who were and were not in touch with formal services (including drug services). I printed a list of support groups from The Hepatitis C Trust website and contacted support groups in turn. I contacted every support group that provided email addresses in England (approximately 12[52]), and local[53] ones (5) by phone, as well as visiting local services both to publicise the research and make myself known to professionals. I made the decision not to recruit from the support groups run by The Hepatitis C Trust, given that they provide a wide range of support services[54] from

---

[52] The numbers of support groups was correct at the time of research.
[53] Defined as being within one hours' journey from Lancaster
[54] Including support groups, awareness raising, welfare benefits advice, telephone support and information.

their base in London and I wished to obtain the views of participants who may not have had access to such services.

I quickly learned that making initial contact with support groups via email was more fruitful than making contact via telephone, often calls were not returned or voice mail messages were not responded to. This may be because this was effectively a 'cold call' (Genovese, 2004) from someone unknown to the support group facilitator, or mobile telephone numbers may have changed, or I may have been calling at inconvenient times. The improved response when recruiting via email may have been because support group leaders were able to absorb the information I provided in written form more easily, before responding to my request to visit.

Due to the uneven distribution of support groups in England and the concern that my email/phone contact would have to pass through a support group leader who may or may not pass on the research details to those in the support group, I was advised by a support group co-ordinator to contact an online forum with whom they had close contact. Online recruitment proved to be the most rewarding way of contacting participants (see below) and there was some crossover between forum participation and support group attendance, which helped with snowballing. I anticipated that recruiting via online forums may also mean I accessed those who were not currently accessing services in relation to their hepatitis C, though this was not borne out in the sample.

It became clear when I visited support groups to advertise the research and hand out flyers, that those who wanted to participate were more interested in doing a one to one interview than participating as part of a group (also reported by Carrick et al.,2001), so the method was altered to accommodate their preferences (Kerruish, 1995). In retrospect, this allowed me to gather more in-depth data and to side-step issues, such as preventing those who did not wish to participate from attending their support group, maintaining confidentiality, and

logistical issues such as access to rooms, which support groups often paid for and I would have had to fund.

As I was aware that those most at risk of contracting hepatitis C were those who used drugs, I also made a concerted effort to advertise and make contact within drug services. I sent information and flyers to local services, including hepatitis C specialist clinics (three), homelessness services (one), housing support services (one), drug services (five), a local drug user forum (one), sexual health services (three) and residential rehabilitation services (three). I also tried, as far as possible, to visit and spend time in these services (though this may not have been enough), and I know of professionals who approached those they knew had hepatitis C and invited them for interview. During this time, I obtained only one interview with a participant who reported using illicit drugs, though he was unsure of his hepatitis C status (waiting for a test result), so his data has not been included in this study. Thus, although some participants were in recovery or had used illicit drugs in the past, no-one in the study reported actively using illicit drugs at the time. This may also be a performance of candidacy for treatment (Coupland and Maher, 2010) (i.e. those who are actively using drugs are not routinely offered treatment despite guidance to the contrary) and thus, may not have wanted to come forward to talk about their experiences. Notwithstanding this obvious limitation, this focus on those who were not using drugs could be considered a virtue of the study. The research has provided insights into areas which at present remain under explored, namely what happens after diagnosis, what it is like to live with the virus, and support and information needs on treatment.

Eight participants were recruited from online forums, seven were recruited from support groups, four were snowballed from existing contacts, one saw an advert on an email list, and one was recruited through advertising in a service.

Recruiting from an online forum

The potential afforded by the internet (in my case, online support forums) in making contact with those who are isolated, hidden, or difficult to engage, has been widely recognised and utilised (Davies, *et al.*, 2004; Sanders, 2005). Two separate support group leaders recommended two different support forums to advertise my research and make contact with participants. I contacted a named moderator on each of the forums[55] to explain who I was, what I was doing and asked to post information about my project in order to encourage people to come forward for interview. Brownlow and O'Dell (2002) question the ethics of recruiting from online forums when these may be the only groups people have to talk about difficult issues. Mindful of this, I maintained throughout that I would not be using the comments on the forum in the research. The forum would only act as a means of recruiting.

However, this in itself may require additional assurances and the researcher may be explicitly required to establish credibility (see Sanders, 2005 for a robust discussion of these issues), as I learned from one forum moderator. After posting information about the study and my contact details on the forum, this message was posted:

'Heather, There's no problem with a researcher joining the Forum and asking questions, BUT as a former research student I/ we would:-

a) - ask you to post to the moderators first (just to ensure the questions/survey is appropriate).

b) - provide ethical assurances about your research from a supervising lecturer.

C) - research is done in an open post - not a private post where appropriate.

---

[55] For both forums there were a number of moderators unbeknown to me at the time.

I know how hard research is and we'd like to help in any way as long as you're happy to comply'.

This gave me the opportunity to clarify the role of the forum in the research and provide ethical and confidentiality assurances, which one participant in particular indicated was key in his decision to participate in the research. Interestingly, this only happened on one forum. Those on the second forum appeared to be happy to participate without these explicit assurances (though these were given on the information sheet), where forum moderators acted as gatekeepers. Indeed these moderators suggested that advertising the research gave *their* forum credibility (see Brownlow and O'Dell, 2004).

One participant did wish to check my credentials prior to going any further and contacted my research supervisor. The name of my second supervisor was given as a contact point on the information sheet for anyone who wanted further information or who had any concerns (see appendix three).

It is important to note here that although the online forum provided a valuable opportunity to make and maintain contact with participants, including those who may not be in touch with support groups, or who were too impaired to attend in person (Hopwood *et al.*, 2006) - there were clear influences and limitations on the sample. Most obviously, that participation on an online forum depends on access to the internet, so those who do not have it, cannot afford it, or for whom it is inaccessible (Watling, 2011) are excluded. In addition, those who participated on the online forum and were available for interview may have had some particularly extreme experiences as Keith indicated: *'the people that do go on tend to be the kinds that are having a hard time'.*

However, the sample did include those who experienced no treatment effects and who worked full time, indicating a range of experiences are included. Participants were also recruited offline through advertising in services, adverts on mailing lists and snowballing. The

sample did include people who were active in moderating forums and developing support for people with hepatitis C, and who may have spoken about aspects of their experiences before which 'crystallise into a certain form over time' (Stacey, 1997:39). Many who participated in the interviews made it clear that they felt it was important to raise awareness of the issues around living with hepatitis C (and being on treatment) and thereby contribute to change (Clark, 2010). However, their involvement in the field meant that they frequently moved from talking about their personal experiences to talking more widely about the experiences of others. Thus the account is a co-construction between me, the participant and others with hepatitis C, the accounts cannot be considered in isolation, but are connected to (and a materialisation of) wider connections to the community.

Semi-structured interviews

This section explores the use of semi structured interviews which were undertaken on a one to one basis with 16 of the participants. Three others participated in a group interview and two were interviewed as a couple.

I was mindful that in asking people with hepatitis C to talk to me about their experiences, that this should be treated as a sensitive topic (Lee and Renzetti 1993) and that it may have taken considerable effort for them to come forward[56]. With this (and possible impairment and treatment effects) in mind, participants chose the mode of interview (face to face, telephone, MSN or email) to make it as easy as possible for them to participate (Sturges and Hanrahan, 2004; Hanna, 2012). 11 participated in face to face interviews; five at their home, one in the workplace, one at a residential rehabilitation centre and four at a local support meeting (three in a group interview). Eight participated in telephone interviews and two interviews were conducted via MSN messenger. Face to face and telephone interviews were

---

[56] This may explain why no one came forward to be interviewed in drug services being seen with me, as someone who interested in researching hepatitis C, might imply a positive status for those who are concerned about it.

recorded with the consent of participants, using a digital voice recorder. One telephone interview recording failed, so notes were made and then sent to the participant for checking.

Semi structured interviews were chosen for their informal nature, described as 'conversations with a purpose' (Burgess, 1984; 102) providing direction for those who may be unused to talking about their experiences, but also allowing room for flexibility to elaborate on their specific experience[57]. Interviews ranged in duration from 55 minutes to three and a half hours, and were typically two hours long. I have chosen to use the term 'generating accounts' rather than 'collecting data' to acknowledge that the interview is not a process of excavating fully formed experiences from a participant, in which the researcher plays no part, but that interviews are dialogic, multiple processes whereby utterances and questions shape the interaction (Mason, 2002).

The interview guide

The interview schedule (see appendix four) explored the experience of hepatitis C broadly, including the first time participants heard of it, the experience of diagnosis, access to treatment, types of support received, areas where support was required or missing, together with positive and negative aspects of living with the virus. After each interview, I listened to, reflected on and made notes on each account. This meant that I refined the interview schedule to include specific areas of questioning that participants had raised (i.e. post treatment support), thus enacting these as important and worthy of discussion.

---

[57] I have tried, as Law (2004) and Mellor (1998) advocate, to acknowledge the fuzziness of the world and to explore it. The open-ended nature of the interviews, and the flexible way in which I approached data collection, has allowed for some of this mess to remain unrepressed, whilst acknowledging that this mess has itself been refined and tidied in specific ways (i.e. in deciding what to ask of interviewees, in making decisions about which participant groups to include).

During analysis and writing up, the linearity and unidirectional nature of the schedule became apparent, re-enacting hepatitis C care pathways and existing policy responses (see for example: DH 2004; HCV Action, 2012; NHS Medway, 2010).

Here it became clear that I had attempted to enforce a kind of order and that accounts had wriggled out of this (Smart, 2009; 2010). The flexibility of the interview schedule, together with my decreasing reliance on it as I participated in more interviews (Stephens, 2007), and my willingness to go with the flow of research, meant that the messy, nonlinear, non-chronological nature of the experience was enacted. The multiple nature was also made clear when participants frequently asked for the tape recorder to be turned back on to record their thoughts as the interview drew to a close. This is not to say, however, that the interviews generated a 'full' account experience, as they are always partial.

Face to face interviews

Face to face interviews are commonly considered superior to other modes of interviewing (Sturges and Hanrahan, 2004)[58] as they enable both parties to participate in embodied communication, as well as verbal. Many of the face to face interviews took place in participants' homes. These interviews enacted a reality which was not present in the other, non-face to face interviews. Treatment and post treatment effects and the impacts of these were much more visible. For example, some of the issues Morgan later discussed in her interview became clear before I had even arrived at her house. The nearest large town was half an hour from where Morgan lived, requiring a bus journey and then a taxi journey. This travelling provided me with an additional understanding of the disabling structural barriers she faced when travelling to appointments (discussed in chapter five). Furthermore, before the interview began, Morgan showed me the rash which covered parts of her upper body

---

[58] Though as discussed below, I would argue that the experiences enacted in telephone and MSN interviews were just as strong they merely bring different realities into being,

and the hair loss she had experienced as an effect of treatment. Here, hepatitis C was enacted as something which needed to be justified, as well as something which had serious effects. The intra-action and inclusion of details concerning participants' bodies is also part of engaging with the messy and embodied reality of hepatitis C. The rashes and itching in particular, were characterised by Morgan as the toxins of the treatment seeping through her skin. Charlie, who was interviewed in his workplace, enacted a reality whereby his employer was supportive of his experience of hepatitis C (explored further in chapter nine). Other, documentary evidence of participant experiences were provided in the face to face interviews, such as letters from doctors in support of applications for benefits[59], manuscripts they were working on to tell their story, government consultation responses, completed questionnaires and poems they had written as part of their recovery. This makes the multiple nature (Mol, 2002) of hepatitis C visible and gives strength to the use of flexible qualitative methods used in this study.

Between a focus group and a group interview

Two participants chose to be interviewed as a couple and three participants were interviewed in a group at their local support service (in line with what I had originally planned at the outset). The interview with the support group highlighted issues that I did not encounter so visibly in the one to one interviews, notably working with gatekeepers. Access to these participants was facilitated by a professional with whom I had contact and who provided advice and support to the group. I had no idea how many participants would be in attendance before I arrived for the interview that day, and had not corresponded with individuals in advance to explain the study and provide the questions and information sheet

---

[59] This could also be seen as an effort by the participant to be seen as 'credible' and' genuine' (see Werner and Malterud, 2003; Werner et al., 2004) - explored in chapters five, eight and nine.

in the same way I had for previous interviews[60] - which had been valuable in establishing rapport. The support group facilitator was present throughout the discussion with these participants. Whilst I initially had some concerns that participants might be less inclined to talk openly, the worker's input, prompting and existing relationship and knowledge of the participants, meant that she prompted further dialogue or elaboration.

I have used the term 'group interview' to describe this method of data generation, rather than focus group. Gibbs (1997) indicates that it is important to note the difference between focus groups and group interviews. Where focus groups explore the dynamics and interactions between participants and use this as a source of data (see Kitzinger, 1995; Krueger and Casey, 2000), group interviews are questions and answers asked of each participant (Thompson and Demerath, 1952) although in indexing of studies, these terms are often used interchangeably. In practice, the data generation fell somewhere between a focus group and an interview, with participants building on and disputing each other's points of view, as well as responding individually to questions. The intra-active nature of the group interview meant that topics were covered more broadly and this led to frustration that I had not been able to hear more about one participant's views. Brad had spoken openly prior to the arrival of other participants, but had been less vocal in the group setting. Here, more confident and vocal participants enacted their particular hepatitis C, whereas less common hepatitis Cs (Brad's was contracted through rape) were marginalised, or less easily shared in a group setting. Clearly this also depended on my ability to facilitate and shape the interaction, which I could have taken greater control over, to give Brad more space to speak. That being said, the participants did enact hepatitis C in shared ways, particularly in relation to how they felt about treatment and their own blood.

---

[60] Although I sent these to the (professional) support group facilitator.

Two other participants were interviewed about their experiences together; they were not only able to build on each other's points, but to interject with their perspectives to encourage the other participant to reflect on their statements, although they sometimes 'tuned out' when the other one spoke and had to be brought back up to speed. Interestingly, the participants interviewed as couple had met during treatment and had worked together to develop support services and raise awareness therefore, their interview re-enacted hepatitis C as under resourced and poorly addressed.

Telephone interviews

Eight participants chose to participate in an interview by telephone, at a time convenient for them. Historically telephone interviews have been perceived as better suited to quantitative research (Shuy, 2003; Holt, 2010) and as inferior to face to face interviews due to the absence of non-visual and nonverbal cues (Novick, 2008). However, I found that telephone interviews were a mode particularly suited to generating accounts of hepatitis C. This is not to say that the telephone interviews did not present some difficulties. Sturges and Hanrahan (2004) state that telephone interviews offer a greater opportunity for note taking as the researcher is not seen by the participants, but I found it extremely difficult to make notes at the same time as trying to listen, think and respond, and thus abandoned the practice early on, scrawling key words on 'post-its' where absolutely necessary. I also felt that it took longer to establish rapport, with the introductory question *'tell me a little about yourself'* requiring greater elaboration and reassurance that participants were giving the 'sort of thing' I wanted (Irvine *et al.*, 2012). Upon reading the transcripts, I also felt that I had sometimes missed the opportunity to probe or follow up on specific threads, having been reluctant to interrupt and disturb the flow of the conversation (Stephens, 2007) this was easier face to face where a participant was able to tell by movement or facial expression that I wanted to interrupt, or via MSN where I could relate questions back to previous text (discussed below).

There was little noticeable difference in the length of the accounts generated by telephone compared with those generated in face to face interviews, (consistent with Sturges and Hanrahan, 2004; Stephens, 2007). Indeed, the longest interview was conducted by telephone. I found that although the phone interviews required precise concentration, the everyday nature of the telephone conversation (Irvine *et al.*, 2012) encouraged participants to talk openly. Further to this, telephone conversations about hepatitis C might be considered more 'everyday' than a face to face in-depth discussion, given that the participants often described interactions with specialist nurses or consultants as brief. The suitability of using the telephone to talk about hepatitis C was further reinforced by participant accounts of supporting others by telephone; for example, at one support group the participants were planning to develop a telephone buddying service.

In keeping with my ontological position briefly outlined earlier, the methods outlined in this chapter participated in the enactment of realities each interview enacted hepatitis C and the participants in particular ways. This was made clear in Grace's interview. I first met Grace at a hepatitis C support meeting. She initially refused to participate in the research face to face, but left her number with the support group leader inviting me to contact her. During the telephone interview Grace explained that she had disclosed to very few people (as she felt intensely negative about her hepatitis C status) and attended support groups very rarely, thus she had not wanted to risk missing any important and new information by participating in an interview there and then. Grace indicated that she found it easier to talk about her experiences of hepatitis C knowing that I was physically a considerable distance from where she was (Joinson, 2005; Buckle *et al.*, 2010) and there could be no connection made between us, outside of the support group leader. This afforded her a greater degree of anonymity (Rose, 1998; Giles, 2006) and control, as well as side stepping a number of awkward and potentially anxiety producing situations where my physical presence might have been difficult to explain (Sturges and Hanrahan, 2004). Grace made it clear that there had been a

number of incidences where her hepatitis C status had been disclosed (or nearly disclosed) by others. Thus, interviewing by telephone simultaneously reinforces Grace's negative feelings around hepatitis C and challenges them, Grace could quite literally keep the interview, and hepatitis at arm's length, whilst simultaneously being able to talk about it openly on her own terms. Similarly, Boab resided on a remote island off the coast of the UK and thus, the telephone bridged the gap by reducing travel, but also highlighted the difficulties he had in travelling to appointments.

Online interviews

Law's (2004) position that realities are the effect of particular inscription devices (e.g. laptops and specific computer programmes) is particularly visible in interviews with two participants which were undertaken using synchronous online chat programmes (Windows Live Messenger previously known as MSN Messenger). Electronic typed messages are exchanged in 'real time' between researcher and participant (Oppendakker, 2006). Throughout both interviews there was no audio or visual communication, only typed messages. This initially felt both cold and very immediate: the typed medium and 'one off' nature of the interview meant that informal conversation felt minimal (even though it took the same amount of time as a face to face or telephone interview) however, I felt pressured to respond swiftly, in order to convey that I was interested and engaged.

This was both assuaged and heightened by the indication of activity in the bottom corner of the screen, e.g. 'Laurie is typing'. This sometimes explained why there were long gaps between messages. However, lack of any other forms of communication meant that it was impossible to determine what the participant was thinking or doing. Thus, it was important to convey warmth and develop the relationship as much as possible in a limited medium. Whilst Opendakker (2006) pointed to the use of emoticons and text speak in developing this, I found that I relied less on these (on reflection I was concerned about coming across as too

informal or not taking the interview seriously), preferring to be explicit in my responses to participants.

One of the strengths of this mode of interviewing was the readymade transcript. This meant that I could scroll up and down the conversation, reading over previous answers in order to absorb and formulate new questions, although this had to be done quickly in order to not feel as though I was keeping the participant waiting. As a result, I felt that my prompting and probing was more thorough during the MSN interviews and these needed to be carefully linked to avoid confusion and loss of the conversation thread.

Online interviews have been described as time and resource saving, reducing the need for travel and transcription, convenient for participants and providing a level of distance and anonymity (Davis *et al.*, 2004). However, the length of the accounts generated in the time period was considerably shorter (Oppendakker, 2006). An interview which was two hours and 45 minutes long generated 15 pages of typed text, with answers tending to be shorter. Davies *et al.* (2004) has indicated that the nature of the MSN interviews necessitates closed and focused questions and negates the in-depth exploration of meaning, although this was not my experience as I found that participants shared sensitive and emotionally charged experiences. This is potentially connected to refinements in the design of MSN messenger and the development of broadband internet, improving the speed and reliability of internet connection since Davies *et al.* (2004) published their findings. Joinson (2005) indicates that the act of typing means that both participant and researcher have to think more carefully about their answers, and researchers may gain increased access to attitudes and emotions. One aspect which I had not considered prior to interview is that participating via MSN requires embodied work from participants in a way which is different from face to face and telephone interviews. Both of us were required to type for prolonged periods which resulted in fatigue. Within the literature, online participation is often presented as being enabling for

disabled participants, given that there is the opportunity to rest or break off (Seymour 2001; Bowker and Tuffin, 2004; Guise *et al.*, 2009). However, the immediacy of the interview and the physical work involved is not extensively documented in the literature, but is important in considerations of access.

As mentioned above, there is a lack of visual cues, body language and even tone. This became clear in an unexpected way:

Freda: *'I am toying with the idea of possibly joining a support group...*

Heather: *Is there something holding you back?*

Freda: *Also because I am so labile at the moment I cry so much*

Heather: *Really?*

Freda: *I have cried most the way through this*

Heather: *Through this interview? Freda, I'm so sorry. I didn't mean to make you upset*

Freda: *No it isn't you upsetting me.........I would have stopped if it was.*

Heather: *As long as you're sure. We can stop anytime.'*

I had absolutely no idea that Freda was crying at any point, highlighting the partial and constructed nature of the interview (I only know what the participant chooses to tell me). The partial nature of the interview mode means that certain aspects of hepatitis C (such as depression and the side effects of the treatment) are silenced, as they are via lack of support provision – explored further in the data chapters.

Another clear example of the intra-action between the method and participant experience in enacting hepatitis C is visible in the extended extract from Freda below. In the excerpt (eight minutes of the interview) Freda describes being unknowingly referred to a hepatitis C nurse

after experiencing bleeding from her bowel (though it is not immediately clear the two are connected) and proceeds to recount the events that precipitated the referral:

Freda: 'I didn't even know I was being referred to a hep c nurse!!

Heather: Really?

Freda: Yes

Freda: I went to my GP as one morning I woke up went to the loo and there was so much blood it scared the life out of me

Freda: I have had problems with painful bowels but just assumed it was Irritable Bowel Syndrome

Heather: Had that never happened previously then?

Freda: Had haemorrhoids but never blood like that

Heather: So what was the GP like when you went to see them?

Freda: He was fine he asked about it the bleeding frequency etc. then said he would refer me to a specialist

Heather: Did he know about the hep C?

Freda: Received an appointment very quick for a colonoscopy? Camera investigation

Freda: Yes as it's on my records

Freda: but he never mentioned it

Freda: I saw it on computer screen as he flicked through my history

Heather: Right, so, was it through the colonoscopy that the hep C came to the fore again?

Freda: Heather this may sound stupid but I don't know

Heather: It doesn't sound stupid...

Freda: I went and had a couple camera things [examinations] at one hospital then I had an appointment at my local hospital then I had another appointment with the same doctor but at the big hospital. It seems this doctor is the hep c doc

Freda: But I still didn't know!!

Heather: So, can I just clarify? You were being sent to see a hep C doc without really knowing you were going is that right?

Freda: So just over a year ago I went to local hospital to the chest clinic area!!

Freda: yes

Freda: I was going for my bowels.'

Here the short sentences exhibit aspects of the experience being drawn together and enacted by both myself and Freda, bit by bit. It is slow, tentative and not immediately clear[61]. Freda indicates that the presence of blood in the toilet motivates a visit to her GP, who knows about her hepatitis C, but does not mention it in the consultation. Freda is referred for further investigations of her bowel at two separate institutions (the reasons for which are not clear), where along the way, invisible work (Law, 2004) is done by professionals who establish her hepatitis C positive status, which is dealt with by the same doctor and thus, the specialist nurse joins them in the consultation. This highlights the contingent nature of hepatitis C, and the fuzzy and uncertain nature of the eventual engagement with services,

---

[61] Cf. Applebaum's 'stop' in Law (2004:10)

which is enacted in the short asynchronous dialogue. Here it is not possible to obtain an overview of the experience rather it is made visible slowly. This extract demonstrates the impossibility of a single fixed truth there are multiple threads at work, only some of which are visible.

Benefits of interviews

The potential for qualitative interviews to be beneficial to participants, as well as the researcher, deserves some exploration here. A number of participants indicated, unprompted, that they had found it helpful, enjoyable or valuable to participate in the interview, or had gained new understandings as a result.

> *'It's probably helped me talking to you more than anything' (Boab)*

> *'I am only just realising that here now' (Charlie)*

It is well documented that talking to someone who is genuinely interested in experiences - which participants may not get the opportunity to otherwise relate can provide catharsis (Hutchinson *et al.*, 1994), validation that experiences are meaningful and worth listening to, (Elmir *et al.*, 2011) and provides an important outlet for stories that may be otherwise silenced (Charmaz, 2002). This was particularly important for those with hepatitis C who may not often have the opportunity to talk or whose experiences may be distressing this is closely intertwined with findings discussed in chapter five. Freda referred explicitly to participating in the interview so she could 'practice' disclosing. There was some evidence that these interviews had a therapeutic function given that the chance to be introspective in a safe and secure environment was rare (Clark, 2010) for these participants[62]. This works to enact hepatitis C as an experience which requires both emotional and social support as well as medical. Clark (2010) indicates that participants may also take part in order to feel that they

---

[62]Although I am far from trained to be able to provide this - discussed further below.

are contributing and that their experiences have a purpose. This was evident in interviews with participants for whom it was clearly tiring or upsetting to continue, but did so. Though it is important not to be disingenuous here, I will be the one who benefits in terms of career advancement and academic recognition (Oliver, 1997; Priestley, 1997; Mason, 2002).

Ethical issues

Here I explore in depth some of the ethical issues I faced during the fieldwork. These occurred in the fieldwork process and were different to those I had initially anticipated during the ethical approval process:

Travelling to participants

As I was aware that participants may be experiencing impairment and/or treatment effects, I indicated that I would be prepared to travel to them, both to make participation as accessible as possible and to send a clear message concerning the importance of their views. This offer was taken up by 11 participants who were interviewed face to face in different parts of the UK. One was interviewed in his workplace during working hours, one at a rehabilitation centre where he lived (in a meeting room) and four were interviewed at support meetings (where others were present or in close proximity).

Travelling raised a number of issues. My own impairment effects mean I do not drive, requiring me to use public transport. Thus, in prioritising participants' own impairment effects, this meant compromising my own in order to 'get' the data. This was aided by funding from my department which covered travel costs (including taxis) to help manage impairment effects, but highlights how different identities (researcher identity) are prioritised over others (disabled identity) at times (Brown and Boardman, 2011).

There were additional issues concerning researcher safety (see also Sampson and Thompson, 2003; Bahn, 2012). Although I was aware that the possibility of a dangerous incident was highly unlikely, and I do not wish to 'other' the research participants given that I travelled long distances alone by public transport, sometimes requiring an overnight stay, means that it was a frequent concern and is worthy of discussion here. The possibility that researchers may travel via public transport was not often considered (see for example, Patterson *et al.*, 1999 and Kenyon and Hawker, 1999) with transport advice extending to car maintenance and parking. A different set of issues arise for those on public transport, including: inclement weather, distances between stops and participants' houses which have to be travelled on foot, unanticipated diversions which are not shown on route planners, and late or cancelled buses or trains. Whilst this may seem mundane, at times these issues were a source of anxiety and additional stress for me, both on my way to and from interviews, which I managed as part of the fieldwork process. Not including them in the write up contributes to the silencing and marginalisation of these issues[63].

However, there were some aspects of travelling via public transport that proved beneficial to the fieldwork process. In my case on buses, trains and in short bursts on foot. I particularly came to value the time spent travelling on trains (Watts and Urry, 2008, for a fuller discussion) when sitting was possible. I found that the motion, warmth and dedicated liminal (Turner, 1966) journey time, where I was between stops but unable to be anywhere else facilitated thinking and writing, especially when taking notes after interviews and winding down. Travelling also enabled preparation for interviews or annotating articles and drafts, which ultimately helped me to make connections between chapters or points of interest. This could be interspersed with looking out of the window which I found helpful in allowing ideas to flow, and I often gained flashes of insight. Sometimes travelling during rush hour

---

[63] There is a link here with the often unspoken or unconsidered issues of transport in relation to attending welfare benefit appointments (cf Soldatic and Chapman, 2010), discussed in chapter nine.

was unavoidable and this proved to be both physically tiring and anxiety provoking, when neither sitting nor note making was possible. During these times, the need to make notes in order to document fleeting thoughts or questions meant I developed strategies, such as scrawling key words on post-its which were small enough to be held in my hand whilst leaning against handrails in train vestibules and adhering to surfaces to enable writing. When travelling on foot, this afforded a sense of space, an opportunity to be in the fresh air and aid my clouded brain.

Safety

Participant safety was also paramount. I was aware that the people I interviewed were effectively allowing a stranger into their house. To provide assurances, all correspondence by post was on university headed paper and emails were sent from a university address. I also provided contact details for both of my supervisors. Although there are some suggestions that social researchers are underequipped for lone working, my social work training meant that I was able to employ similar strategies as I had when visiting service users at home. For every interview, I left the name and address of the participant, with a colleague - also a close friend who would continue to support me out of office hours where necessary - in a sealed envelope with the time of interview and expected time of return, with agreed strategies in the event I had not made contact. I made contact via text or phone at the beginning and end of every interview (Bloor *et al.*, 2010). Interviews were arranged for the middle of the day where possible, avoiding arriving or leaving in the dark. I developed clear, methodical and contingency route plans for areas I had never visited before and called a taxi to collect me from the address if I was unsure. Participants themselves were often aware of the risks taken by a lone female researcher on foot with one participant (who was part of a feminist group) providing me with a personal alarm during the course of our interview.

Safety concerns aside, travelling to participants and meeting them face to face - in one case even staying for the weekend[64] - meant that I was more able to continue conversations after the tape recorder had been turned off which provided additional insights and context, to share cups of tea, to chat and show my appreciation for their time.

Through staying with one participant, I also experienced first-hand what another described as the benefits of the *'physical presence of others with hepatitis C'* (JB) after attending an informal support meeting. This also meant that I was able to advertise the research to more participants, who could ask me questions in the flesh before agreeing to participate. This proved invaluable as I was able to snowball and interview four participants as a result.

Recruiting from a pool of people who know each other

As explored above, a number of people who participated in the research were members of a forum which existed both online and as a physical network which holds meetings at regular intervals. Whilst the snowballing of people who knew each other was useful in gaining access to participants who might not otherwise have seen the research or volunteered to participate, it also raised issues around confidentiality and the maintenance of on-going relationships in this small supportive community. As indicated above, I spent one weekend with a participant. On my return journey to Lancaster, I planned to take a detour to interview another participant who had seen my advert on the forum. During the weekend I became aware that these participants knew each other, though not how well. As the weekend drew to close and I was asked about my plans I felt unsure what to say. Although I knew they were in contact I was unaware whether both parties knew I was interviewing them. I made a swift decision (cf. Punch 1994) not to say anything about where I was going next in order to avoid potential breaches of confidentiality and awkward questions. As I was arriving at the second

---

[64] Prior to this I got to know the participants over the phone and via email, and also received unsolicited assurances from other professionals who knew them personally.

interviewee's hometown, I received a phone call from her asking if I had arrived, indicating that she had spoken to the participant I had stayed with, who was under the impression I was heading back to Lancaster. Although I had done my best to try and maintain confidentiality I felt as though I had deceived them both. I was concerned that I may have damaged the relationship with the participant I had not yet interviewed, and refuted the kindness and support shown to me by the participant who had given up their weekend to host me, as well as behaved unprofessionally. I made it clear to both participants why I felt I had been unable to say anything about who I was interviewing and both indicated they understood. Reflecting on this, it would have been better to indicate that I had additional interviews lined up and been clear that I could not indicate who these were with for reasons of confidentiality.

In addressing issues around maintaining confidentiality, Clarke (2006) has pointed to the importance of not identifying the community within the research, but the practicality of this is questionable. Whilst the name of the forum is not included here and no location data is included for any participants, it is possible that in reading the thesis and the outputs, participants who know each other will be able to identify others (either from their stories or the contextual data included) even when data has been anonymised. This has implications not only for individuals but for networks too (Clarke, 2006). It is suggested by Morse (1998) that contextual data is removed, but this decontextualized form of research may be of little value or relevance to services, and potentially neglects the personhood of the people who participated. I have managed this using a number of strategies It has remained important throughout to remain respectful of participant accounts and to be mindful of the maintenance of their relationships beyond the research.[65] The thesis has been written as if participants would read it themselves, which has meant taking additional measures to protect participant identity in some instances e.g. not using the pseudonym in some extracts,

---

[65] Especially given their importance, discussed in chapters five and seven.

choosing to hold back sensitive data [privileging participant wellbeing over potentially interesting findings (Damianakis and Redford 2012)]. Participants were also offered a copy of the transcript to edit, and a summary of findings and key themes. I also modified participant descriptors by removing some specific detail which could potentially identify them, for example their occupation or number of children.

An additional implication of recruiting from a network of people who knew each other was that it became obvious that they were talking to a potential audience (see Taylor, 2012) who they felt might read their contributions and took it as an opportunity to make their appreciation clear. One participant explained she was made aware of the forum following a contact on Facebook. She stated: *'after I had accepted her request [on Facebook] and thanked her for taking an interest in me'.*

However, these on-going relationships can also affect the data and findings. One participant, who indicated that the online forum was a vital source of information and support, was so anxious not to damage relationships that she removed all references to it on checking her transcript (even though she had made no disparaging comments). This may mean that those who had negative experiences in their close knit community would have been reluctant to disclose them, although other participants were more open about the limitations as per see Keith's comment regarding forum participants *'having a hard time.'*

Participants using their own names in the thesis

In the interests of protecting participant anonymity, it was outlined in applications for ethical approval and participant information sheets that no identifying information would be used and that participants could either chose or be assigned a pseudonym. In practice, this was more complex than I had anticipated. Some were happy to choose a pseudonym; others were less concerned and were provided with a pseudonym by myself. There were a small

number of participants who explicitly chose to use their own names in the research as part of a political commitment to raising awareness of hepatitis C, and what they felt was an act of tackling the negative attitudes towards hepatitis C head on. Grinyer (2002) reported a similar experience in her study with parents of young people with cancer who felt that the use of pseudonyms provided a sense of 'removal' from the research process. Thus, I maintained the real names of participants who requested this, in keeping with their wish to identify as a person with hepatitis C.

The limits of the consent process

Informed consent is considered to be the cornerstone of ethical research although it has been recognised as problematic and debates continue over whether the role of consent is to protect individuals who participate or the institutions that support the research (Hammersley, 2006;Dyer and Demerritt, 2009). Given that the on-going and complex nature of informed consent has been raised in relation to treatment and post treatment for hepatitis C (see Hopwood *et al.*, 2006), recognising informed consent as an on-going process rather than a one off event (British Sociological Association, 2002; Alderson and Morrow, 2011) was really important.

I obtained written consent from each of the participants, in line with the ethical approval provided by both the UREC and NHS REC. However, in practice I felt uncomfortable asking participants to sign the consent form prior to beginning the interview, consistent with Buckle *et al's.*, (2010) observations about the difficulties of anticipating in advance what will be disclosed. As a result I undertook consent in stages. I sent out information sheets, consent forms and interview guides to all participants in advance, prior to them agreeing to the interview, and then went through the information sheet and consent form verbally before conducting the interview. Signed consent was given after the interviews had taken place.

For the majority of participants (some have not responded to emails) I have been able to continue to check consent through provision of transcripts and provision of a summary of findings (discussed below). This proved difficult for two participants who participated in the group interview and were happy for the transcript to be emailed to the support group leader. Although I did this (and I was informed these have been passed on), I have received no additional comments although this may be because participants were interested in participating, but not necessarily in revisiting the transcript or the findings.

In addition, the limits of informed consent were made clear to me via an interaction with one participant whom I lost contact with after her interview, when her email address no longer functioned. Eventually, I was able to re-establish contact with her, via her online business. She indicated that she would like to be sent her transcript and the summary of findings. However, her response to these was initially disconcerting:

> *'It was a bit weird reading it to be honest, I am so far away from where I was then...TBH [to be honest] I don't remember the interview, was it conducted face to face? If so was it held at my house? Guess that goes to show what the combination drugs do to your mind. Good luck with the PhD and please do keep me up to date.'*

Here, issues are raised about the situated nature of informed consent. At the time I had gone through information and consent processes face to face and she had made it clear she understood. Further to this, she had made notes, and provided additional material, and had indicated how important it was to her to participate. Here, Hammersley's (2006) observations that situations may present multiple ethical quandaries, pulling in numerous directions are particularly pertinent. Given that the participant explicitly refers to having no recollection of the interview, this raises issues about whether her data should be removed altogether. I made the decision not to do this. She clearly had some recollection of participating (she knew she had contact with me before) and the amount of preparation she

had done prior to the interview (both in terms of taking notes, managing childcare, and coping with impairment and treatment effects), coupled with her on-going interest in the research, meant that I felt it would be *more ethical* to keep it in. Furthermore, she did not ask for any modifications to be made to the transcript or indicate that she was uncomfortable.

It also points to the ethical issues raised when interviewing people who are unwell, including, as the participant alludes, experiencing serious side effects from treatment. There are ethical issues around interviewing people who are unwell (Kadushin, 1990) and side effects can influence that which is discussed or remembered (addressed below). However, Small and Rhodes (2000) indicate that illness should not preclude people from providing an important contribution. Not including the data of someone who is unwell (when they have voluntarily participated), or not interviewing those on treatment, further silences the impact of hepatitis C treatment (see chapter seven) and reinforces the perception that illness or difficult situations are individual issues which should not be explored in the public arena (Corbin and Morse, 2003). Furthermore, interviewing people on treatment made the experience much more immediate and reinforced the importance of paying attention to the embodied experience.

There is an important point to be made here regarding the status of the interviews within research. The participants comments above, reinforce that the interview was a 'snapshot' of her life at that time, though it has played a central role in a significant part of mine! It is both behind her and a significant part of her biography. What can be taken from the interview is clearly partial and situated, but nevertheless provides vital insight into the difficulties on treatment, and thus is important to document.

The withdrawal of one participant

Specific ethical issues around unanticipated participant circumstances, and the appropriate level of support that can be provided by a researcher, arose in my interaction with one participant who later withdrew from the study. The participant contacted me via email and we arranged a face to face interview at her house in the south of the UK. It became very clear from the outset of the interview that the participant had been very distressed by her experiences, which were entangled, messy and very immediate. I did not even have time to remove my coat before she began speaking. Not wanting to lose her comments, I hastily obtained verbal consent and switched on the tape recorder. This was less of a concern for the study and more in recognition of the effort and difficulty it was clearly taking for her to recount her experiences. I intended to revisit the information sheet and consent form when there was a break in her narrative. These difficult experiences literally flooded out. I barely spoke and she barely stopped for breath. She recounted fury at her treatment by professionals and extreme distress that she had not been provided with greater mental health support within the community. The interview was intense, and I felt very affected by the difficulties and problems she had faced[66].

Here the boundaries between an interview as research encounter and an interview as fulfilling a therapeutic role were blurred (Dickson-Swift *et al.*, 2006). I had very little input; merely listening and indicating that anything which became too difficult could be moved on from. The ambiguous nature of the interview as simultaneously beneficial and harmful (Morse and Corbin, 2003) became clear. Although some participants had found the interview to be a positive experience, and my social work training proved valuable, this participant was deeply distressed and needed far greater support than I was able to give, which left me feeling uncomfortable, inadequate and guilty (Dickson Swift *et al.*, 2006;

---

[66]Here I am reminded of Smart's (2009) observation that interviews can enter unchartered emotional territory. This particular messy experience would have been very valuable to the research, but to include it would have been exploitative.

Mitchell and Irvine, 2008; Woodby, et al., 2011)[67]. It was also lengthy and I became aware that I would have to leave, and wanted to pay attention to the phase of emergence (Corbin and Morse, 2003). I indicated that I would have to leave soon and that if she wished to, the interview could be continued at a later date. Despite my efforts, it was very difficult to bring the interview to a close. I attempted to address this via pointing to support groups and services, offering to do some further research into support, and returning to the formalities of the interview by asking her to sign the consent form. This proved very hard to manage and I was conscious of criticisms of doing 'helicopter' research (McCauley, 1994), where researchers 'swoop in' to ask questions and then disappear again.

I attempted to address this with post interview support (Kavanagh and Ayres, 1998) by contacting her the day after the interview, thanking her and asking if I could provide anything further. In practice, I faced the difficulties Mitchell and Irvine (2008) warn against in being able to offer very limited support (see also Dickinson-Swift et al., 2006) in my role as researcher.[68] Particularly given the messy and intra-active nature of the circumstances and difficulties she faced and the one off nature of our contact. The emails went on for some weeks as I suggested varying forms of support and information, during which time she requested to be removed from the study and eventually severed the contact, indicating that I could not help her. This was frustrating for me the issues she faced stayed with me for a long time after the contact was severed and I continue to be concerned about her wellbeing.

---

[67] On reflection, it is possible that this participant, having seen my engagement with the online forum, was aware of my social work background and perhaps participated in the research anticipating that I might be able to offer support that local services had not.

[68] In their interviews with people with hepatitis C, Conrad et al. (2006) provided participants with access to free counselling from an agency not involved in the study, as well as referrals into hepatitis C support and care. This is possibly as a result of their on-going relationships and involvement with local medical services. As a student not directly connected to services, I could only signpost and provide information. In addition, the one off nature of the interview and my lack of local knowledge also limited my ability to provide support. See Winter et al. (2008) for an excellent discussion of how the research team have developed support mechanisms over time with drug users in their local area.

This issue was further exacerbated by the participant later copying me into letters of complaint (both personal and professional), and copying others into my emails to her, after she had withdrawn from the research, *including others I had interviewed*. The reasons for this were not clear and I was wary of initiating any further email contact in the event that this too was forwarded on. This created a very difficult and highly sensitive situation, whereby I risked damaging existing relationships with other participants and breaching confidentiality. In this instance, I was contacted by a forum leader who had been copied in to one of my emails which gave us the opportunity to clarify the relationship. This shows that researchers are not in total control of ethical conduct given that this involves another person who makes their own ethical decisions (cf. Moore and Measham, 2012).

Transcription

Transcription is recognised as a key phase of analysis, an opportunity for the researcher to immerse herself in the data (Bird, 2005) and an integral part of the process of data interpretation. Transcription involves numerous (political and theoretical) decisions about how to transcribe, what to include or leave out, and how to represent information that is obscured in the typed transcript (i.e. crying, sarcasm, thinking time) (Hammersley, 2010). I made the decision to transcribe interviews verbatim[69] and in full, with additional nonverbal communication or information noted on the transcript. This was done as swiftly as possible after the interview and was especially useful during early interviews, enabling me to listen to and evaluate my own interviewing technique and make adjustments to the schedule prior to the next interview. When immediate transcription was not possible, notes and thoughts were recorded to refer back to and placed alongside the interview transcript. I used the free software programme 'Express Scribe' which enabled me to drop audio files from my digital voice recorder directly into the programme, ready to transcribe.

---

[69] This is not to imply that the transcript is a fixed representation of reality, but that it was transcribed word for word as I heard it.

Initially, play back of the recordings was attempted using a foot pedal connected to my computer. I found that in practice this felt counterintuitive, with my preference being to use my left leg to control the foot pedal. However, I did not have enough control in my foot to operate the keys without shifting my whole body, meaning I was unable to relax and focus on what I was hearing. After persevering with my right leg (the foot pedal was expensive!), I eventually settled on controlling ('stop' 'play' 'rewind') the recording with specific keys on the keyboard which felt more comfortable. Although I do not think that this had an overall impact on the quality of the transcription - as I found a strategy early enough which meant I could get on with it - this was not an issue I had anticipated and highlights how the researchers' own body, as well as the laptop, recording device and programme, act as inscription devices to bring particular realities into being.

Law (2004) indicates that it is not possible to separate out the realities being made from the inscription devices that make it. I treated the transcripts as somewhere between a construction (acknowledging that I had made interpretive decisions) and a reproduction of the event (it is not entirely constructed, an event did happen), as discussed by Hammersley (2010). A transcript cannot be treated as a form of raw data - interpretive decisions are always already being made and, with them, particular realties come into being. This was especially apparent in that during transcription I often experienced flashes of inspiration or realisation (Mason, 2011), or found myself questioning why I had not probed further or asked a particular question noted in the margin; this shaped the research, enacting realities in later interviews and developing ideas for writing.

Selection of quotations

Before exploring data analysis in greater depth, a brief word about the selection of quotations in the thesis is necessary. Quotations are widely used in qualitative research to

provide insight or demonstrate a point, intended to bring texts 'to life'. However, how and why they have been chosen is not always clear (Taylor, 2012).

Smart (2009) points to the use of quotes in opening up space for multiple interpretations, as with the above quote from Grace concerning: *'mixing with people with AIDS'*. Smart (2009) indicates that quotations leave traces for others to follow – possibilities to discuss and explore, which are only ever partly documented in the written form. Indeed, both Smart (2010) and St. Pierre (1997) indicate that they could have written something else and that only part of the responsibility of interpretation lies with the writer – there are also the interpretations of the reader (Williams, 2005). In selecting and including quotations and extracts, I have tried to ensure that context is provided and that participants' accounts, where possible, have been included across the thesis. This has not always been presented as an even split in the final thesis, as some were more vocal about issues that have eventually constituted the chapters. In deciding which extracts to include, I have tried to enact and materialise the multiple nature of hepatitis C via the inclusion of conflicting or shifting perspectives, trying not to settle on one clear outcome[70]. In keeping with the poststructuralist influences, the perspectives presented are necessarily partial - meaning is fluid and changing rather than fixed and static - single resolutions are avoided, with participant accounts viewed as a single snapshot of a stage in a journey which is on-going and in progress (Blumenreich, 2004).

I made a conscious effort not to include quotations because they were exotic, consciously searching for positive aspects of the hepatitis C experience in order not to contribute to participant oppression. This was balanced with the inclusion of aspects which may appear mundane, in order to address the impact on everyday life.

---

[70] The implications of this shifting nature are discussed in chapter ten.

A note on editing

Where '...' appears in the thesis, this represents a portion of the text that was removed because it was repetitive. I tried as far as possible not to cut things because they seemed 'irrelevant', preferring to retain these to show the complexity of the point the participant was making. Yet sometimes this was necessary for length. Transcripts were edited for 'um' and 'err' noises to improve readability, and succinctness. Although I am aware that this impacts on participant accounts, *any* editing and inclusion of specific quotes makes decisions about what is important (Blumenreich, 2004).

Data analysis process

The process of data analysis was on-going throughout data generation and writing up. It was experienced as non-linear, contingent and involved back and forth and circular movements between and around transcripts, recordings, literature, discussion, draft chapters, thinking and rethinking. Data analysis (recognising that it is occurring within the first interview as the researcher follows a particular line of questioning) was thematic in approach, and this was chosen because of its flexibility (Braun and Clarke, 2006). This is not to say that I undertook an 'ad-hoc' approach to analysis - quite the opposite - but the variety of ways in which I engaged with the data whilst potentially unconventional, meant that each interview was treated thoroughly and as a whole. I remained connected to the data throughout (Woodby *et al.*, 2012) and attempted to document what was happening by continuously writing.

My analytical strategies were broadly consistent with the six phase framework outlined by Braun and Clarke (2006):

1.   Familiarizing yourself with your data

2.   Generating initial codes

3.   Searching for themes

4.   Reviewing themes

5.   Defining and naming themes

6.   Producing the report' (Braun and Clarke 2006: 87).

These were often not clearly defined phases, but went back and forth or circled a specific phase. None of these phases occurred outside of writing. Themes often became clearer as I wrote around an issue or occurrence. The inseparable and intra-active nature of data generation, analysis and writing (see St. Pierre, 1997; Minkin, 1997) is discussed further in chapter three.

It is important to remember that data was being analysed and written up in the context of other professional interviews - although these have not been included in the thesis they cannot be removed from my analysis. Professionals shaped respondents' experiences and have in turn shaped my research into those experiences. Thus, pertinent observations have been interwoven in the relevant data chapters.

Data analysis occurred through a number of different practices. As indicated above, I made notes and observations at the time of transcription. I also loaded interviews onto an MP3 player (stored securely) and listened to these when I needed inspiration. I listened to each of these at least twice. I made separate notes from these listenings to familiarise and immerse myself in the data, which had the added advantage of checking that my interpretations were consistent[71]. It was this process which first alerted me to the possibility (and enactment of) multiple and contingent interpretations of the data. Listening to the interviews as well as

---

[71] Meaning they were consistent in that I maintained the political decision to focus on what I did, but I was aware of multiple threads that could be pulled.

reading them helped me get to know them well[72], meaning that I was able to recall the data to make links at later stages - consistent with phase one of Braun and Clarke's (2006) analysis framework.

I read over completed transcripts using the 'comment' and highlight functions in Microsoft Word to develop codes and memos (phase two 'generating initial codes'). Here memos played a significant role in developing initial ideas and links to other interviews. The 'comments' function in Microsoft Word proved to be an invaluable reflexive tool, which I continued to use throughout the drafting and redrafting of chapters. I then made notes in my research diary concerning things that I felt were unexpected or that I had been drawn to, together with references for any relevant papers - though these were eventually incorporated onto the transcript, or typed directly on there, so that I could see them in one place. As I felt more familiar with the transcripts, I developed a summary of each participant's interview to refer back to quickly, some of which was later moved into an Excel spreadsheet in order to provide a visual table of contextual details[73]. This helped me to be able to see themes and commonalties, as well as differences, across accounts.

Braun and Clarke (2006) critique the position that themes *emerge* from the data in a similar way that Duffin (2004a), and later Fraser (2010), critique the discourse around the emergence of hepatitis C. These did not exist fully formed waiting to be found, but were shaped and made by my engagement with the data, surrounding literature and other people.

---

[72] Listening to the tone, intonation and texture of their voices as well as for pauses and changes in emotion.
[73] For example: year of diagnosis, duration of treatment, employment status, place of diagnosis, experience of post treatment effects.

The development of themes

As might be expected, themes and chapters did not develop chronologically. Analysis was greatly assisted by presenting my work at conferences throughout the PhD, both in encouraging me to explore across the data and in developing and refining themes and ideas for chapters. A paper presented at the International Hepatitis C conference in early 2009, and the positive feedback on it, helped me to develop the theme of talking about hepatitis C and the comparison between hepatitis C and cancer, and the difficulties on treatment, both of which became key themes in chapters. The cancer comparison and the frequency with which it occurred, unprompted, in participant interviews (see chapter six) meant I became interested in why and how participants talked about cancer and the position it occupied in relation to hepatitis C. The comparison with chemotherapy also contributed to the development of the key themes of treatment and post treatment.

As explored in chapter seven, treatment was enacted as central in participant interviews. It was an area where they described needing vastly increased support and information. This contributed to the development of treatment support and particularly social work involvement as key themes. Post treatment developed as a theme after it was raised by participants in the first interviews I did. This was augmented by the realisation that post treatment was a marginalised area which needed to be more robustly discussed within the hepatitis C literature, social work literature, disability studies literature and health literature. Discussion at three further international disability studies conferences (two at Lancaster, one in Iceland), also intra-acted with writing and developing ideas around welfare benefits, psycho-emotional disablism and post treatment effects.

As these themes and draft chapters took shape, my attention turned to the structure of participant narratives around hepatitis C and to the early phases of participant experiences. This led to the development of themes of 'pre' and 'post' diagnosis and the need for support.

The chapter on social security benefits and employment experiences was developed last, although the themes of employment, reasonable adjustments and financial support (including welfare benefits) were present in drafts and writings during the early stages of data generation. It was in 2010 and 2011, as changes in welfare benefits were announced and the coalition government came to power, that the timeliness and pressing importance of the two themes became clear. As Law (2004) discusses, some patterns in the research were amplified and others were silenced, to the point where it became difficult *not* to listen to particular patterns. Presentation of my work to practitioners also helped. For example, discussion of cancer and the moral aspects of illness in 2010, followed by later discussions about the lack of social support on treatment, were important in both reinforcing some findings (i.e. the lack of social support) and interrogating and encouraging reflection on others (the cancer comparison)[74].

Regular writing (and discussion of that writing with my supervisors) was a key component of analysis, consistent with Richardson's (1994) use of writing as a method of inquiry. Indeed I was struck by the sense of identification with the words of Smythe *et al.* (2008), who indicate that themes are not necessarily the same sentiment expressed repeatedly, but are moments of understanding about a bigger issue which is felt to be important for the reader to know and understand. This kind of understanding is achieved for students through the circular process of 'reading, writing, talking, mulling, re-reading, re-writing and keeping new insights in play' (Smythe *et al.*,2008: 1393). As I returned to the data and to writing, I found that I was able link smaller findings with larger frameworks; participant comparisons with cancer connected to feelings of stigma and deservingness, which linked to psycho-emotional

---

[74] As will be discussed in the recommendations, I do have some concerns that the rapid development of the treatment and the major reform to welfare system, cuts to social services and NHS reforms will mean that the research is less useful and relevant than I had hoped (see Sampson al., 2008). For this reason I have made concerted efforts to indicate its situated nature, to look ahead to the future and to disseminate it as far as possible as a topic for discussion.

disablism. Thus the thesis enacted particular aspects of hepatitis which formed the thesis as Desai (2009 quoted in Smart, 2010) explains:

> 'You do not start with the bigger issues; you start with some very tiny details which have been in a way haunting you, that you have been thinking about and brooding over. Those are really the big issues.'

The starting point for notes and summaries which later developed into chapters, were issues the participants felt were important, or needed exploring or addressing. The transcripts were analysed as a whole rather than selectively, thus there are codes and enactments which would have been equally interesting and valuable to include, but I found that as I wrote, presented and talked, the themes and thus the chapters took shape - this magnified the presence of some aspects and reduced the presence of others (cf. Law, 2004). This was political in nature and consistent with my overall aim of exploring and addressing the support needs of people with hepatitis C.

Data was analysed manually, as explored above. A combination of factors influenced my decision not to use a data analysis software programme, such as Atlas Ti., to assist with data analysis. By the time a place became available on the course, I had already developed an analysis strategy with which I was comfortable and which allowed me to look at the transcripts as a whole, together with the codes, as well as produce chapters. I attended the course, but felt that the need to ready my data for input was counterintuitive.

The value of early dissemination of the research findings

Presenting findings to meetings of professionals (county wide), was helpful in validating and interrogating the findings (specifically those in chapters, five, six and seven). However, further discussion was potentially inhibited by reshuffling services and one cancelled presentation at a World Hepatitis Day event, due to people being unable to attend. I am not

aware of a similar event being held since in the local area. Here the intra-action between validation, findings, priorities and funding is made visible. Something which I was (and remain) committed to, was the provision of a summary of findings both during and after the research. Participants were also provided with a link to the Hepatitis C International Conference in 2009[75].

An initial summary which gave an insight into the 'threads' of the research I had picked up was provided to participants who responded to my email, in early 2011. Three participants commented on how interesting it was to read about the experiences of others, and one participant made detailed comments on some of my findings to provide clarification and unpicking of a point. A later detailed summary of research will be provided as this thesis is completed. It was important for me to share my findings with the participants in order to thank them for their participation and to show them that their perspectives were being utilised. This took much longer than I had initially anticipated, given the messiness of the experience and the eventual decision to focus on the perspectives of those with hepatitis C. In future, I need to be clearer about what I will provide and when, i.e. links to any published abstracts and presentations, an initial summary of findings and then a final summary and access to the final report.

It is important to say at this point, that the analysis and interpretation of the findings is my own and participants were not involved in this (Taylor, 2012). It is likely that I have interpreted differently than they would have. The provision of a summary was therefore less

---

[75] Here, participants who both participated and did not participate commented on the slides and my brief summary. There was one particular exchange which sticks in my mind, where participants disagreed over the use of 'cancer' as a 'cover' on treatment. One indicated that they had never seen this, whilst another indicated she had. Further, their comments helped me to refine my interpretation (and perhaps unclear wording) that participants were not only 'passing' but that there was a hierarchy in place with regard to disease. In retrospect, it is unfortunate that I was unable to do this for every conference I attended. This was, in part, due to the messy and developing nature of the findings, which didn't feel 'finished 'enough to present as well as residual concerns about 'giving away' my findings at an early stage. Furthermore, I shared Reeve's (2008) concerns that instead of validation what I might end up with was more data!

of an opportunity to validate my findings and more a means of giving back what participants had given to me[76].

Limitations of the research

This final section of the chapter highlights some of the limitations of the research. As has been emphasised throughout, the perspectives presented in this thesis are partial and thus the research is inherently limited. However, it is important to highlight some of the specific constraints:

All of the participants had taken up combination treatment at least once[77] (some more than once). Thus the realities enacted by this sample, obscure some aspects of the circumstances (and difficulties) around access to treatment - a major area of concern worthy of further research. In addition, none of the participants were using illicit drugs at the time of interview. Whilst this means that the research provides a unique insight into a group that are frequently overlooked within existing research, the needs for support and information may be very different and there is a need to explore the needs of those who use drugs and access treatment.

Participants frequently described poor experiences on treatment. All participants, except Pixie, described experiencing side effects, which may mean that treatment is presented as particularly difficult. However, my findings do appear to be consistent with other research that emphasises difficulties on combination treatment (see for example, Hopwood *et al.*, 2006).

A number of participants were heavily involved in activism and awareness raising, which may have been a reason for participating in the interview. Therefore, their views may differ from

---

[76] I have been unable to do so with the professional findings and feel guilty regarding this, especially given that I am not sure these will be written up - though I would like them to be.
[77] In January 2012 at the time this thesis was being written up; triple therapy treatment was approved for use in the NHS by NICE. Thus the sample does not include any experiences of triple therapy.

those who were less involved in activism - although the sample did include a number of participants who were less open about their hepatitis C status. In addition, whilst these participants were key forms of support to others, and could potentially raise a richer range of issues, this should not be taken to be any more representative of the needs of people with hepatitis C.

Most of the participants had cleared hepatitis C future research is needed to focus on the needs of those who have not. Further, the sample of co-infected men interviewed was small; future research needs to include a wider sample to explore how it is possible to best support those with co-infection. The needs of participants from South Asian populations have not been included. This research focuses on the experience of hepatitis C from the perspective of the person with hepatitis C. There is a need for further qualitative research exploring the experiences and views of professionals – both involved and not involved in hepatitis C - to explore and develop multidisciplinary responses.

This chapter explored the fieldwork process from start to finish. The following chapter, the first of five concerned with findings, explores participants 'first encounters' with hepatitis C.

Chapter Five: She said you're positive - I thought positive for what? First encounters with hepatitis C.

Introduction

This first findings chapter details participants' early experiences of living with hepatitis C. It follows on from the theoretical position outlined in chapter three, by exploring how hepatitis C, and people with it, are enacted and materialised through specific practices and intra-actions, specifically prior to, during and immediately after diagnosis. Forms of support and information are discussed in greater depth, including information requirements, peer and online support, and the role of GPs. The chapter moves on to consider how structural aspects of available hepatitis C services enact the virus and those with it. The chapter ends with an exploration of hepatitis C awareness messages and the need for attention to representations of living with the virus beyond testing.

Before diagnosis

The first theme this chapter focuses on is participant experience prior to diagnosis. Existing medical literature makes reference to the possible experience of symptoms for a number of years prior to diagnosis (see Dolan, 1998; Foster, 2008), but the impact this has on eventual diagnosis, the way participants saw themselves and the level of support required is under-explored. However, undiagnosed hepatitis C is *also* described in the literature as frequently asymptomatic and indolent[78] (Glacken *et al.*, 2001; Dore *et al.*, 2003; Liang *et al.*, 2013) and

---

[78] The dictionary definition of 'indolent' (Oxford English Dictionary Online, 2013) acknowledges that within medical terminology this is used to mean 'slow moving', 'painless' or 'causing minimal pain'. In characterising hepatitis C in this way, clinical literature is not neutrally describing the experience of the virus, but imbuing it with a set of assumptions and expectations. This contributes to a reality where hepatitis C has a minimal impact on a person's life, which was not the case for many of these participants. This is further reinforced given that as an adjective, indolent, it is used as a synonym with 'lazy' 'slothful', 'idle' or averse to work - enacting those with hepatitis C as potentially undeserving of support (explored in greater depth in chapter nine).

this is used as a reason to encourage testing (RCGP, 2007; Duncan *et al.*, 2012). Thus diagnosis is frequently enacted as *the starting point* in discussions and responses to hepatitis C (RCGP, 2007; Duncan *et al.*, 2012).

However, the diagnosis as starting point was not the case for almost half of the participants in this study, who reported seeking support from their GP for impairment effects, later attributed to hepatitis C, and undergoing numerous tests and treatments prior to being diagnosed. Participants frequently described knowing *'something was wrong'* (Morgan). Holli estimated that she had been feeling unwell for about 20 years and had sought support from a variety of help centres, including her GP and alternative health organisations (see also Glacken *et al.*, 2001). Kerry described joint pain and constant fatigue. JB described visiting his GP repeatedly and Steve described being given treatment for scabies and fleas, before eventually being tested for hepatitis C. Similarly, Grace described:

> *'[The doctor] was a new one up from [city].He was the only one who had sent off to test for it [hepatitis C] because I'd been not very well for two years. I'm not one to go to the doctor[79] but I kept getting high blood pressure. One doctor had tried to give me HRT[80] for menopause and another doctor said 'take Paracetamol'- but I knew something wasn't right and that's when he said we will try for this [test for hepatitis].You won't have it; I'll just try it as an off chance.'*

Hepatitis C was not asymptomatic or vaguely felt, but participant experiences were frequently enacted as something else, prior to being materialised in a test result as hepatitis C. Here, GPs are addressing a range of complex and intra-acting issues at diagnosis, rather than one single thing. The experience also appears to be gendered, as all the women in the

---

[79] In making it clear that she does not visit the doctor often, Grace is attempting to present herself as credible and 'genuine' (Werner *et al.*, 2004), suggesting that she has absorbed wider ideas about chronic illness (see for example, Jackson, 2005; Barker 2011). Similar sentiments are expressed below in Morgan's need not to be seen as a 'hypochondriac'.

[80] Hormone Replacement Therapy is used to treat menopause in women. It replaces female hormones that have stopped being produced by the body (NHS choices, 2013).

study reported impairment prior to diagnosis and Grace's reference to the menopause suggests that the possibility of hepatitis C was obscured by gendered expectations (Dunne and Quayle, 2001; Werner and Malterud, 2003). Thus, rather than *the virus* being asymptomatic (cf. Fraser, 2012) as is reported in existing literature, participants suggested a range of structural barriers which inhibited their diagnosis, including GPs' limited knowledge, or awareness, or not being *'tuned in'* (Morgan) to the possibility of hepatitis C. Here the virus is marginalised, or *othered, in* that it literally remains *unthought* (Law, 2004) by GPs it is not part of the reality they are searching for in making the diagnosis.

Others pointed to poor communication or flagging systems which delayed diagnosis or discussion of it. Both Freda and David knew that hepatitis C was on their GP notes, but this was never discussed. There was a similar gap in communication for Keith (elaborated on below) and Morgan described not being given her results for six years after being tested, because these were not returned from the laboratory.

The lack of validation and the impact this had on participant confidence and wellbeing is explored below. These gaps in communication might be addressed with a recent suggestion made by the London Joint Working Group for substance misuse and hepatitis C (LJWG,2012), that GP practices should implement strategies to search records for indications of substance use and invite patients for a hepatitis C test. This should also extend to screening for previous tests and checking results have been shared with patients, simultaneously providing an opportunity for discussion.

Diagnosis as a tool to access support

Despite participant experiences of impairment effects and disabling barriers prior to diagnosis, the diagnosis as starting point is enacted and materialised as central in institutional and administrative processes, and thus receipt of support (Dumit, 2006; Jutel,

2009; De Wolfe, 2012). For example, care pathways begin with the referral for a test or recommended actions based on the results of a test (see for example Kent Health Protection Unit, 2007; RCGP, 2007). Thus, cumulative prior impairment effects and the need for support are not explicitly included. Whilst this is perhaps understandable in providing a clear, digestible trajectory through testing and treatment *on paper*, in practice it contributes to the marginalisation of experiences which exist alongside the circumstances of a test and contributes to the enactment of hepatitis C as a solely medical issue.

Pinder *et al.* (2005) maintain that rather than providing a neutral framework to direct patients through a specific system, these frameworks impose their own order - enacting people (with hepatitis C) in specific ways to fit with organisational, or in the case of welfare benefits, political and ideological priorities. For example, the period of undiagnosed hepatitis C is used as a reason for participants to access treatment at the earliest possible opportunity (RCGP, 2007), but is not necessarily included when considering applications for benefits or support, because official diagnosis functions as a means to access this. This is an enactment of hepatitis C as a medical entity - enforcing the power of medicine to test and diagnose it, and privileging diagnostic testing over participant's knowledge of their own body (Race, 2001; Persson *et al.*, 2003; Stoddard Holmes, 2006).

This is visible in participant descriptions of a lack of understanding from family, friends and professionals (see also Dunne and Quayle, 2002). In the absence of a clear diagnosis a number of participants suggested their experiences were dismissed:

> Morgan: *'I think lots of people just kind of thought 'get on with it'... One of my very dear friends - I was saying 'there's just something definitely wrong. I get really tired. I don't feel inspired' and she was saying 'oh its 'cause we're getting older' and I was saying 'no I don't think it is'... I knew it was something else and I do think there is that*

thing of 'well we all feel aches and pains because we're getting older'. [81] it's quite

hard to say, 'yeah, but this is more.' So if you don't get a quick diagnosis I think it's

pretty stressful.'

Similarly, Steve's father-in-law could not understand why he could not work, and other

participants referred to a sense that they were 'malingering' prior to diagnosis (see below).

Participants experienced a sense of liminality here (Turner, 1966; Murphy *et al.*, 1988); the

lack of recognition from doctors, friends and family, impacted on their self-belief and worth.

Mendelson (2009) (in relation to Lupus[82]) and Barker (2005) (in relation to Fibromyalgia[83])

also reported a protracted period of diagnosis, without the validation provided by a medical

label which damaged relationships and self-esteem.

For Boab, the lack of diagnosis and subsequent validation led to discriminatory treatment

from nursing staff and had far reaching material and social consequences:

'For the last eight to ten years I'd been suffering various nonspecific symptoms,

lethargy, tiredness, depression, bowel problems. I went to see my GP who... took a

blood test and said 'oh yes your liver functions are seriously deranged you're drinking

too much' so I cut out alcohol completely....Year after year I'd report back and 'oh

---

[81] The reference to ageing by Morgan's friend contributes to the ambiguity and multiplicity of the experience of living with hepatitis C. Though Morgan did not think her impairments were age related, they intra-acted and materialised in a context of age related expectations and assumptions. Siegel *et al.* (1999) in their research with older HIV positive adults, found that, like Morgan's friend, participants attributed illness to age as a more benign cause - preferring to see their impairments as part of the ageing process rather than the onset of serious illness. Yet this potentially delayed seeking medical support. This has important implications; the long term nature of living with hepatitis C and the ageing population in the UK means hepatitis C among older people is an area requiring urgent attention. In the US, this has recently been addressed with the Centre for Disease Control recommending mandatory testing for 'baby boomers' born 1945-1965 (CDC , 2012), although there are no similar plans to introduce this in the UK.

[82] Lupus is a complex, fluctuating, long term autoimmune condition (where the body attacks its own healthy tissues and organs) which is still poorly understood. Symptoms can range from mild to life-threatening (NHS Choices, 2012).

[83] Fibromyalgia is a long-term condition which is also poorly understood. It is also more commonly found in people with hepatitis C than in the general population (see Fransiscus, 2012). Impairment effects include severe pain and fatigue and sleep disturbance (NHS Choices, 2012).

well you're still drinking too much' 'I'm not drinking at all -or I drink very occasionally.' One practice nurse actually said to me at one time 'oh well, you would say that because you're an alcoholic in denial.'

Despite the long term nature of Boab's experiences and his assurances that he complied with his GP's advice to stop (any and all) drinking, alcohol use is the only explanation offered. This was recorded in his medical notes, enacting hepatitis C as an alcohol dependency and thus constituting him as potentially unfit for his job.

'I almost lost my driving licence actually. I had a heavy goods license and I went for a medical and the guy examining me, looked through my notes and said, 'oh you've got a drink problem' and told the DVLA[84] *I'd got a drink problem'.*

The constitution of Boab's symptoms as related to his perceived alcohol use, resulted not only in frustration and anger, but also a delay in diagnosis - with serious consequences. Later in the interview Boab suggests that had he been diagnosed earlier, treatment might have been successful.

Experiences of diagnosis

Participants in the sample were diagnosed in a number of settings, including GP practices (eight), NHS Blood Service (two), during a hospitalisation related to HIV (one), prison (one), drug services (three), sexual health services (one), HIV services (one), and during other consultations (three). One participant's place of diagnosis was not clear. The year of diagnosis ranged from 1990 – 2009. Whilst the variety of settings in which diagnosis takes place might at first glance be considered encouraging, it also highlights the multiple and far reaching nature of hepatitis C and the need for testing from a wide *but informed and trained* range of venues and professionals. A key finding is that participants frequently described

[84]Driving and Vehicle Licensing Agency responsible for facilitating road safety, maintaining registers of drivers and vehicles and collecting vehicle excise duty (Direct Gov, 2012).

feeling underprepared or being diagnosed without adequate explanation, information or aftercare (see also Gifford *et al.*, 2003; Hopwood and Treloar, 2003; Crockett and Gifford, 2004).

The situated nature of diagnosis was clear from Freda's account. The earliest diagnosis in the sample, Freda was diagnosed by a nurse from the NHS blood service after a routine donation in 1990. She describes being given very little information and support beyond being warned not to have sex without using a condom. The timing of the diagnosis, coupled with the limited information, enacted hepatitis C as *the same as* HIV and in this particular case clearly fulfils a public rather than personal health function (Fraser and Seear, 2011). Freda was informed in the absence of additional information, against a hinterland (Law, 2004) of HIV, for the purposes of not transmitting it to others. This had serious consequences for her wellbeing:

> *'I was so ashamed I refused to acknowledge it and hoped it would go away... I just associated it - same as HIV.'*

Freda described feeling so ashamed that she had not disclosed her status outside of the healthcare system to anyone (apart from me and her friend, a matter of weeks before the interview) and had not accessed any support in the intervening years. Here, Davis and Rhodes' (2004) observations regarding hepatitis C being understood in relation to HIV are relevant. Freda does not understand hepatitis C as a disease in its own right. The intra-action between hepatitis C, HIV, media messages and ideas about contagion (Harris, 2009a) prevent Freda from seeking out any kind of support until she eventually accesses it by accident (discussed in chapter four). Freda later indicated that she was able to forget about it for so long because it was never mentioned or visible which has implications for awareness raising, as explored below.

Andrew and Carl, who estimate they were diagnosed between 1995 and 1997, similarly describe a lack of support or even any further information. Carl states:

> ' I was kind of handed it on a plate... I went back to the hospital for my liver function results and I was just told that in a room – 'there you go your liver's okay but by the way you've got hep C' and off you cop. There were no sitting down with anyone and discussing my options and what was available. Back in them days there weren't any options available to you – you just had to get on with it.'

While Carl's assertion regarding the limited availability of information at the time is accurate, his use of the phrases 'handed it on a plate' and 'off you cop' suggest that he experienced the diagnosis as dismissive and it remained a marginalised issue prior to entering recovery.

Three participants were diagnosed via telephone [Pixie (diagnosed 2000) JB (diagnosed 2005) and Grace (diagnosed 2007)]. Harris (2005) has previously drawn attention to the way in which a telephone diagnosis enacts hepatitis C as being of little concern not serious enough to warrant a face to face conversation. Pixie described never having heard of hepatitis C prior to diagnosis, so she did not find out the implications until later when she researched it herself. She was told that whilst treatment was possible, 'there was no money for it in this area'. Here, hepatitis C is constituted as important only if it can be medically managed and Pixie was left with the 'weight' of it in the interim.

JB described 'alarm bells ringing' when the doctor who diagnosed him began the conversation with 'I'm sorry to have to tell you this'. Here hepatitis C was enacted as serious and alarming (as bad news). Whilst JB reported finding a satisfactory level of information himself on the internet and joining an internet forum, Grace reported a very different experience when she was diagnosed in 2007:

'The receptionist from the doctors phoned me to tell me. She told me...'you're positive' and I thought 'positive for what?' And she goes 'hepatitis C' and [I said 'what is that?'] and she said 'I don't know you will have to make an appointment to see a doctor'... I went on the internet and looked it up and that's when I saw what it was. So by the time I got to the appointment, to the doctors, because they're rubbish up there, all I could do was cry. Then you have the fear of your children and everyone around you have you infected them? Because it says on the internet it's more contagious than AIDS.'

Here the insensitive conditions in which the diagnosis of hepatitis C was given, enacted the virus as trivial, which was in direct contrast to the information Grace absorbed from searching online. The diagnosis of hepatitis C over the telephone should never have happened, especially not by a receptionist who was not trained to participate in a post-test discussion[85]. Further to this, the provision of such information via a disembodied voice on the phone enacts a distance between the GP surgery and the participants, and, as Grace later indicates *('they're all rubbish up there')*, negatively influenced her perceptions of, and relationships with, services (see also Hopwood and Treloar, 2004).

Whilst some participants described their diagnosis as a *'shocking'* (Steve) or *'difficult to absorb'* (Boab), and Grace and Freda made explicit links between drug use and the transmissible nature of hepatitis C, most participants described feeling shocked as a result of *poor preparation and a lack of information,* rather than the diagnosis of hepatitis C. Six participants had never heard of it before being told they had it. Eight participants described not knowing they had been tested for hepatitis C at all when the diagnosis was given, as they were tested for a variety of things, which enacted hepatitis C as unimportant. Others were

---

[85] Although perhaps it highlights the lack of visibility and awareness among the general public and in General Practice if a receptionist in a GP surgery is unaware of the significance or implications of hepatitis C.

188

aware of being tested, but 16 participants described feeling unprepared for a hepatitis C diagnosis including not understanding what hepatitis C was, how many people have it or the implications of a positive status. Grace described being tested for 'hepatitis' (and was possibly tested for A, B, and C at the same time):

'Actually I don't know if he said hep C I think he might have said hepatitis... He wouldn't have said hep C no.'

Grace subsequently believed that she would not receive a positive test because she had been vaccinated against 'hepatitis'. In her study of the lived experiences of hepatitis C in Australia and New Zealand, Harris (2009b) describes an even split between people who were completely shocked by their hepatitis C diagnosis, and others who felt it was a foregone conclusion, which challenged the notion of diagnosis as a biographical disruption or as inherently negative. The idea that diagnosis was troubling was also challenged by participants in this study; Ken and Richard both described anticipating that they might have hepatitis C before they were diagnosed. David described hepatitis C as an 'opportunity' to give provide support and information to others, and Daniel described being 'glad he knew he had it so he could do something about it.'

Here it becomes clear that hepatitis C itself is not inherently troubling or bad, but it is the context in which the diagnosis is delivered which constitutes it as such. Hepatitis C is enacted and re-enacted as participants gathered information. This is illustrated well in Keith's extract:

'I got diagnosed with Diabetes first and then I had what I thought was a diabetic episode so I went to the GP. The GP basically decided to send me on for a load of blood tests...In the meantime I was passing a tiny amount of blood in my urine. I had been referred to a consultant at the hospital for that - so you've got think I was being poked about for a couple of things. I had gone to see the consultant at the hospital which I thought was the problem with my bladder and he just said 'oh by the way you have

189

hepatitis C', .and it was like 'hey what?' You know? And he said 'haven't you been told that? I was like 'no not at all' ... and then he told me to book an appointment with the hep C clinic. What I thought hepatitis was I got confused with that and dermatitis. I thought you got it from playing about with concrete and stuff like that you know? I didn't think anything of it. I came home that night and had a look on the internet – basically found out what it was but the same time, scared the living daylights out of myself.'

At the time of diagnosis, Keith was being treated for a number of impairments, so hepatitis C was bound up and intra-acted with a range of other issues[86] this led to an unexpected diagnosis for which both Keith and the consultant were underprepared. Keith described the lack of information associated with his diagnosis, and the subsequent confusion, as detrimental to his mental health. He described finding the online forum (from which he was recruited) as key in gaining understanding, though he described not finding this until part way through his second treatment and feels he should have been signposted there much earlier.

Diagnosis as a form of validation

Although participants may not have expected the initial diagnosis, many described feeling that past and current embodied experiences made (new and different) sense in light of new knowledge and information (Aveline, 2006). For example Daniel stated:

'When I read that hep C could cause mood swings and depression – that rang a bell for me because I had taken anti-depressants for a number of years before I knew I had hep C... and it just made me wonder in what ways it affected my emotional stability really.'

---

[86] Type 2 Diabetes can be an extra hepatic manifestation and is more common in people with hepatitis C than the general population (Franciscus, 2012).

Here the contingent and messy nature of hepatitis C diagnosis (and of life) and participants' efforts to make sense of new realities are particularly visible. Understandings of the past are revisited, revised or confirmed based on intra-actions between previous experiences and new knowledge (Aveline, 2006). This is particularly visible in chapter eight, in relation to post treatment and chapter nine, in relation to understandings of their experiences in the context of welfare benefit applications. However, non-coherences are also visible other participants described experiencing no symptoms prior to diagnosis.

Those who had their views confirmed, described feeling relief at *'not having to keep fighting anymore'* (Morgan). Holi described the diagnosis as a shock, but also a relief after such a long time. The sense of validation and legitimacy (Nettleton, 2006) described at the point of diagnosis is illustrated by Boab below:

> *'I'm sorry I've been off so long, but now we know why. There is something wrong with me I'm not taking the mickey out of you or anything like that. In a way it was a relief actually, that there was something wrong with me and I wasn't just, malingering '*

In a robust review of the sociology of diagnosis, Jutel (2009) notes that diagnoses are the tools medicine used to organise and stabilise embodied experiences and develop courses of action, granting status to some and not to others. Diagnosis is, maintains Jutel (2009), both a process and a label, central in maintaining medicine and associated professionals' powerful position in the lives of people with hepatitis C. Though this is not to say that this is static and fixed – participants worked with and resisted medical understandings of their experiences, as explored throughout the thesis.

Mendelson (2009) provides keen insight into the validation experienced by women with Lupus after a protracted diagnosis. She too characterises the period prior to 'official' diagnosis as liminal (Turner, 1966), and documents participants' sense of guilt and attempts to position themselves as credible or as one of my participants, David, stated *'productive*

functioning members of society'. The receipt of a diagnosis can provide permission to be ill (Nettleton, 2006; Jutel, 2009). It is a social process which makes visible societal beliefs concerning specific experiences and is often shaped and materialised by involvement of those affected (see Zavestocki *et al.*, 2004, in relation to Gulf War illnesses and Moser, 2008, in relation to Alzheimer's).

Although Hodge (2005), reflecting on the process of diagnosis for parents of children with autism, states that to see diagnosis solely as helpful and validating is naïve. Diagnosis can frequently lead to feelings of being deskilled - even if strategies of dealing with the impact of the impairment have worked well to the point of diagnosis[87] – i.e. participant's concerns about transmission, or fear of what lies in the future. Further, diagnosis can increase the role of medicine in participant's lives. For example, the expansion of pharmaceutical treatments to incorporate wider swathes of the population, thus vastly increasing profits made by pharmaceutical companies (Jutel, 2009) visible in the vastly increased number of clinical trials for hepatitis C treatment or enacting and subsuming disablist treatment under the heading of medical intervention (Aphramor, 2009; Beresford *et al.*, 2002).

For many participants, the initial optimism and relief associated with diagnosis proved to be premature (Mendelson 2009), as they anticipated that the label would engender far more support, help and understanding, than they subsequently got. Participants found they were expected to participate in everyday life in a way which was imbued with expectations concerning appearance, ability to work and the need for support.

Support following diagnosis

The need for support in the period following diagnosis has been documented in the literature. Fry and Bates (2012), in their Australian study, stated that participants expressed

---

[87] For example participants described changing hygiene or domestic practices (such as refusing to grate or chop food) following their diagnosis, when they had previously done it for years.

anxiety and frustration around the lack of information they were provided with at diagnosis, and that diagnosis was experienced as more positive if they had time to talk it through with someone who was informed. Similar findings were reported almost a decade earlier by Gifford *et al.* (2003) who indicated that the most important aspect to diagnosis was the time and space given over to discussion of the meanings and implications.

After diagnosis, participants described needing clear explanations and clear pathways of support. Daniel referred to his diagnosis in 2009 as *'clinical'*. He described being clearly informed of his status and referred on to a consultant for treatment, but spoke at length concerning the lack of formal, social and emotional support in the days and weeks following diagnosis, and negotiating issues such as testing for his daughter and ex-wife with limited help. Hopwood and Treloar (2004) indicate that upon diagnosis, services should be aware of and refer into key agencies of support, in addition to treatment.

Clearly participants may require support to varying degrees. Laurie, Keith and Kerry pointed to the need for clear, credible information (see Stewart *et al.*, 2012). In particular, they felt they needed printed British information which could be revisited and followed up, via accessible and digestible websites, with contact details for local and national services. A key difficulty here is that services in the UK are limited in availability, funding and reach.

In a recent study of specialist nurse support in Northern Ireland, Grogan and Timmins (2010) found that some of their survey respondents also reported receiving limited information after diagnosis. A small amount did not know what genotype they were or whether they had cleared the virus. The authors acknowledge that this is concerning and suggest that this is perhaps connected to patients' health literacy, stress, or learning style. They acknowledge that patient education is complex and that even if extensive information is provided, some may feel that they have not been provided with enough. Thus, it is important to provide

signposting to an organisation or form of support which can answer follow up questions or provide clarification.

In contrast, Laurie spoke positively about his experience of diagnosis by the National Blood Service.

'They were excellent - called me in, described the virus - explained that I could have caught it via accident (probably from my brother - I looked after him many times), they were professional, non-judgemental and excellent - both to me and the wife... [Gave me] leaflets, web sites - as much info at hand that they had. Referred me to a consultant, recommended testing for wife - vaccination for hep B, excellent service.'

Notable in Laurie's description is the dedicated time and the provision of a range of information, paying attention to his family life. In spite of this, Laurie described setting up his own forum because of the lack of social support around hepatitis C. Others described needing signposting and referral to support services and support groups (see also Fraenkel *et al.*, 2006).

Participants frequently described being provided with a referral to a consultant and hepatitis C specialist nurse and little else. This enacts hepatitis C in particular (medical) ways and reinforces the authority of medicine and treatment (Fraser and Seear, 2011) (discussed in chapter seven). Both Boab and Kerry received printed information from pharmaceutical companies:

Kerry: 'They [specialist team] gave me the drug company books which had the side effects and management in them. I don't think they are particularly practical tips, so that is why I have got involved in writing my own book for families because I don't think the tips in there are particularly helpful you know. They are written by the drug companies, so obviously they want to minimise the fact that you are going to be

feeling all these side effects but especially, psychological side effects. It's very difficult

to explain to a family member that a drug is going to cause you psychological effects.'

For Kerry, there was a need for information which addressed wider issues and circumstances during treatment and beyond. She felt that information specifically tailored for friends and family was severely lacking and that this should be addressed urgently, particularly given that many reported receiving informal support from family members or having to answer questions. Participants felt that information - written in partnership with family and professionals as well as service users - should cover diagnosis and how to provide (and access) support immediately after. Participants wanted information about the following; the impact of hepatitis C and treatment effects (including the invisible nature of the impairment), forms of support that may be required, advice on managing the impact on relationships, details on both local and national support services where they exist.

The next section of the chapter explores the role of GPs in supporting participants through diagnosis, given that the majority of the sample was diagnosed by a GP. These findings are particularly important given that one of the *major concerns* at present is accessing and testing those who may have been exposed to hepatitis C through experimental drug use or tattooing a number of years ago, but who would not perceive themselves as needing a test (Hepatitis Scotland, 2013). Hellard *et al.* (2009) maintain that GPs are often the first point of contact for those with hepatitis C or those who may be exposed to it.

The role of General Practitioners in diagnosis and support

The role of GPs in testing for and supporting those with hepatitis C has been explored both in the literature and in policy, with a specific focus on improving awareness and education among GPs (Department of Health 2002a; 2004; Gupta *et al.*, 2006; Treloar *et al.*, 2010) which has historically been recognised as being poor. A systematic review of US healthcare

provider knowledge of hepatitis C, found that doctors did not ask about risk factors for hepatitis C and even in the event of risks becoming apparent, 20% did not recommend or order hepatitis C testing. Others either over or underestimated the effectiveness of treatment, and even provided misinformation (Zickmund *et al.*, 2006). In Gupta *et al*'s. (2006) study, Australian GP participants identified educational needs related to the interpretation of tests and pre- and post-test counselling, but were less concerned about addressing social or cultural implications of living with hepatitis C an important finding for this thesis.

Zickmund *et al.* (2006) conclude that brief education is important and effective in increasing knowledge among general practitioners, but simple distribution of guidelines was not enough and required in-depth education. Particular efforts have been made with GPs in the UK, though D'Souza *et al.* (2004) found that knowledge among GP's following a dedicated awareness campaign was still low. A recent consensus by The London Joint Working Group on Hepatitis C (2012) recommends that at least one GP in every practice should have a basic knowledge of hepatitis C, through completion of the Royal College of GPs certificate in the diagnosis and management of hepatitis B and C in primary care.

Recent awareness raising by Hepatitis Scotland[88] points to the imperative of testing those who may not perceive themselves as requiring a hepatitis C test (Stewart, 2012). This was borne out in this study a third of participants in the study were diagnosed in their local GP surgery after a number of tests, and there was a sense from participants that diagnoses were unnecessarily delayed due to a lack of GP awareness or testing mechanism. As JB states:

'You know anyone going to the GP with something he can't immediately diagnose

should be doing a blood test. I believe they do it in France, full blood count, liver

---

[88] An organisation funded by Scottish government to support the voluntary sector to engage with hepatitis.

function test, a whole kit and caboodle...Because it took six months for me to be diagnosed – and in all that time there was drugs and time and everyone... that blood test as soon as I went in I would have been diagnosed quicker, they wouldn't have wasted the medication trying to cure something that wasn't there. So I think blood testing at GPs. When people go in, with something that's that should happen.'

Here JB cites the model currently used in France to test liver function, resulting in an increased diagnosis of hepatitis C (The Hepatitis C Trust, undated), and this view was also shared by Boab. In a timely observation, given increasing funding constraints, JB refers to the money *'wasted'* on medication that was erroneously prescribed to treat what was eventually diagnosed as hepatitis C. Clearly the development and rolling out of more expansive testing would need to be accompanied by increased services and support, without which testing would be of questionable value.

Although some participants spoke positively of their GP's involvement (Steve, Boab, David, Morgan, Holi), they frequently qualified this by indicating that GPs had limited knowledge around hepatitis C, but were realistic about the generalist role of most GPs and that they worked under difficult circumstances.

Thus there is an acknowledgement that there may well be other factors apart from individual GP knowledge that affect hepatitis C testing, including: resource allocation, caseload and continuing professional development. Though Kerry and Steve both emphasised the importance of their GPs in being aware of, and involved in, supporting them and acting as a point of contact and information.

Kerry felt that her GP should be more involved in her care she described accessing further testing regarding genotype via her drug service, when she felt this should have come through her GP. Steve suggested that the accessibility of GPs meant that they could prove to be a

valuable and much needed point of contact for those who have been diagnosed or are undergoing treatment:

'The GP they should give you maybe even a weekly check just to make sure you're alright they're not psychiatrists I know that, but just to make sure they can get to know the person they're treating and making sure there is no subtle changes that they can see'.

In an Australian context, Richmond (2004) points to the importance of the GP in referring people with hepatitis C to dietetic support, counselling and social work, but indicates later that a lack of adequate funding potentially inhibits this response. Swan *et al.* (2010) described mixed experiences of GP consultations some participants described their GPs as informed and supportive, whereas others used medical terms and jargon which proved to be a barrier in their support seeking. RCGP (2007) guidance on prevention and testing notes the importance of good communication between primary and secondary care, with a GP providing on-going support through treatment and prescribing for side effects. Similar findings have been recently reported by Harris *et al.* (2012a).

Ben indicated that his GP was kept informed of his progress but *'didn't get too involved really'*, although his involvement was helpful with respect to prescribing anti-depressants and Ensure (nutritional drinks) when Ben experienced involuntary weight loss on hepatitis C treatment. This was very different to Kerry's experience:

'I would like my GP to be informed of the virus and of the treatment and the medication and side effects because at the moment he has no clue at all...but because he doesn't know anything about the drugs he is unwilling to prescribe because he doesn't know interactions... He is saying I couldn't possibly help you with your weight loss and prescribe you Ensure because it might interact with your drugs. What a load of rubbish'.

However the reason for the lack of involvement from GPs could be attributed to the lack of presence of hepatitis C in GP surgeries. A number of participants referred to the lack of advertising of hepatitis C testing and support groups in their local GP surgery, or even its purposeful silencing:

Ken: 'I had a job putting up posters - going round doctors surgeries on my own back on [behalf of] the hep c support group and there are lots of places that wouldn't even let you put flyers up – that really disappointed me – medical people as well...

Heather: When you went putting your posters up did they give a reason why they wouldn't display them?

Ken: No they just said - there would be various answers there would be 'oh the doctor thinks there is enough posters in here' – or 'I never saw it' – or 'it must have fell off' but most of them stay in place now that was two year ago [in 2008] when I was having problems – it is getting better now the hospital itself – there's big posters advertising the support group and our details.

Although Ken goes on to say that the posters are now displayed more widely[89], other participants described a lack of posters within the doctor's surgery (see Morgan's comments below). The lack of visibility of hepatitis C had serious implications for David in terms of talking about hepatitis C with his doctor:

*'I went to the doctors – so many times after [being diagnosed] and never talked to him about my hep C - now that's fair enough I didn't bring it up, I didn't want him to talk about it, **but it was like it was okay to keep it as a secret**. I don't know whether I would have been more receptive had there been made more aware' **(my emphasis)**.*

---

[89] Ken's comments are supported by a recent Hepatitis C Trust Campaign where volunteers were recruited nationally to display and check the presence of posters in their local GP surgery which goes some way to combating the silence.

Here David describes not raising the issue of his (prison diagnosed) hepatitis C with his GP in the intervening years. Without speaking to his doctor it is not possible to know whether his GP was provided with his results, but David indicates that not knowing how to bring it up with his GP meant he did not feel able to talk about it.

This finding is supported by recent World Hepatitis Day campaigns, which have drawn attention to the silence around hepatitis C by using the proverb 'Hear no evil, see no evil, speak no evil', usually represented by three monkeys each performing the related action. The World Hepatitis Alliance (2013) state:

> 'The monkeys have been chosen for our campaign to highlight that around the world hepatitis is still being largely ignored. We are calling for people to uncover their senses and confront the realities of hepatitis'.

In GP surgeries this could be combated through increased visibility in the surgery and information which included 'conversation starters' about hepatitis C, both for GPs and for patients (Stoddard Holmes, 2006). The silence associated with living with hepatitis C is expanded on below.

Online support

Given the lack of support and information at diagnosis, many participants described doing their own research online. As eight of the participants were recruited directly from internet forums, this is perhaps unsurprising. However, even those recruited via other methods described using websites, support forums and videos on YouTube to research hepatitis C. 17 of the 21 referred to it explicitly. In a US based study around online information seeking, survey respondents in Bell *et al.*, (2011) reported seeking information, both when they were mistrustful of the information provided by the doctor and when they were curious to know more. Online support and information has been recognised as highly important for people

with hepatitis C (Grogan and Timmins, 2010), especially for those living in rural areas, both in terms of access and anonymity (Richmond 2008). Mo and Coulson (2009) described how participation in an online HIV support forum reduced participant isolation and addressed disabling barriers which might inhibit physical access to support, although clearly this depends on having access to the internet and raises additional issues concerning disabled people being 'hidden from view' in their own homes (Watling, 2011).

Many online support forums are illness and diagnosis focused[90] (Jutel, 2009). Mendelson (2003) recognises online support as a non-judgemental and rich source of information for women with Lupus, using Turner's (1967) term 'Communitas' to describe the sense of collectivity and belonging the women felt (Mendelson, 2009). Dumit (2006) also refers to the validation and support from the online community for those with medically unexplained symptoms. The practical support and freedom to express thoughts that might be negatively received elsewhere has also been documented (Evans et al. 2013). Whilst this chapter was being refined, The Amy Winehouse Foundation issued a press release with Beat[91] announcing funding for an online support forum and other online services for young people (Beat, 2013), indicating that the value of online services is being increasingly recognised.

Despite concerns about the quality of information, participants in the above studies did not report receiving inaccurate information. Mo and Coulson (2009), and Bell et al. (2011), conclude by stating that participants should be signposted to credible and accurate websites, and even that health centres could provide internet connections to enable access to online support. Contact with others with hepatitis C emerged as a key benefit of online support - see the section on peer support below.

---

[90] There is a clear thread of exploration here concerning people with hepatitis C as biological citizens (Rose and Novas, 2001) and their role in the Disabled People's Movement (Hughes, 2009; Goodley, 2011) - a robust exploration of which is beyond the scope of this thesis. The application, or not, of the concept of biological citizenship for people with hepatitis C has been discussed by Orsini, (2006; 2008), Harris, (2010) and Fraser (2010b), and the intra-action between the disability movement, hepatitis C and biological citizenship is worthy of exploration in a future paper.

[91] A charitable organisation supporting young people with eating disorders.

Others pointed to the need for caution and to use it in tandem with professional support. Professionals advised caution with regard to the information, as Boab explained:

'The nurse who told me [she gave me] the website of the British Liver Trust to contact them and advised me to keep clear of the American websites because, well, too much hysteria. Basically her advice was to look for facts and make sure they are facts'.

Fry and Bates (2012) noted that seeking out information for themselves was experienced by some participants as empowering and helped them to feel better about diagnosis. However, the authors stressed that this should not be something they are left to do alone. For Grace, who was diagnosed without any accompanying information, support or signposting, unmediated information on the internet was experienced as extremely distressing. Ben, diagnosed at a time when there was limited information available (2003), was advised to use the internet carefully, but he also had a strong and existing link with a service which meant that he was able to talk through information (in terms of what was useful and credible) with his doctor:

'My consultant was quite good, he said,' right, don't panic over everything if you try and read everything you'll drive yourself mad'....He said just go and do some research and think about things before you come back and we discuss whether you go on medication'.

Specialist support

It is important here to emphasise that a number of participants spoke positively about the support they received from their specialist teams (see chapter seven), with some describing their consultants as particularly valuable in providing up to date information. Many referred to the vital support from their hepatitis C specialist nurse. Examples given included: advice and encouragement to begin treatment, advice to family members, support with learning to

inject Interferon, advice and information on side effect management and access to prescribing,[92] liaison with other professionals, a listening and non-judgemental ear, encouragement to keep going with treatment and letters of support in applications for welfare benefits. Some participants described support which extended outside the boundaries of working hours, as exemplified by Carl:

'But the thing about him [specialist nurse] is - he explored all the options and all the avenues he never left me with a problem he always talked me through it – it was a day or night thing with him as well it wasn't just a turn up for an appointment then off you go'.

Others referred to needing greater support than the specialist nurse was able to provide, either due to caseload, the nascent nature knowledge related to hepatitis C, or requiring support that went beyond the boundaries of their role. Here, participants referred to the vital role of peer support

Peer support following diagnosis

All participants talked of the importance of sharing the experience with others who had done it. Freda and Morgan referred to the value of other people's stories. Similarly, JB referred to talking to people who had gone through treatment, or were going through it, as *'good medicine'* for those that might be thinking about it. Here the role of peers provided a layer of expertise which augmented and validated participant experience. As explored in chapter two, peer support workers can provide important insights into issues faced by people with hepatitis C (Winter *et al.*, 2008) a trusted link to facilitate engagement with services (Aitken *et al.*, 2002) as well as emotional and practical support (Hopwood and Treloar, 2003; Norman *et al.*, 2008). Other studies have referred to the shared knowledge based on

---

[92] As explored below, the difference in costs and budget allocations meant that some medication was only prescribed by the GP.

experience (Treloar *et al.*, 2010; 2011). Pixie and JB described regular meet ups to enable people with hepatitis C to make contact face to face:

> JB: *'I think it's the fact you realise you're not alone and not only that you had people who were on treatment together and they could sort of compare rashes and compare side effects.'*

This physical meeting provided the opportunity to compare the embodied experience of treatment. The body became a site of comparison and validation, rather than merely being contagious or assessed. Interestingly, JB and Pixie also spoke of making the 'meet ups' accessible by providing 'quiet rooms' (for resting) and nutritional food and drink for taking with medication. Here, peers are the ones developing accessible and supportive services rather than the services themselves.

Richard talked about the value of *'creative loitering'* with peers and Shaun felt that a local support group for gay men with hepatitis C provided a 'safe *space to sound off'*. David and Carl, as members of 12 step support programmes[93] talked about the importance of therapeutic identification: *'it was important for me to have a network outside of my close friends who have been through it all' (Carl).*

However, Richard emphasised that the support of professionals is essential and suggested that the move towards increased responsibilisation for our own health (see Crawford, 1994; Harris, 2010) has undermined professional expertise.

Given that participants spoke at length about the need for post diagnosis support, Charlie pointed to the value of being tested by those who were actually living with the virus:

---

[93] 12 step programmes form the framework of a programme of recovery. Originally developed by 'Alcoholics Anonymous' these programmes (based on 12 guiding principles) have now been adapted to providing support to a range of people including alcohol, drugs (narcotics) and gambling.

'[HIV organisation] do point of care testing and they use someone living with HIV to do the test because there is a huge impact of someone who is living with HIV saying 'okay your test result is reactive' and that person [being tested] knowing that they [person doing the test] have HIV and actually they are sat there fit and well and not sitting there conforming to some stereotype'.

Here, being tested by someone living with hepatitis C would enact the experience in an alternative (not necessarily medical) way; as one which is also experienced by others - thereby combating isolation - and which it is possible to live well with. It could also provide an immediate link to others living with the virus as well as a referral to medical support. However, the co-infected gay men interviewed as part of this study felt there was a lack of support and silence around the experience of living with hepatitis C for gay men, as Charlie indicates:

'Just as I started treatment they had started up a hepatitis C support group which... was one of only two support groups in the city at that time. The other group actually ran during the day which meant it was completely inaccessible because I was at work. The [group] was run on an evening – again difficult in some ways, because most of the clients attending that had caught hepatitis C through substance misuse, rather than through sexual transmission. So one of the things I have been quite able to do really is try to be an advocate for people living with hepatitis C in a minor way... certainly national HIV conferences, you know mention it, make sure that HIV and hepatitis C are discussed'.

There are two pertinent issues here. First, a lack of acknowledgement of co-infection and second, that those with co-infection have different support needs. The limited availability of support groups (only two in a large city) marginalises the social support needs of those on treatment. In addition, the timings of the support groups during the working day, enacts

hepatitis C as something that would impact on working hours, or indeed be difficult to work with (see chapter nine.)

Accessing services and experiencing disablism

Chapter two briefly explored how lack of funding for hepatitis C services is steadily being recognised as a form of institutional discrimination (Butt *et al.*, 2008a; Paterson *et al.*, 2013). One of the key ways in which hepatitis C was enacted and re-enacted as marginal and low priority was noted by participants in their descriptions of the structure and organisation of some services.

Morgan and Boab, recounted in detail the inaccessible and arduous nature of the journeys they made to their hospital and DWP appointments. For Morgan, this involved travelling by taxi and then catching two bus connections each way. There was both a high financial and physical cost to this and Morgan described her disappointment with the lack of accommodations provided (i.e. patient transport, treatment at local locations). Here the act of seeking treatment actually exacerbates impairment effects and structural disablism.

Boab recounted the spaces in which services were delivered:

> *'This one particular hepatitis clinic was appalling. The waiting room was tiny there were people in there in wheelchairs and pushchairs that couldn't get in and out, no windows in the waiting room. The nurse was embarrassed actually, she said 'I'm really sorry but the medical, the health trust don't take this seriously.'*

Here experiences of structural disablism and psycho-emotional disablism blend together – what Reeve (2012a) terms indirect psycho-emotional disablism. The physically cramped waiting room presents physical barriers and the inadequate space for patients, enacting hepatitis C as begrudgingly accommodated within the hospital, and people with it as unwelcome and unwanted. The placement of the clinic in a building with no windows is

evocative of a holding cell, suggesting that people with hepatitis C are herded together and literally hidden from view. Kitchin (2000) indicates that this is an example of space being used to keep people 'in their place', and power relations being used to maintain and re-enact oppression.

Similar observations were made in a support group in the south of England, when I was making initial contact with participants. One woman described requesting her treatment be moved to a different hospital because the 'dingy' nature of the clinic was depressing and she felt reflected the low level of concern afforded to people with hepatitis C. Similarly, a social worker I informally interviewed indicated that the placement of the local drug and BBV service in a dingy and run down building on the edge of the town, with infrequent litter picking and difficult access by public transport, served to segregate those who attended (and made it very difficult). She contrasted this with a recently built medical centre where services were provided under one roof.

Here I am reminded of the arguments made by Fraser (2006) (see also Fraser and Valentine, 2008) concerning the queuing practices of people waiting to pick up their dose of methadone. Fraser (2006) explores how the queuing practices implemented by services and followed by clients, rather than reflecting the marginalisation of these clients, actually enact it and further undermine their recovery strict clinic opening times make it difficult to secure employment and close contact with other clients in the queue means that they are frequently offered drugs. Similar findings are reported by Harris and McElrath (2012), in a Northern Irish context, where services provided in dilapidated buildings with segregated entrances and serving systems, enact methadone clients as unwelcome and unworthy of respect.

In the same way, people who attend hepatitis C services such as those described above, are enacted as afterthoughts, deserving of poor treatment and limited resources. These spaces

207

are neither welcoming nor acknowledging of the effort and motivation required from participants to attend. This is particularly important given the difficulties that participants described in continuing treatment and the push to increasing the numbers of people in treatment (Scottish Executive, 2006; The Scottish Government, 2008; Grogan and Timmins, 2010; London Joint Working Group, 2012). Further, the cramped nature of the service enacts hepatitis C as a materialisation of the lack of interested afforded by public services to people affected by hepatitis C.

There is further evidence of the intra-action between indirect psycho-emotional and structural disablism (Imrie, 2002; Reeve, 2008; 2011) in both Carl and David's accounts. Both described being segregated in hospital (David) and in prison (Carl), which affected their self-esteem: *'that sort of treatment tells you how you're meant to feel'* (Carl).

Other participants did give examples of spaces they felt were accessible and which combatted their previous experiences of disablism. Freda attended the 'chest clinic' for her appointment with the hepatitis C specialist. She described the degree of anonymity afforded by sitting in an area which was not directly related to hepatitis C and therefore, did not single her or others out. However, the structure of the appointments meant that people with hepatitis C were able to recognise others on treatment:

'When I sit in the chest clinic waiting to see [the specialist nurse] I look at others around me and think 'are you here for the same reason?' One day I finished with [the nurse]...and went to get my bloods taken and was waiting there, when a bloke that had been sitting in the chest clinic started to talk to me and asked how long through I was in treatment! I was horrified at first! Luckily the waiting area for the blood clinic was just me and him... This guy then proceeded to tell me about his treatment and how at time it was awful but he was so glad he done it and he was at the end of his treatment...I then thought maybe a support group would be a good thing'.

Although Freda is concerned about her anonymity, it also shows her the value of speaking to others and was instrumental in her thinking about attending a support group. Other participants described the therapeutic value of shared space for people with hepatitis C, or the possibility of the waiting room facilitating contact with peer support 'buddies'.

The postcode lottery of services

As indicated above, participants described a lack of information after diagnosis. Laurie felt that the support infra-structure for hepatitis C had not yet been developed and this was echoed by a number of participants who referred to post code lotteries in provision of care and support. Granley *et al.* (2011) maintain that such variations in services appear arbitrary and are not necessarily linked to a perceived (lack of) need, indeed the existence of a post code lottery and a lack of services have been recognised by the All Party Parliamentary Group on Hepatitis (2006, 2008).

Steve and Ken both referred to being 'lucky' in terms of where they lived in accessing support, but confirmed that their participation on the forum had clarified that this varied by region. Morgan described the lack of support group in her area:

'There isn't one. I am thinking of starting one but my problem with that is that I think it's a bit rural here... I think it would be better in [nearest city] and because I don't drive it's pretty difficult for me to work out you know how to do that.... Someone would have to come here, but I mean that's very difficult because I find going up to [nearest city] on public transport [exhausting]'.

The disabling nature of treatment made it difficult for Morgan and others to drive or to travel. Here the geographical allocation of support services actually constitutes the experience of hepatitis C in particular ways (cf. Fraser and Seear, 2011), possibly affecting adherence to treatment and coping with side effects (including suicidal thoughts). A recent

report by campaign group 'We Are Spartacus' (Campbell *et al.*, 2012) found that transport was an area where disabled people already faced significant barriers - which are likely to increase following welfare reform - so this issue is likely to be exacerbated, rather than relieved, for people with hepatitis C.

As Charlie makes clear in the extended extract below, it is not just the physical existence of (in this case, HIV) services which matters there also needs to be engagement from professionals with those services (cf. Teague *et al.*, 1999) and a higher profile of these services within the wider community:

> *'Certainly we have got clinical staff who are deciding if, when and to whom they are actually referring our clients... we provide courses; newly diagnosed courses, positive self-management programmes...and the referrals have been – you know one or two people actually doing a favour to us. And it's not enough to actually run the courses. It's trying to get them to understand - the clinical stuff - and some of it is down to the service users it's like if you don't use these services you are going to lose them. You know it's really frustrating because then you will get on the other hand – 'oh well we have no services round here' (laugh) so very frustrating. And often it means actually just going out... and doing it myself... we have three support groups now and all of those I have had a major part role in actually getting off the ground and it takes hard work and a lot of perseverance and a lot of time you know for a long time you will just have two or three people attend and it will take ages before the numbers start building up but eventually you do get them'.*

Here the investment - financially, temporally, emotionally and politically - required to develop services and support is made visible. Solutions are neither simple nor straightforward and require commitment at a number of professional and personal levels. This is explored further in chapter seven.

Awareness and public representations of hepatitis C

Many participants expressed strong views on the need for greater awareness and a greater public presence of hepatitis C. JB pointed to the lack of funding provided for national campaigns. This links to hepatitis C as a 'silent' disease, discussed in chapter six:

'You know the government can spend 14 million on the digital switchover and spend something like two million on awareness of hep C and it's usually targeted at drug users. What about the poor woman that had a caesarean and a blood transfusion back when, who is not going to be looking at the drug related advertising on illnesses? Those are the ones slipping through the net'.

Morgan felt awareness needed to be raised in innovative ways:

'And I think buses like that should be in – everywhere not even major towns and cities I think they should kind of tour round everywhere and I think festivals is a great way to get the word across to have the buses at festivals. I've got a friend who does 'drop the debt' at festivals and that's what they do they just give out postcards to people and I think, because you certainly couldn't be doing testing at a festival really, so I think that would be a great way to spread the word would be to have a bus that goes round all the festivals in the summer'[94].

The example given by Morgan would contribute to embedding hepatitis C within a broader cultural fabric, whereby hepatitis C knowledge and awareness is developed cumulatively as well as alongside more dedicated campaigns. As explained above, eight participants had heard of hepatitis C prior to being diagnosed. Kerry reported being aware of hepatitis B (but not C) from the posters in the probation office, but didn't really think about hepatitis C until

---

[94] The Hepatitis C Trust has recently visited the 'Rewind' festival in Scotland providing information and raising awareness (Hepatitis C Trust, 2013f).

her partner was diagnosed it only acquired meaning after it affected her personally[95]. Those who had heard of it described only being vaguely aware of it - similar to Harris's (2009a) observations that awareness of hepatitis C depends on social networks and groupings.

Ben made reference to the silence around hepatitis C in the media which he felt added to its low profile:

'I do feel the media always has a part to play in most things and I feel that HIV is still a bigger issue to them than the hep C.'

This links to an observation made by Martha Stoddard Homes (2006) in relation to cultural representations of ovarian cancer. The author indicates that she was unaware of representations of ovarian cancer until after she was diagnosed and began to look for them. Similarly, Morgan describes looking for a poster in her GP surgery:

'There's not enough awareness about it at all. I mean when you go into the doctors surgery, there's no leaflets at all about hep C. I mean I'd been going to the clinic for months before I saw a little notice that said 'Hepatitis C Trust', 'hep C forum' I'd been going for months and I only got up because I was thinking 'god there is just nothing' and I walked around and read all the leaflets on the wall until I found something, (laugh) but who does that? Only somebody wonders why there's nothing!'

The awareness materials that do exist privilege some enactments of hepatitis C and make others absent. As was explored in chapter three, this is to some degree unavoidable, but it is important to draw attention to the particular political and material implications of these. Recent hepatitis C campaigns have focused on the theme of testing. Example slogans included: 'Get tested. Get treated' (The Hepatitis C Trust, 2011a), 'Get tested' and 'Are you at

---

[95] It is possible that the lack of awareness among these participants in the sample was connected to the situated nature of recruitment (and awareness raising).Participants recruited had experienced and been treated for hepatitis C prior to the first World Hepatitis Day (2011) and the launching of wider hepatitis C campaigns by the Hepatitis C Trust and the NHS, though these still vary geographically.

risk? The more you know the better' (NHS Choices, 2012).   Here, obtaining a test as a responsible health conscious citizen (Crawford, 1994) is the most important thing. There are no posters which provide insights into what it is like to be diagnosed with hepatitis C or undergo treatment, as Shaun indicates:

> *'It's interesting, there was a radio campaign about two years ago, I think, maybe a year ago, and it was on the radio stations I guess targeted it for the younger people. You've probably heard of it. It was the one that said: if you've done these things you're likely to have caught hepatitis C, there is a treatment available. It's interesting, what they don't say is: there's a treatment available but it is really horrible!'[96]*

Shaun refers to information being limited in order to encourage treatment, privileging the medical response over attention to the need for a holistic view of living with hepatitis C. For David, who had already accessed testing, posters did not make him want to act on his diagnosis or seek support:

> *'I used to see hep C posters and I had hep C and those posters didn't make me want to just turn around and go and tell someone about it and make me go do you know what I want some help. Maybe we need graphical ones, maybe we need subtler ones, I don't know.'*

David's comments highlight the lack of poster campaigns (and the subsequent lack of visibility of) addressing the needs of people who might be living with a diagnosis, but have not accessed support. Posters which encourage testing, enact hepatitis C as something which immediately leads to support, which David clearly indicates is not the case. There are no UK representations of people *living with* hepatitis C in awareness campaigns, apart from the recent Hepatitis C Trust (2011a) campaigns which feature pictures of people who have

---

[96] YouTube videos and treatment blogs are becoming more common, though it is likely that a person would not necessarily look for these until they themselves were on treatment.

hepatitis C with the tagline 'she/he shows all the signs of hepatitis C[97]'. This campaign is intended to highlight the unseen nature of the symptoms, rather than the experience as an embodied one. Participants felt there needed to be an extension of awareness campaigns beyond encouraging testing, to ones that depict what it is like to live with hepatitis C and to be on treatment. That said, these representations which only pay attention to testing, can be seen as reflective and constitutive of current service realities in the UK, given that limited support exists post diagnosis and into treatment.

This first data chapter has introduced and begun to explore the processes and social and political forces which enact the experience of living with hepatitis C, prior to, during and immediately following diagnosis. Chapter six explores participants' use of metaphor and comparison when talking about hepatitis C.

Chapter Six: 'People with HIV and cancer get all the publicity'. Talking about hepatitis C - metaphors, comparisons and implications.

Introduction

The current chapter builds on chapter five, by exploring in greater depth how specific metaphors used by participants in their interviews actually *constitute* their hepatitis C. I begin by clarifying the reasons for the focus on metaphor. The constitution of hepatitis C as 'low profile' both politically and socially, and the resulting sense of 'invalidation' (Wendell, 1996 2006; see Reeve, 2008; 2012a) experienced by participants, clarifies the participants management of interactions, the focus on strategies used to explain their hepatitis C, and how these strategies *enact and re-enact* both the virus and the participants. Specific attention will be given to the use of the metaphor of hepatitis C as a 'silent killer' or 'silent disease' to elucidate key ways participants gave their experience meaning (Fraser and valentine, 2008).

A major focus of the chapter will be the way participants made comparisons with cancer and HIV/AIDS - both often described together owing to their status as two of the most prolific (and uncertain) diseases of recent decades (see Sontag, 1991; Weiss, 1997 and Lupton , 2003). I will explore how HIV and cancer were both *used as* metaphors and *became* metaphors (Fraser and valentine, 2008) in participant accounts. This will be followed by a discussion of the consequences (both intended and unintended) and the way in which all three illness concepts are enacted. The chapter will end with a discussion of the hierarchy of impairment (Deal, 2003; Reeve, 2008) and the implications for participants and services.

As explored in chapter three, I follow Duffin (2004a), Fraser (2011) and Fraser and Seear (2011) in working from the position that hepatitis C is not a fixed and a stable disease, which

exists prior to the discourses and methods which produce it (Law, 2004 and Mol,2002), but that it has been, and is, actively enacted and re-enacted by social, cultural and political forces. These forces impact how it (and the people it affects) are constituted, engaged with and responded to. This chapter is a response to a call made by Fraser and Seear (2011) for the need for in-depth work which explores the way diseases (including hepatitis C) are shaped by such forces. The focus on metaphor is particularly important in illuminating the experience of illness (Lupton, 2003), the ideological and cultural foundation of a group or society's values (Froggatt, 1998), and the way that metaphor can work to constitute particular groups (and viruses such as hepatitis C) in negative and oppressive ways (O'Brien, 2009).

Metaphor

In her path breaking work on the use of metaphor in illness, Sontag (1991:91) uses Aristotle's definition, 'giving the thing a name which belongs to something else'. Lupton (2003) maintains that metaphor brings together two non-related entities and focuses on ways they resemble each other. In her essays 'Illness as Metaphor' (1978/1991) and 'AIDS as metaphor' (1988/1991), it was not Sontag's (1991) intention to describe what it was like to experience illness, but to explore *the metaphors used to explain it.* She maintained that metaphors are used for diseases (Tuberculosis, Cancer and later HIV/AIDS) which are poorly understood by medicine and the wider public. She criticised the pervasive use of metaphor (particularly in relation to cancer, when she was being treated for breast cancer herself), arguing that it contributed to the sense of shame and oppression experienced by those with it and made them responsible for the illness and its cure (see also Stacey, 1997). Sontag (1991:3) argued that it was vital to detach the metaphorical understanding from disease itself, with the aim of seeing disease as something 'purified from metaphoric thinking'. Whilst her work was pivotal in highlighting how metaphor shaped thinking and research around illness, Sontag's

(1991) position concerning the possibility of separating metaphor from the disease has been critiqued. DiGiacomo (1992), Stacey (1997) and Fraser and valentine (2008), follow Ricoeur (2003) and hold that this separation is not possible, that metaphor and reality cannot be prised apart from each other and that metaphor should be considered not as a creative addition to language, but fundamental to making it.

Metaphor is central to how we understand the world and function within it. Lakoff and Johnson (1980) and DiGiacomo (1992) state that it is not possible to see disease as a purely biological entity just as no one experiences cancer merely as the proliferation of cells (see also Stacey, 1997), neither do people with hepatitis C experience it as the transmission and proliferation of a virus - although the way that the virus is discussed within medical literature (and recounted by professionals – see Grace and Daniel's data) shapes both the participant and others' hepatitis C.

In recognising that metaphor is part of everyday life and that our use of it is largely unconscious, (Lakoff and Johnson, 1980) the ubiquity of metaphor necessarily means focussing on some metaphors so that others become obscured (Altman, 1990; Fraser and Seear, 2011). As was explored in greater depth in chapters three and four, all methods make some things present whilst making other things absent, and political decisions must be continually made about what needs to be foregrounded. Thus the metaphors presented and explored here, have been foregrounded. They are necessarily culturally and temporally situated, and contingent both on the tools used in generating the data, as well as my own sensitivities to what I felt (and what participants told me) was central to the experience of having hepatitis C. These included the low political and social profile of hepatitis C, the level (or lack) of resource allocation, limited understanding from friends, family and professionals, and the lengthy and debilitating treatment and post-treatment effects.

As will be explored, metaphors were used by participants with the aim of facilitating a change in perspective (Miller, 2006) concerning hepatitis C and its treatment. However, the work to produce this change in perspective had consequences for participants' sense of self. I will discuss how this was experienced as beneficial, to some degree, in managing interaction with acquaintances and providing personal validation of their experiences. I will also explore how that validation (and subsequent invalidation) intra-acted with professional responses (explored in chapters seven, eight and nine). In addition to this, the diseases that participants used also *became* metaphors (for deserving and undeserving illnesses, and for entitlement to, and availability of public and social support services) which had unintended consequences for their sense of self and organisation, and identification with other groups.

Stigma, psycho-emotional disablism and hepatitis C

As was outlined in the literature review, stigma and discrimination are recognised as being one of the main issues faced by people who live with hepatitis C (Hopwood and Southgate, 2003). Although the concept of stigma is frequently used within the literature on hepatitis C, and is useful, in this thesis I use another concept developed within disability studies – psycho-emotional disablism. This concept was first developed by Thomas (1999; 2007) and later expanded on by Reeve (2002; 2008; 2012a) as a means of understanding oppression that operates at an inner level as well as externally. I will use psycho-emotional disablism, not to merely describe the experience, but to explore how it *gets* made and to recognise that oppression that people with hepatitis C experience – disablism – should be given equal weight as other forms of oppression, such as sexism, ageism and racism (Thomas, 2007). The degree to which people with hepatitis C identify as disabled will be explored in chapter nine.

I did not initially intend to explore the experiences of disablism among people with hepatitis C. This came about as I read Reeve's (2008) recently completed thesis as a means to aid my understanding of what was required to gain a PhD. I revisited Reeve's work as I generated

data and I could see more and more links between disability studies, psycho-emotional disablism and the disabling experiences my participants were describing. This was cemented by a serendipitous conversation with members of Lancaster University's Centre for Disability Research I noted that even though participants did not necessarily talk about being 'disabled', they did talk about, or allude to, feeling ashamed or responsible for their illness and this impacted on their sense of self, and sense of entitlement to support. In interviews, this led to participants talking about cancer instead of hepatitis C as a 'more acceptable' disease. Thus, although not all participants consciously called themselves disabled, naming the oppression they experience as *disablism*, potentially provides a validation of the experiences, and a sense of entitlement to support, as well as a potential means of organisation.

The profile of hepatitis C

As was explored in chapters two and five, the level of awareness and profile of hepatitis C among the general public has been, and continues to be, low. The low level of awareness intra-acted with participant illness and interactions with professionals, which resulted in a sense of invalidation (Wendell, 1996; Hughes, 2012). The strategies and the use of metaphor both resisted and reinforced this described below.

Awareness of the disease at the outset was most commonly reported by participants who had been in recent (or current) contact with drug services who worked in the area (Richard, Charlie).[98] Others who disclosed their status, described a lack of awareness among friends or family (an area which itself requires further research), as Daniel's extract makes clear:

> *'I am really open about it, told my family almost immediately and they did not know what it was. I find that quite a lot people look at you and say 'hep c'? They don't know*

---

[98] Employer awareness and knowledge of Hepatitis C is further discussed in chapter nine.

what it is - My step father even got it confused with a cold sore - he thought it was that

virus, Herpes... so I had to explain and he had a look on the internet.'

For Daniel, this lack of knowledge about the virus was explained as a potential reason for the negative perceptions associated with hepatitis C:

'I think [there needs to be] more awareness and understanding. I was surprised at how

many people who didn't know what it was and didn't understand it and maybe there is

some sort of stigma attached to it you know?'

For others, the link between knowledge of hepatitis C and stigma[99] was a complex one, as this extract between Andrew and Carl shows:

Heather: 'Do you think it's stigmatised?

Carl: Not so much

Andrew: A lot of people just don't know about it or if they do they stigmatise it.

Carl: [I]nearly ended up fighting at Christmas actually ..... I have known this guy for a

lot of years and he knew I had hep C and was making sandwiches with him and he says

'you need to be putting some gloves on I don't want to be catching that hep C'. And I

thought 'how fucking rude are you? How ignorant are you?' it really upset me that

did'.

Carl initially states that hepatitis C is not stigmatised; it is only when Andrew makes the link between knowing about hepatitis C and the potential for negative treatment that Carl recalls a difficult experience. This suggests that participants were not always immediately conscious

---

[99] The term stigma is used when participants referred to it themselves or I used it in an interview. As is explored above, I did not set out to explore the concept of psycho-emotional disablism, so stigma (a term which participants understood) was often used to elicit experiences, which I then came to understand were accurately described as psycho-emotional disablism.

of their experiences and these were constituted, and made sense of, in interactions with others.

For Carl, knowledge (or a limited amount of knowledge, such as an individual's status) is associated with the experience of stigma. For Laurie, this lack of awareness meant he felt there was no stigma because '*I found most people never knew what it was, never heard of it'*. This was also described by participants with co-infection in Lekas *et al.*'s study (2011), who indicated a lack of awareness of hepatitis C negated some of the negative feeling[100].

The relationship between knowledge and stigma/oppression is a complex one. Academic work around hepatitis C often refers to increased knowledge as a means to address and negate stigma, (Van De Mortel, 2002, 2003; Day *et al.*, 2004; Brener *et al.*, 2007) though it depends how this information is used. If it provides assurances to individuals that they are unlikely to have the virus, or as an issue which does not concern them, this may further reinforce individual responsibility for infection and for telling others about it.

The link between knowledge and disclosure

The interlinked nature of '*stigma*', disablism and knowledge emerges in the interview with Pixie, who felt that '*knowledge to answer questions*' was a key aspect of being able to address negative feelings:

> '*I think people that talk about stigma and are those that don't have enough knowledge to answer questions. I think that's what they're afraid of. It's not having the right answers. I don't think it's the fact that people are going to shy away from them ...sometimes I wonder whether or not the stigma's with that person because they have not got the answers of the questions they think might be fired at them.*'

---

[100] Similarly Grace reported a lack of knowledge among professionals, particularly those working for the Department for Work and Pensions. This will be discussed in greater depth below and in chapter nine.

Here Pixie states that having the answers to questions is the key to avoiding stigma, though as seen in chapter five, the connection with, and support from, other people with hepatitis C might also lead to greater confidence in telling people about their hepatitis C status.

Whilst increased knowledge may lead to improved understanding, and therefore reduced experience of stigma in some instances, this overlooks the assumption that an individual *should have* to answer questions or act as a source of information to others.

Disability studies scholar Lois Keith (1996), points to the energy required to take on the role of educator, indicating that as a result she only engages with this if the other person is (or is likely to become) a friend or colleague. Although people with hepatitis C are urged to disclose their hepatitis C status only if they undertake exposure prone procedures (DH, 2002b; 2004), there were many other instances when participants felt they had to disclose or at least *'say something'* (Kerry) - what Krug and Hepworth (1999) refer to as the moral imperative to disclose.

This sense of responsibility echoes UK and wider western ideological focus on personal responsibility for health and wellbeing (Crawford, 1994; Lupton 2003; Fraser, 2004; Harris, 2010; Cranshaw and Newlove, 2011; Paff-Ogle *et al.*, 2011) potentially constituting a form of psycho-emotional oppression.

Sinclair (2005) developed the term 'self-narrating zoo exhibit' to describe the experiences of autistic people who were often expected to act as sources of information or to tell their story to interested parents or professionals. The impact of this is that people may feel as though their experiences are merely being displayed rather than listened to, and that they are acting as a source of information (and reassurance) for other people (Sinclair, 2005), rather than having their own support and information needs met.

Donna Reeve (2012a) describes this form of continued questioning as a form of oppression - direct psycho-emotional disablism. Reeve (2012a: 81) states 'the questioner needs to be reassured that [the person] is not contagious and that it won't happen to them'. For people with hepatitis C, the need to provide answers to questions *'that might be fired at them'* (Pixie) also constitutes a form of direct psycho-emotional disablism. Here, a lack of culturally agreed rules for interaction about how to treat disabled people (and people with hepatitis C), results in participants having to tell their stories to anyone who wants to know (Reeve, 2008). For people with hepatitis C (which *is* potentially transmissible) this is a complex issue.

Managing the interaction

For some participants, reassuring others (acquaintances, friends) that they would not contract hepatitis C *was not* part of their disclosure. If anything, their intention was to *'normalise'* hepatitis C by clarifying and emphasising the 'everyday nature of transmission routes. Keith (and others) viewed this as part of raising wider awareness of hepatitis C. This is a delicate balancing act, between explaining clearly that hepatitis C is transmitted under certain circumstances, without perpetuating the idea of contagion and the resulting 'hysterical responses' (Crofts *et al.*, 1997). Thus, disclosure becomes a continual 'coming out' (Stacey, 1997), where uncertainty exists as to the reaction of the person to whom their hepatitis C status is being disclosed. Participants are not disclosing solely as a means of obtaining support or sharing experience (although this may well be part of it), but to *address other people's concerns,* with the overall aim of avoiding negative reactions. Similarly, the pressure on individuals to answer questions ignores the structural factors (including the low public profile, lack of easily available information and support services) and places responsibility for education firmly at the feet of individuals. Keith described employing a particular strategy in providing information and disclosing:

'I was surprised [when told work colleagues] – no stigma...Absolutely zip... I didn't get

any false sympathy or anything and the majority of the people that I worked with had

no idea, what it was about and I have developed a way of telling it... you list the most

amenable [ways of transmission] first so like sharing toothbrushes – razors, and you go

down the list and what you do is, you tackle the most unpleasant ones you know...

anything drug related on the bottom. By the time you have got to that one – people

are too busy thinking about the first few going, 'Oh I have done that, I done that,' to be

even bothered about that one thrown in and people don't think about it from there so

you don't get any what do you call it? You have basically normalised it. Does that make

sense?'

Here Keith is acutely aware of the possibility of negative treatment, but manages this through focusing his colleagues' attention on the ubiquity and possibility of the transmission of hepatitis C via everyday items, such as toothbrushes or razors, before he introduces the possibility of drug use. Whilst raising the profile of hepatitis C as something which is not just contracted via drug use is no doubt important, this potentially has the unintended effect of reinforcing ideas about drug use, sidestepping rather than challenging them. Here, hepatitis C and people with it become liminal via the act of disclosure. Keith's strategy, whilst enacting hepatitis C as something which can affect people with a wide range of life experiences, simultaneously acts to reinforce the 'otherness' of drug use. Hepatitis C and people with it become both 'normal' and 'not normal'.

Information and enactments of hepatitis C

There is an important point to be made here knowledge *about hepatitis C* and knowledge *of transmission* can become conflated and concerns about transmission become the overriding

focus. Kerry shows how the delivery and type of information can have an impact on perceptions of illness (and even treatment). She described her initial appointment with a gastroenterologist, to which she had taken her mum along for support:

*'[The Gastroenterologist] didn't even look at me from his file - ... he didn't say, 'how do you think you got the disease?' he said, 'so I am assuming you're an IV drug user' – I said '**was** an IV drug user I'm not anymore' and I started like that to try and challenge him a little bit and he literally, still without looking up said 'my nurse will give you some printed out information I will refer you onto (a nearby) clinic'* **(my emphasis)**.

Here the information about treatment is used to inhibit any further discussion or questions (and Kerry's opportunity to challenge the doctor's discriminatory treatment of her), bringing the consultation to an abrupt close. Fraser and Seear's (2011) observation that information *makes* hepatitis C in ways which both diverge from and reinforce enactments of it made elsewhere, is particularly relevant here. The information about medical treatment enacts (Kerry's) hepatitis C in a specific way – as one that is carried by a (former) drug user and is therefore worthy of poor treatment by the gastroenterologist - yet also, as one which needs to be treated but which is not worthy of any further discussion of options. This re-enacts hepatitis C as a disease which is insignificant - which needs to be eradicated via medical input, and not much else. Hepatitis C is enacted and perpetuated (Butt *et al.*, 2008a) as negative, and the consultant's discriminatory behaviour goes unexamined and unchallenged.

Later Kerry described being provided with information concerning transmission routes. This information also enacts hepatitis C in a specific way:

'He gave me some pieces of A4 paper with some stuff about side effects and interferon and blah this is another one of my gripes the pieces of paper that you are given are all about transmission to start with we know about transmission and when someone like

my mum looks at some pieces of paper and the first page is about drug addicts,

homosexuals. It's just the wrong way to present information'.

Here the provision of treatment information slides into a discussion of transmission information, the usefulness of which Kerry questions, when *'we already know about transmission'*. This echoes the findings of Minuk *et al.* (2006), who observed that during appointments, consultants focused on transmission, when patient concerns and needs were much broader.

In Kerry's example, the information concerning transmission enacts hepatitis C as a disease where transmission route is important, yet how an individual *acquired* hepatitis C has no bearing on the effectiveness of treatment. Though it may affect how the person with hepatitis C is responded to, (as in Kerry's example above), and injecting drug use may preclude individuals from accessing treatment, despite guidance stating it should not (NICE, 2006; Foster, 2008; APPGH, 2011).

Here it is possible to see how information about transmission routes enacts different hepatitis Cs. There may be more robust services and information for those in contact with drug services, but compensation available for those who contracted it via blood transfusions (Duffin, 2004a). The construction of hepatitis C according to transmission route is explored again in chapter nine.

For other participants a perceived lack of information and support around diagnosis (Hopwood and Treloar, 2003) meant hepatitis C was constituted using the metaphor 'silent killer/silent disease'. It is this metaphor that the next section focuses on.

'The silent disease'\ The silent killer'

Boab: 'I don't think its stigmatised. I think it's just ignored. The medical profession call

it the silent killer and there are probably a number of reasons for that one. It takes so

long to manifest itself, the symptoms are very nonspecific and can easily be ascribed to other things such as alcohol or lifestyle choices... and it's not a dramatic illness, apart from I mean, the last stages.'

As hepatitis C is still 'under construction' (Duffin, 2004a), metaphorical descriptions of the virus as 'elusive', 'sneaky', 'insidious' or 'silent' are evident (Fraser and Seear, 2011). Metaphorical portrayals of hepatitis C as a 'silent killer or 'silent epidemic' are frequently used in medical literature (see Bockhold, 2000; Cole, 2007; El-Zayadi, 2008[101]). Here, it is the virus itself (rather than the structures surrounding it) which is silent, as it exhibits a (reported) lack of *'dramatic'* and visible impairment effects until the disease is advanced, as Boab makes clear.

The 'silent killer' metaphor has also been explored in relation to ovarian cancer. Jasen (2009) states that the metaphor 'silent killer' both reflected and reinforced understandings of ovarian cancer by the time the symptoms themselves were recognised by doctors and diagnosed, the cancer had advanced and become difficult to treat. Thus, the metaphor of a 'silent killer' was potentially dangerous, in that it obscured the barriers to recognition of the symptoms that the women faced and attributed the silence to ovarian cancer. In a similar way, Kerry, Holli and Morgan constituted the 'silent or 'asymptomatic' nature of hepatitis C differently, suggesting that efforts to determine their diagnosis were unsuccessful not because the virus was silent, but because there was a lack of knowledge, poor communication or structural barriers in their interactions with health professionals — discussed in chapter five. Other participants used the 'silent killer/silent disease' metaphor to suggest that hepatitis C is *silenced t*hrough lack of impetus to take action, poor policy response and lack of funding (Edlin, 2011):

---

[101] These are all examples from medical journals which reinforces Stacey's (1997) point that medicine appears neutral because of the way medicine is organised, but that it too is imbued with metaphors.

Charlie: 'Hepatitis C is different [from HIV] it is a silent disease - it's very quiet - we are not going to see the effects of hepatitis C for another 10, 20, and 30 years and then it's going to be big. When you look at the prevalence rate of hepatitis C, they're guesstimates, but they're massive compared to HIV ... You know it's huge, but its silent – it's not knocking on the door to be dealt with yet and it's very convenient and even though that might be being sceptical it's very easy for a politician to think well that's not going to happen on my watch'.

England's policy response, whilst being the first of its kind in the UK, has been heavily criticised for being inert and inadequately funded and supported (APPGH, 2007; APPGH 2008; K.Morris, 2011,). It has not been updated since 2004 and the National Liver Disease Strategy, repeatedly delayed[102] (further silenced) by the uncertain economic climate and deep government cuts to services. As Charlie indicates, the impact of hepatitis C on health and social care resources may not be felt for some years, burying the need for urgent political response. Indeed, the conditions which exist presently are the opposite of those which existed in responding to HIV (adequate funding, urgent political response, involvement of affected groups and community work - see Hulse, 1997). Funding for hepatitis C support (and the comparison which Charlie makes with HIV) will be returned to below.

Other participants used the metaphor of hepatitis C as a 'silent epidemic' to lend support and credence to their own actions, but also to enact hepatitis C and those it (potentially) affects in a particular way. As Morgan states:

' It's a silent epidemic. I think people need to know that – a lot of the time people don't want to know but they need to know.

---

[102] In December 2013 it was announced that plans for a dedicated National Liver Disease Strategy had been abandoned (LJWG, 2013).

Heather: The not wanting to know – what do you think that's connected with?

I think most of us think it's not going to happen to us – 'that doesn't concern me that's going to happen to someone else and not me' you know we are quite good at burying our head in the sand really about stuff. I'm amazed so many of my friends have not gone and got tested. I just think it's crazy but that's up to them'.

Here hepatitis C is constituted by Morgan as 'silent' in order to emphasise that there is a reluctance to know about potential hepatitis C infection and the importance of being tested. However, Morgan's (and Ken's – below) observation is constituted through a hinterland (Law, 2004) of messages from recent campaigns, such as The Hepatitis C Trust (2011a) and the NHS (NHS Choices, 2012), both of which implore people to 'get tested' and 'get treated'. Thus, 'silence' is constituted as a choice and as self-imposed which obscures the difficulties of accessing a test, the lack of support post-diagnosis, the limited numbers on treatment and the enactment of hepatitis C in negative ways all of which may act as deterrents to being tested. This also highlights the divergence between the public health benefits of increased hepatitis C diagnosis and personal benefits, which may not be great, given that diagnosis may well be experienced as burdensome (Fraser and Seear, 2011).

Ken also emphasises the importance of getting treated using the metaphor of the silent killer:

Heather: 'What did you - sort of - think when you found out you had hep C?

Ken: Get treated, get treated straight away because I'd heard of it being the silent killer. I had heard from people like that woman who owned The Body Shop [Anita Roddick] she was brave enough to come out and talk about it wasn't she, even though she couldn't be cured, so that sort of highlighted, that gave people the momentum to go forward on it. Because there is still a lot of stigma around in rural areas like this place. So I just had to get on with it and get it done.'

Here, the metaphor of the 'silent killer' was invoked in a complex way: Ken's response to finding out he has hepatitis C is that he needs to *get treated straight away'.* This enacts hepatitis C as something which needs to be treated and cleared urgently, enforcing the dominance of the medical response. Yet in the same extract, Ken uses the example of the late Anita Roddick, founder of high street chain The Body Shop, who did not clear hepatitis C, suggesting it may not necessarily be something that needs to be cleared because she lived with it, until her death in 2007 from a brain haemorrhage. Here medical treatment is simultaneously questioned and reinforced. Additionally Ken makes a direct link between the potential for negative treatment and the need to get treated and *'get on and get it done'.* Treatment appears to be for moral reasons, as well as medical ones. This also highlights how stigma does not pre-exist hepatitis C, but is made in intra–actions with medicine, personal experience and the public profile of hepatitis C (Fraser, 2011). This is particularly apparent in Ken's later extract when he uses the metaphor of the 'silent killer' to emphasise that hepatitis C can affect anyone:

> *'It is well they say - the silent killer and it is because it spreads right through all members of the public [consultant Hepatologist] explained that a lot of surgeons have got it. He said they wouldn't thank him for mentioning that, but it is a fact that a lot of surgeons have it. Through blood contact and that you know?'*

Here the active enactment and re-enactment of stigma in relation to hepatitis C rather than it being an inherent property of the disease (Fraser, 2011) – becomes clear: Because a *'lot of surgeons have got it',* hepatitis C is enacted as something which can affect people who may have a higher personal and moral status than someone who uses drugs, but then the stigma is enacted when Ken (reporting the consultant hepatologist) states *'they wouldn't thank him for mentioning it'.* Here, the silence around hepatitis C is perpetuated, drug use remains 'othered' and the moral connotations of the disease are reinforced (Sontag, 1991).

The next section addresses a strategy that participants used to discuss, and enact and re-enact hepatitis C and its treatment:

Making comparisons with cancer

As with all illnesses, current understandings of cancer are culturally and temporally situated (DiGiacomo, 1992) and dependent on context (Clarke and Everest, 2006). Cancer has been described as 'the disease of our time' (Herzlich and Pierret, 1987; Weiss, 1997) and has historically been constituted as uncertain and unknown [the very reason for the proliferation of metaphor (Sontag, 1991)], frightening, evil and associated with morally culpable behaviour (Lupton, 2003). The degree to which cancer is perceived as shameful as Sontag (1991) suggested has been disputed (see Clow, 2001). Although it may still be seen as unwanted, there is evidence to suggest that cancer is being enacted in new ways, with a discourse of fear being replaced by one of hope (Delvechio-Good et al., 1993), and - specifically in the case of (female) breast cancer - one of activism, (Klawiter, 2008) high profile public support and positive thinking (King, 2008; Ehrenreich, 2008). This activism and emphasis on positive thinking, survivorship and the opportunity to be remade (Stacey, 1997) has been heavily criticised (Engelberg, 2006; Abel and Subramanian, 2008; Ehrenreich, 2008; King, 2008) and highlighted as a form of moral oppression (DeRaeve, 1997), but this emphasises how cancer is materialised through intra actions between participants, material conditions and public profile (Barad, 2003; Fraser and valentine, 2008).

Comparisons with cancer were present throughout the interview process, from the pilot interview onwards, when Morgan stated '*I think the treatment for hep C and the side effects are as bad as cancer really*'. It is likely that the richness of this first example - which uses one of the most culturally prolific (Weiss, 1997) diseases of recent decades and evokes a comparison with chemotherapy - had an influence on my sensitivity to this comparison, and silenced others (Law, 2004). However, a total of 11 participants made comparisons between

hepatitis C and cancer in their interviews and nine participants made a comparison between hepatitis C and HIV/AIDS.

Although Fraser and Seear (2011) state that HIV and hepatitis C are symbolically linked (discussed further below), my initial thoughts were that comparisons with cancer were peculiar to participants who were recruited or received support from the same online forum. However, similar comparisons (between HIV/AIDS and cancer and chemotherapy) also emerged in interviews with participants who were neither recruited from the forum, nor spoke of it as a source of support. Further to this, when presenting my research to two local (separate) professional meetings, the comparison with cancer and chemotherapy was also present. This suggests that such comparisons were not specific to the online forum and thus, that these findings have relevance to a wider population of participants with hepatitis C.

The cultural position of cancer and chemotherapy

To date, the comparison between hepatitis C and cancer has not been extensively explored in the literature, though cancer and/or chemotherapy are mentioned briefly (see for example Glacken, 2001; Butt *et al.*, 2008b; Hopwood *et al.*, 2006; Harris, 2009a; McCreaddie *et al.*, 2011). Fraser and Seear (2011:116) refer to the frequent comparison between hepatitis C treatment and chemotherapy, acknowledging that whilst it may be useful in clarifying the challenges faced by people on treatment, it must be used cautiously. They continue:

> 'This is because, most obviously, chemotherapy is not delivered in the politically charged environment of drug treatment and drug addiction. Nor do the recipients of chemotherapy figure as sources of horror, disgust or shame in the same ways as do people with hepatitis C.'

Whilst I would agree that this comparison should be used with caution, the differing political and social values and assumptions attached to cancer is *precisely why such a comparison is made* by the participants.

Cancer (as a single concept – discussed below) was used in a variety of contexts when participants talked about their hepatitis C. David used cancer as an example of an illness which is (perceived to be) widely known about and understood when discussing the 'illness in recovery' groups he attended as part of AA (Alcoholics Anonymous). Grace states *'I could be diagnosed with cancer tomorrow'* as a way of indicating an extreme form of illness and Carl compares the lack of information when he was diagnosed:

> *'There was no information available you couldn't phone someone up it just wasn't there - it was like being told you've got cancer and there is no cure for it.'*

Cancer was perceived by participants as one that currently garners significant public support and has a high public profile, complete with organised structured support services. The comparison was intended to highlight shortcomings in the support available for hepatitis C in the UK, which participants perceived were based on cultural beliefs about particular diseases rather than support needs. In some respects this comparison was useful and hepatitis C was constituted in a particularly powerful way (see below). However, the comparison simultaneously created solidarity *and* divisions between people with cancer and people with hepatitis C. Additionally, in making the comparison, 'cancer' and 'people with cancer' became metaphors for 'moral worth' and 'being deserving of support', providing direction on how to respond to a particular person or group (O'Brien, 2009) and thereby enacting a hierarchy which impacted on how participants saw and described themselves.

Hierarchy of impairment

Hierarchies of impairment (discussed by Deal, 2003 and later by Reeve 2008 – whose observations I am building on here) occur when one group of people differentiates themselves from another, effectively participating in a ranking of experience, especially among groups that are marginalised. Both disabled and non-disabled people participate in the ranking. Participants in Reeve's (2008) research differentiated between themselves and people with learning disabilities. In Crandall's (1991) study, a hypothetical HIV positive man attracted 'fewer stigmas' if the HIV was contracted via blood products than if was contracted through being gay or injecting drugs. Golden *et al.* (2006) found that women who had contracted hepatitis C through blood products, steadfastly differentiated themselves from people who used drugs. Simmonds and Coomber (2009) observed a similar phenomenon among people who used drugs who made a 'downward comparison' with people who had hepatitis C perceiving them as immoral and less clean. Thus the hierarchy functions to affect how people feel about themselves and how they feel about people with other diseases. It has clear implications for comparisons made with people who have cancer and those who have HIV – see below.

Although Deal (2003) describes differentiation between groups of disabled people, some participants in this study emphasised the similarities, creating solidarity between people with cancer and hepatitis C. For others the comparisons were less beneficial and revealed that wider beliefs about diseases had been incorporated by participants, resulting in feelings of worthlessness (Reeve, 2002). It is important to note that this is neither fixed nor a definite outcome, but is made through intra-action between context, people and wider cultural and social values.

I am aware (as were the participants – discussed below) that there may be significant differences between their experiences and those of people with cancer. I am not merely trying to map one disease onto another. However, in not exploring these comparisons and their meanings and implications for participants, I risk enacting the silence and low profile of hepatitis C and thus perpetuating the hierarchy, where certain impairments are seen as more 'deserving' of support. Furthermore, highlighting the widespread use of the comparison with cancer (and with HIV below) emphasises that participants with hepatitis C are not alone in thinking it (Beck, 2005) and thus, provides some validation of their experiences (Abel and Subramanian, 2008).

The recognition of cancer

Boab highlighted the instant recognition that the public now has around cancer (Abel and Subramanian, 2008) and its seriousness in comparison with hepatitis C:

'But it's [hepatitis C] not like cancer it's not you know obvious or in your face that people have it or if they have got it. There's so much ignorance about how serious it is, the general population and even the medical profession don't appreciate that it needs dealing with – am I making sense?'

A similar view was expressed by the support group facilitator who was present during a group interview with Carl, Andrew and Brad:

'The general population thinks they understand what it might be like to have a cancer and there is empathy around that, whereas someone with hepatitis C doesn't experience that empathy'.

Although cancer had previously been treated with trepidation, isolation and fear, the situated nature of knowledge and beliefs (Harraway, 1988) are evident here. In recent decades cancer has gained a much higher public profile and much greater news coverage, as

235

treatments have advanced and activists have gained a higher profile. Clarke and Everest (2006) found that latent themes in media coverage of cancer are that cancer is uncertain but (almost) inevitable part of life experience (which potentially exacerbates fear). Similarly, with the rise of responsibility for personal health, media stories about cancer have a heavy focus on avoiding or engaging in certain activities meaning that cancer becomes ubiquitous (Clarke and Everest, 2006) and 'the new normal' (Mukherjee, 2011). Here, Susan Wendell's (2001) observation concerning disease as a reminder of personal vulnerability is particularly relevant public empathy around cancer stems from the possibility and recognition that 'anyone' can get it (indeed this is used by Macmillan as a means of gathering funding and support – see below), as the support worker present during the group interview indicated: 'whereas cancer is something that you can't help getting'[103].

For Richard, the comparison with the Department for Work and Pension's (DWP) treatment of cancer enacts a disease that is treated as serious, as hepatitis C should be:

'If (the DWP) could just treat it seriously that would be nice in the same way they do with cancer and things like that'.

Although recent developments with the coalition government's proposed welfare reforms highlight that individuals with cancer also experience difficulties accessing financial support in practice (see Thomas et al,.2001; Wilson and Amir, 2008; Moffatt et al., 2010), cancer maintains its strength and weight as a 'deserving' disease. Furthermore, people with cancer have been used by the media as an example to emphasise the unfairness of the government's proposed welfare reform plans (Malik, 2012), which re-enacts cancer's status as 'deserving'.

---

[103] Although Carla Willig (2009) has described the pervasive nature of discourses associated with positive thinking in cancer (see also the powerful critique by Ehrenreich, 2008), as well as the moral discourses which suggest a person got cancer because they did not look after their health. Chapple et al. (2004), in their study of people with lung cancer, found that blame was attributed because of the association with smoking - though these were not acknowledged by participants.

For Ben, a perception around public awareness of cancer co-constituted the legitimacy (or lack thereof) a hepatitis C diagnosis has in requesting a reduction in his hours at work:

'I spoke to [liver charity]... I said now how do I go about it if I wanted to reduce my hours? And they said well you can reduce your hours, but they said it's generally between you and the employer. Because I said if it was something more recognised, like if it was cancer or something else most employers would just say then you can reduce your hours and go on so many hours as sick, but because it was hep C nobody knew.'

The lack of knowledge around hepatitis C, and the difficulties he faced with his employer when he requested a reduction in hours, meant that Ben actually continued to work and thus hepatitis C remained low profile within his organisation. I am not saying here that it is Ben's responsibility to tell his employer in order for them to be more aware of hepatitis C, but rather highlighting the structural barriers and the lack of support from organisations to support with disclosure to his employer – see chapter nine.

For others, the comparison with cancer also served to highlight the low level professional responses to hepatitis C and the lack of available, organised support, as Boab makes clear:

'I think the whole support network is not there, if I had cancer, my wife said this – if you had cancer - the Macmillan trust [there's] all sort of organisations who support cancer sufferers.'

Here cancer support (specifically that provided by Macmillan, a UK based cancer care and support organisation) is treated as the template for support services, represented as well structured, advertised regularly and widely publicly supported:

JB: 'I mean if you have cancer, you do get your benefits, you get your Macmillan nurses and I know I can't compare hep C to cancer but there are similarities and I think that's overlooked definitely overlooked'.

It is important to state here that I am not intending to depict those living with cancer as passive recipients of support, or naively suggesting that Macmillan support services (and similar organisations) have adequate funding, staff and the same level of service provision throughout the UK. Thomas *et al.* (2001) found that people with cancer had a wide range of unmet needs particularly around dedicated social support, information and support, and there is evidence to suggest that this persists. Moffatt *et al.* (2010) in her exploration of the need and uptake of welfare benefit advice among people with cancer and their families, indicated that although many received excellent support from Macmillan, there was a postcode lottery for welfare benefits advice – some hospitals had integrated dedicated services, others did not.

Feedback from presenting my research to a local network of harm reduction professionals, suggested that the stretched financial realities of services provided by Macmillan were not being taken into account by study participants. However, the high profile advertising campaign (national TV adverts, billboards, posters, collections, coffee mornings) *give the impression* that they are available it is what these services represent culturally (in terms of wide ranging response to the disease and an infrastructure of support) that participants were referring to. Thus, Macmillan advertising functions as an offer of support, a request for further funding in order to provide it and a means of awareness raising. Through high profile advertising campaigns, cancer is *enacted* as a well-funded, publicly supported disease with widely available support services, no matter where you are or what type of cancer you have. Thus, the difficulties cancer support services may have in garnering adequate funding or meeting the needs of people who contact them are also obscured.

Participants made it clear they were not necessarily asking for support services from Macmillan, but rather highlighting the lack of meaningful structured support for people with hepatitis C. This was supported with an observation (on a separate occasion) from a manager present at a local network of health and social care professionals, who highlighted lack of dedicated funding for people with hepatitis C and suggested that what was needed was an 'Expert Patients Programme' (discussed in chapter eight) for support following diagnosis and through treatment.

Cancer as a single concept

It is important to note here that participants did not appear to make comparisons with particular types of cancer, but treat it as singular in order to have a greater impact. Some have suggested that 'cancer' should not be treated with any kind of homogeneity (Clow, 2001), given it encompasses so many different diagnoses (Midtgaard *et al.*, 2009). However, enacting cancer as a single disease, silencing the differences and variability associated with different types of cancer, had a particular function producing cancer (and the people affected) in a particular way.

Fraser and Seear (2011) discuss how hepatitis C is enacted as singular in order to give the impression of progress and advancement in treatment of the disease, in the same way cancer has historically been treated as a singular entity in order to garner funding (Delvechio-Good *et al.*, 1990; Muhkerjee, 2011b) and support. A number of large, publicly visible UK based information and support organisations e.g. Marie Curie Cancer Care, Cancer Research, Cancer Relief, Macmillan Cancer Support, do not differentiate between types of cancer. In explaining their brand and the support they provide, Macmillan Cancer Support (the only specific cancer organisation referred to by participants) state:

'Macmillan's ambition is to reach and improve the lives of everyone living with cancer. *No matter who they are what part of the country they live in, or what type of cancer they have.* We want to make things easier for people with cancer, their friends, families, colleagues and carers. We do this by being a source of support – providing practical, medical, emotional and financial support. And we're a force for change – listening to people affected by cancer and working with them to push for better cancer care. *Cancer affects everyone.* One in three people will get cancer, and each of them has friends, families and colleagues. *So, we want Macmillan to be something everyone can be a part of. A kind of 'movement'. We are ALL affected by cancer and we believe we can ALL help.'* (Macmillan Cancer Support 2012a – my *emphasis*).

Here, cancer is used singularly so that no division is placed between different people, types and stages of cancer, treatment, or regions of the country. This can have both positive and negative effects there is no implication of blame and Macmillan positions itself as 'being there' to provide support for everyone,[104] but this simultaneously obscures the processes that have constituted some types of cancer as historically much higher profile [and much more marketable - see King's (2008) discussion of breast cancer]. Mitdgaard *et al.* (2009) described a dearth of qualitative research into anal cancer and thus, it is reinforced as low profile, shameful and stigmatised. Hughes *et al.* (2009) discovered a limited amount of primary research into the experiences of older people with cancer, suggesting that the needs of older people are also being obscured and overlooked.

---

[104] Indeed the last line of the extract **'We are ALL affected by cancer and we believe we can ALL help'** reinforces the ubiquity and possibility of being affected by cancer, ensuring that cancer becomes not just something which affects some families, but effectively places everyone in a risk group. An extension of 'worried well' (see Cranshaw and Newlove, 2011) and 'infected but not yet ill' (Sontag, 1991, Stacey, 1997). This ubiquity and possibility of cancer affecting everyone also played a large part in participant's use of it as an example.

Comparisons with cancer treatment

Cancer and cancer treatment were also used as means of explaining the disruptive, long term nature of the hepatitis C treatment, including the debilitating and varied effects of treatment and the impact on the lives of the participants. Bell (2009: 169) describes cancer as an 'extraordinarily culturally charged disease' and that strong cultural understandings exist around chemotherapy, informed by media representations as harsh, debilitating and feared (Clark, 1999) with effects that may be worse than the disease itself (Abel and Subramanian, 2008; Bell, 2009). Thus, participant comparisons with cancer tap into existing cultural assumptions around what chemotherapy entails:

Keith: Over the past two years, because I have been going through chemotherapy – it's not really chemo its immunotherapy but it's the same thing really...

Heather: The thing about chemotherapy – I have heard a couple of people say that. I know you're saying its immunotherapy but what is it? Is it about likening it to something?

Keith: Well the thing is, everyone knows what chemotherapy is and everyone has heard of chemotherapy and everyone knows how tough it is. Even though they don't know directly - they haven't got a clue - but a friend of a friend has had a relative, who has gone through horrendous chemo, where they lost all their hair and they have been bedridden and all this type of thing and that's very much in the forefront. A lot of the side effects are very much like chemotherapy and if you introduce it as that then that immediately gets the idea that what you have done is not a case of taking a load of antibiotic...I mean these are serious drugs.'

Keith invokes (perceived) public perceptions of what chemotherapy entails (Bell, 2009), (including visible side effects like hair loss and fatigue which also happened to participants

on hepatitis C treatment) to make clear the impact of the treatment on a person's life and to obtain empathy and understanding. Other participants suggested that the only other people who might have an idea what it is like to be on hepatitis C treatment are cancer patients themselves:

> *Heather: 'Do you think the magnitude of what you're doing is understood?*

> *Carl: No...I was just an absolute nightmare to be around. I can only put, talking to cancer patients and things like that, I can only put the medication on a level that's like chemotherapy. You know you lose your voice, your weight, your appetite you're angry all the time, you want to kill yourself, you want to kill others'.*

Here, Carl elicits the potential for some solidarity between people with cancer and people with hepatitis C, as if they are a group that would understand the experience. Although it is important to reiterate that not all experiences are homogenous, there is value in exploring how (some) cancer patients are supported, and this could be used as a template for support for people with hepatitis C, as suggested by Hopwood *et al.* (2009) – explored in chapter eight.

For JB, the cultural association between chemotherapy and cancer, together with the 'hidden' nature of hepatitis C impairment effects, meant that he chose to use chemotherapy to garner a more helpful and supportive service from his local GP:

> *Heather: So you said they wouldn't be treating us like this if we had cancer, so you think there is a difference in the way people are responded to?*

> *JB: Absolutely, if I want a copy of my blood results and I go to my GP, if I said 'I have hep C I'd like a copy of my blood results please?' they might be iffy. If I go in there and say 'I'm on chemo can I have a copy of my blood results please?' As soon as you mention that word 'chemotherapy' - and Interferon is used to treat some cancers so I*

feel quite entitled to use it[105] – as soon as I use the magic word 'chemo' people automatically assume that I should get the best service possible and they bend over backwards to help me. And I do it I use that word and I tell people to use that word, 'I'm on chemotherapy', and the level of understanding and care they get just sort of like changes up a gear. They are treated with a bit of respect and dignity and care which you should get'.

Here 'chemotherapy', 'cancer' and the 'best service possible' are collapsed together, reinforcing the belief that people with cancer are entitled to (and actually) receive a better service than someone with hepatitis C. Similar findings have been reported by participants in Butt *et al.*'s (2008a;2008b) study where participants maintained they received a poorer quality health service than those who did not have hepatitis C (e.g. being made to wait, not being provided with adequate pain relief).

Yet there is also evidence to suggest that a hierarchy (in terms of priority, willingness to provide support and funding), exists for professionals too. Comparisons with cancer and HIV were echoed in an interview with a consultant gastroenterologist who stated *'things that get all the money are the sexy things like you know, ' poor kids,' you know, kids with cancer and HIV'.*

In the quote above, JB is also 'passing'. Originally described by Goffman (1963), 'passing' is the concealment of an attribute considered stigmatising in social interaction. This can be beneficial, for example, keeping his hepatitis C status concealed (and replacing it with something else) means that JB is avoiding *'iffy'* treatment and obtaining *'dignity, care and respect'*. Other participants made the comparison with chemotherapy and cancer in interactions where they did not wish to disclose their hepatitis C. For Laurie, this was a means of explaining his ill health without going into detail:

---

[105] See Bracarda *et al.*, (2010) for a discussion of using interferon to treat cancer.

'For people that weren't close and I didn't need to explain to I would just say "I have six months of chemo lined up" and leave it at that'.

Both Kerry and Keith (whose extracts are included below) described a similar strategy. Thus passing functions as a means to halt conversations, so that participants are not drawn in to answering more and more questions concerning their illness. The opposite of what Pixie describes on page 222.

Although this may provide only short term reprieve. Feminist disability studies scholar, Jenny Morris (1991:28), states that to 'pass' is to deny disablism and to deny who we are. Thus 'passing' makes and remakes the 'silence' referred to above around hepatitis C and its treatment, and re-enacts hepatitis C's status as inferior to cancer. Although participants did not make direct reference to this, there is a possibility that passing with cancer might also mean that they miss out on information or support from friends, family and colleagues (Glacken *et al.*, 2001), or may be drawn into more elaborate discussion about 'their cancer' by people who might also have had it [what Goffman (1963) terms 'in- deeperism']. In addition, the current lack of recognition around difficulties during treatment and post treatment continue to go unrecognised. Similarly, the pre-existing ideas about how impaired people look and who disabled people are, continue unchallenged (Lingsom, 2008).

Here, hepatitis C and the people with it remain liminal prior to and following disclosure. They have (partially) disclosed their status (see Hopwood and Treloar, 2003; Fry and Bates, 2012) in order to obtain support or understanding, but remain liminal as that which they receive may be lacking.

For people with hepatitis C [like those with cancer, as Stacey (1997) highlights], the ability to 'pass' may be part of the problem; the lack of clearly visible *and recognisable* effects of hepatitis C have had a significant impact on participants beliefs about themselves as 'really' ill and deserving of support, as Kerry describes:

'The girlfriend I talked about, she'll say 'but you look fine Kerry!' and I'll think 'yeah but I feel like shit!' That is a bit of a problem.'

Yet Kerry also explains the emotional weight conferred onto her as a result of her 'passing' using chemotherapy:

'It's a double edged sword because I'm campaigning for awareness, but I still feel stigmatised and like I can't tell people what's really wrong with me. I had to tell the playgroup something was happening because (daughter's) behaviour started to change when she wasn't with me… and I had to say something so I told them it was a chemotherapy, which it is but, it's a shame, because I would have liked - on the one hand I'm doing this campaigning about stigmatisation and that we shouldn't be ashamed and I wear a badge on my coat. Then on the other I am lying to people in the playground and school teachers….'I am having a course of chemotherapy'. So they instantly think I've got cancer and they're going to feel sorry for me and if they find out I haven't got cancer, they're going to think I've lied - and I haven't - because it is, chemotherapy, the definition of it is chemical therapy. So I am not lying, but everyone associates chemo with cancer.'

Here, Kerry describes the difficulties associated with passing (Goffman, 1963), living with the constant concern that she might be exposed (Thomas, 2007), the pressure on her as a mother to explain the changes in her daughter's behaviour, in a morally acceptable way given the way drug using mothers are frequently portrayed (Ettore, 2007), and in a way which elicits sympathy. Yet, also the difficulties (and possible guilt) she feels in terms of campaigning to reduce the stigma and lack of knowledge of hepatitis C, whilst feeling stigmatised and unable to talk about it herself. This requires what Samuels (2002) terms a high level of cognitive dissonance, and a high level of emotional work (Hochschild 1979; Thomas *et al.*, 2002) in managing both personal responses and those of others. Similar

findings are also visible in Fry and Bates (2012) and Rodkjaer (2007).

Feedback from a specialist hepatitis C nurse on this finding, suggested that this comparison with chemotherapy was also used among her patients, but that this comparison was unhelpful because it deterred people from doing treatment and caused unnecessary anxiety concerning side effects (see Munoz-Plaza *et al.*, 2008; Lekas *et al.*, 2012). The nurse acknowledged the real difficulties of doing treatment - including the lack of financial support - but rejected the direct comparison between hepatitis C treatment and chemotherapy *'have you seen people on chemo?!'*. This highlights the difficulties inherent within the comparison. It may be helpful in short term management of interactions with acquaintances or health professionals, in conveying the severity of the side effects and highlighting the oppression that people with hepatitis C face, whilst deterring people from doing treatment.

The moral superiority of cancer

The comparison also serves to reinforce the perceived moral superiority of cancer as evidenced in participant's use of caveats. Later in JB's interview, I asked him to elaborate on his comparison with cancer. He appeared aware of the moral implications of his comments and responded by justifying the comparison:

> *'People think of chemotherapy, your hair falls out which it does on treatment people*
>
> *think of people on chemo as being tired, the parallels are the same. The treatment for*
>
> *cancer is really concentrated where treatment for hepatitis C is similar. It's not as*
>
> *concentrated and its spread out over a longer period, you do get people who have*
>
> *interferon every day[106] and they're in a bad way so it's obvious - so yeah that's why I*
>
> *think the chemo, when you use that chemo word it changes people's attitude'.*

---

[106] JB is referring to a clinical trial in the US.

It is the end of the extract which is most revealing when JB suggests that people respond more positively to the comparison with cancer. Though participants in Janke's (2008: 497) focus group described the opposite, with one participant stating 'it's almost like you are afraid to tell anyone, it is taboo – it was like when I had cancer. People would say: you are walking around with a big C on your head. Instead you've got a big H on you.'

The comparison between cancer and hepatitis C also conferred an additional emotional burden as Morgan makes clear below. Here, the enactment of cancer in the public view, as something which is high profile and deserving (Kaiser, 2008), impacts on the constructions of self that are available to people with hepatitis C (Fraser and Seear, 2011). This is a prime example of disabling barriers affecting who people with hepatitis C *can be,* as well as what they *can do* (Thomas, 1999):

*'I think, I mean I think the treatment for hepatitis C and the side effects are as bad as cancer really... I mean **obviously I have not had cancer but knowing people who have had cancer treatment - which is horrendous - I would say that the hep C treatment is equally as horrendous actually.** It's relentless. You inject yourself once per week I mean **and I'm not saying you have an easier deal with cancer just because you have chemo once every three weeks you know but it is relentless** - and as with cancer, the toxins really build up in your body and for me that was what was most debilitating. I think that if there are **a lot of allowances and special treatment for people with cancer... and the weight on their mind is just as negative as cancer, because cancer kills but I mean, hepatitis C kills. It may not kill as many people but it may.** Because who is to say....I know of two people, who've died from, three people, who have died from hep C. And you know that's just me there are millions of people and I think hepatitis C treatment should actually be dealt with in the same way as cancer patients,*

that's something I feel very strongly and have felt during the treatment' **(my emphasis).**

Here, each time Morgan makes a comparison with cancer treatment, a caveat or qualification is added. This suggests that Morgan has aligned herself with public (and government) constructions of what it is to be 'really ill' and deserving of, support to the degree that she has anticipated a sense of moral indignation and is compelled to defend herself against any recriminations. Morgan ends by making the link between hepatitis C and death, suggesting she has absorbed and reproduced wider social beliefs about cancer and about hepatitis C, to the degree that she feels the only way to emphasise the difficulties and barriers faced by people with hepatitis C is to highlight the worst possible (fatal) outcome. Another participant, Grace, also does this in relation to welfare benefits (discussed in chapter nine).

Additionally Boab, after making his comparison with cancer, similarly feels compelled to qualify it:

'I mean I'm not trying to make light of cancer. You know it's not a nice disease, but it's out there and it's very common and it's very well-known and there is a lot of support for people with that condition whereas with this, there's – if there is its pretty low key – it's pretty kept under wraps'.

Thus although the comparison is useful in many ways, the negative values and assumptions related to hepatitis C, and the (perceived) public view of it, are turned back in on the participants through their use of the cancer comparison, which creates and reinforces a hierarchy of disease.

The comparison with HIV

As was explored in chapter two, HIV and hepatitis C have frequently been compared within the literature. Their blood borne status means that understandings of HIV inform and shape understandings of, and responses to, hepatitis C (Fraser and Seear, 2011). Qualitative studies have noted that HIV is viewed more negatively that hepatitis C, as more visible, deadly and blameworthy (see Davis *et al.*, 2004; Munoz-Plaza *et al.*, 2010; Lekas *et al.*, 2011). However, an important contribution made by this thesis is that it was actually experienced *the opposite way* for many of the participants in this study with HIV seen as preferable to hepatitis C, explored below.

HIV is part of the hinterland (Law, 2004) which enacts hepatitis C. For participants in this study, the comparison with HIV arose in a number of contexts. The position of HIV within the hierarchy of disease shifted between an 'inferior' (having HIV perceived as worse than having hepatitis C) and 'superior' (HIV perceived as better than having hepatitis C) position. As the data will show, HIV's position on the hierarchy of impairment was frequently enacted through personal experience and the historical legacy of HIV, and its heavily publicised nature in the UK in the 1980s (Wallis and Nerlich, 2003; Persson and Newman, 2008; Slavin, 2006). As with cancer, these comparisons enacted hepatitis C and HIV in ways which both highlighted and obscured aspects of living with both conditions, and promoted divisions between people with them. Thus, this was both beneficial and potentially harmful, not only for the participants but for others with HIV and the wider disabled population.

Four participants I interviewed lived with (or had lived with) both hepatitis C and HIV. Three of these participants described how they felt HIV was experienced as more socially acceptable and that living with HIV had been embraced by (some) gay community members (Owen 2008):

Charlie: 'I mean I can only go from what I have read and learnt and my own experience

which is certainly in terms of that double stigma ... where people will almost use a

different illness to cover it [hepatitis C] up. Where there is almost a feeling that, ok

people will accept that I have HIV but once I tell them I have hepatitis C they're going

to be going for the door'.

As with the cancer comparison, hepatitis C is silenced. This had clear effects in terms of a lack of information and support:

Charlie:' And if there is a lack of education about HIV then there is even more so about

hepatitis C – it's the elephant in the room- no one talks about it. So as long as the

health promotion campaigns which are run by things like the (HIV health promotion)

partnership in the gay press will talk about things like sero-sorting, and you know, and

it's like 'hang on a minute I have this, no one ever says anything about, you know hep

C.'

Here the messages that Charlie receives regarding safer sex, do not take account of the experiences of men who have sex with men, who have both HIV and hepatitis C (Owen, 2008). This means that hepatitis C is enacted as something which does not concern gay men. Participants described a lack of access to information and to a visible community of support: where Charlie felt that there had been a degree of protection associated with both his identity as a gay man and then as an HIV positive gay man, this *'safety net'* was negated when he found out he had hepatitis C.

Here it is the lack of a sense of community and shared group identity [which Reeve (2008) states is threatened by the hierarchy of impairment] which enacts hepatitis C as unacceptable. Just as hepatitis C is described as 'silent' in the section on metaphor above, it is similarly 'silenced' here. There is a silent community of men living with both HIV and hepatitis C which places them in a liminal (Turner, 1966) position. As Charlie describes, they are both inside (because they have not disclosed) the gay HIV community and outside (because they have hepatitis C).

However, there are incidences where this liminal position provides an advantage and opportunity for resistance. Charlie describes attending HIV conferences and ensuring that hepatitis C is moved onto the agenda. Shaun describes raising the profile of hepatitis C among gay men via social media, where online awareness raising affords both a degree of protection (Gilbert *et al.*, 2010) and reaches a wide audience in an accessible way.

As with the concept of cancer above, HIV was often presented as a singular disease, obscuring important aspects. Both Ben and Charlie described differences between views and beliefs about HIV and hepatitis C. There was a feeling that in the west, HIV has become a long term manageable chronic illness, whereas hepatitis C was treated with trepidation. Ben referred to HIV as *'run of the mill'* where hepatitis C was *'the big doom and gloom'.* These observations have been mirrored in the literature. Farrell and Comisky (2012) point to the advances in medication and treatment which mean HIV is a chronic illness, whereas hepatitis C remains a low priority, experienced as uncertain (Sinclair *et al.,* 20011).

For Ben, this was connected to the legacy by the UK based HIV campaigns of the 1980s and the subsequent high profile nature of HIV, including the development of effective treatments (available in the UK) to control HIV and maintain health. Although Squire (2009) questions the 'normalisation' of HIV in the UK and suggests that this obscures the uncertainty which exists around treatment and longer term health outcomes, as well as access to other goods and services such as appropriate housing. Charlie makes a similar point (included in chapter nine) in that there is a need to address hepatitis C and HIV holistically, in terms of needs that may not be directly related, but are vital for living well.

Daniel and Grace exhibited how hepatitis C is constituted through specific forms of information (from professionals and via websites) as contagious, given that hepatitis C survives for longer outside the body than HIV.

'When we think that this virus is more it's able to survive longer outside the body than the AIDS virus. It's more deadly than AIDS in that respect...If I was to cut myself - blood on this table now [the hepatitis C virus] would - two months - it could survive. That could spread, but the AIDS virus, 24 hours I was told.'[107]

Similarly Grace suggests that she felt HIV was less concerning than hepatitis C because she had read that HIV dies more quickly outside the body.

A major area of comparison proved to be the differences between treatment for hepatitis C and HIV the difficulties associated with treatment for hepatitis C, made the less complex HIV treatment the preferable option:

Shaun: 'Now, with HIV I kept saying to my friends on the first time on hepatitis C the treatment was so awful I said I'd rather have HIV any day; it's easy (laughs), it's easy to manage I take a handful of pills every day and I stay alive; that's all I know. With hepatitis C it is treatable, but my god, what a vile treatment. I mean, it's really awful'.

For Ben, the prior experience with hepatitis C treatment left him well prepared when the time came to go onto HIV medication:

'I think everybody was right in the medical circles if you can go through hepatitis C treatment you can go through anything was their policy, and they said, you know, this will be a doddle and it actually has been. So in reality I've never gone through the people who have had the scary image of going, oh I've got to do HIV medication, what do I do? What's it all mean? I've got to take all these tablets. I'm like, oh it's easy, just take it, and life carries on'.

---

[107] Conflicting reports on the lifespan of hepatitis C and HIV also exist and clearly depend on the conditions, environment and surface on which the virus is present (see for example, Dolan *et al*, 2009; Exchange Supplies, 2009; Doerrbecker *et al.*, 2010),

This was similarly noted by Hopwood and Treloar (2007) concerning the development of resilience in preparing for treatment. Later, Ben describes feeling as though he needed less information in order to undertake the HIV treatment. Ben makes reference to the wealth of HIV information which did exist for hepatitis C.

When discussing the possibility of notifying organisations of her hepatitis C infection, Grace succinctly describes and enacts the complexity and contingency of her comparison with AIDS and its position on the hierarchy of impairment:

'Labelled. You feel like a label. I felt I may as well have AIDS except AIDS might be understood a bit more. I think I would have more stigma. I wouldn't want to have AIDS don't get me wrong, because that would be worse stigma, but people don't know about hep C put it in the AIDS category anyway, and more than anything else because no one knows what hep C is'.

AIDS is simultaneously implied as the ultimate disease (and the ultimate label) which Grace would not wish to have, because she perceives that this would attract *'more stigma'*. However, she acknowledges that there is simultaneously a greater level of understanding around 'AIDS' and that hepatitis C and HIV are often confused (Rhodes *et al.*, 2004).

Lack of information around hepatitis C was also raised by other participants. Holli explained that she felt it was important that the general public's awareness of hepatitis C was raised and that there was more awareness around HIV. However, it is likely that this is connected to participants temporally situated nature – given their ages, they are well placed to recall the 'Don't Die of Ignorance' (Central Office of Information for the Department of Health, 1987) campaigns in the 1980s and witness the shifting position and material consequences of HIV in the UK and globally. It is highly likely that views around HIV among younger people are very different. Recent research by the National Aids Trust (2011) shows that public

awareness is diminishing among young people: one in five young people did not know that HIV could be transmitted via heterosexual sex without a condom.

As is described below, participants compared the level of information and support available around HIV with the support for hepatitis C. Indeed, as indicated below, there are existing funding sources as well as a degree of legislative protection for people with HIV, which does not exist for hepatitis C[108] (see Munoz-Plaza *et al.*, 2010) explored in chapter nine. This comparison may also be useful in the sense that high profile activism connected to HIV (and some forms of cancer) could prove a template for hepatitis C activism although Charlie felt that there is a lack of political impetus to do this:

> *'You know you look at HIV that's a big issue in comparison to hep C ,in terms of the way its dealt with. You have a specific funding stream for HIV social care. You've got HIV specific organisations, you have national awareness days and vigils about HIV and that's because the history of HIV is very different. 25 years ago in the early 80s people were dropping down dead within six months, people in the prime of their lives with really nasty deaths. You look at places like Africa where it's absolutely been decimated by HIV. But HIV has moved on, and in fact, in some ways, we haven't moved on to where HIV is now, whereas actually, you know, it's actually not that big a deal, certainly not in this country at this time – it's a different matter in other countries obviously'.*

Here Charlie's extract makes visible the contingent and shifting nature of HIV. He refers to being mindful of speaking from a western position on HIV (where HIV in increasingly being enacted as a manageable chronic disease) and that this is not the case in other parts of the world. Yet enactments of a hierarchy persist. Hepatologists, Lemoine *et al.* (2012), have

---

[108] Though NAT (2011) indicate this is of limited use and point to the lack of understanding of the drug use practices of Men who have Sex with Men who inject drugs (NAT, 2013) within mainstream services.

pointed to the influx of funding in sub Saharan Africa in relation to HIV, which they argue has

marginalised other health issues including Diabetes and hepatitis B and C.

One participant in particular (who had also worked in the HIV field) described the high profile

nature of HIV as 'well networked', supported by celebrities and powerful cultural institutions

(although some of these celebrity campaigns [notably Product (red)] have been criticised

(Barnes, 2008; Anderson, 2008) in an African context, for obscuring the circumstances and

social relationships which perpetuate the spread of HIV. However, the high profile and

celebrity endorsed nature of HIV and the relative absence of such for hepatitis C, highlights

how people with hepatitis C 'take their cues from society' (Munoz-Plaza *et al.*, 2010: 525)

which indicate and enact HIV as more important than hepatitis C. Indeed, workers in Munoz-

Plaza (2010: 525) referred to HIV as a 'cash cow':

> *Richard: 'If you look around you at what there is for HIV, compare that with the*
>
> *number of people affected by liver disease or hep C and then think in sort of every*
>
> *almost every large market town there would actually be an organisation with premises*
>
> *for HIV, somewhere you could potentially drop into one or another day a week'.*

Given that hepatitis C and HIV co-infection is emerging as a major issue, HIV organisations

are well placed to provide additional hepatitis C support[109]. In a US context, Munoz-Plaza *et*

al. (2010) have drawn attention to the discrepancy in funding between services for HIV and

hepatitis C among drug treatment services. The authors maintain that funding for support

provision for hepatitis C trails far behind resources and funding allocated to HIV. Where

federally funded services exist across the US, the same does not exist for hepatitis C and has

thus, been addressed on a patchwork basis by local services. This includes where services

have been 'added on' to existing models, without adequate training or funding. This has

serious material consequences, similar to the postcode lottery described in chapter five,

---

[109] The Hepatitis C Trust (2013b) has recently highlighted the issue of HIV co-infection and need for development of support services.

where concentrations of people with hepatitis C will materialise in areas with poor responses, placing additional pressure on health services and social work services as a range of needs begin to emerge, which demand to be addressed.

These findings have recently been echoed in Deacon *et al.* (2013), who point to the need for community organisations that have traditionally focused on HIV to incorporate hepatitis C, and to widen their remit to support a diverse range of communities. They refer explicitly to the partnerships formed between the government and the community in addressing the HIV community and the need to do the same with regard to hepatitis C. As explored in chapters five and seven, the level of peer expertise that exists across communities needs to be harnessed, trained and funded using peers with a wide range of backgrounds and experiences. In addition, there is also room to forge stronger links between groups, not based on illness/impairment (or transmission route), but based on common barriers to participation the Disability Benefits Consortium is a good example of this, as it brings together a range of organisations to advocate for a benefits system which recognises the rights of disabled people and is fair and accountable (see DBC, 2013 for a full list of members and aims). This will be revisited in chapter nine.

This chapter has explored how the ways in which participants spoke about their hepatitis C actually enacted the disease and those with it, with serious material and emotional consequences. The next chapter will explore participant's experience of treatment in more depth.

Chapter Seven: 'Left in limbo' Hepatitis C treatment experiences as pharmakon and pharmakos.

Introduction

This chapter first and foremost explores the participants' experiences of hepatitis C combination treatment in the UK. Treatment experiences have been emphasised as being particularly important by Korner and Treloar (2006), given that the voices of those with hepatitis C are frequently absent from treatment research, or present only as subjects in clinical trials which further enacts the current dominant medical focus in responding to those with hepatitis C. As was indicated in chapter two, the meaning and the implications of hepatitis C treatment are not extensively explored within social research in the UK.

My aims in this chapter are threefold. I will briefly outline how medical responses are enacted as dominant in living with and addressing hepatitis C, and show how these responses constitute those with hepatitis C and those undertaking treatment. I open up a space for participants' enactments of the hepatitis C treatment experience, which moved beyond hepatitis C as a solely medical entity, to discuss their social support needs on treatment and gaps in support provision. I then suggest possible ways in which we might support those living with hepatitis C who undertake treatment. This chapter responds to a call made by Grogan and Timmins (2010) for further research into support centred on the needs of people on treatment.

This is a particularly important time to explore both how treatment is enacted and how this in turn, co-constitutes participant's experiences and needs. The current surge in the development of new treatments (Trigg, 2012; Dusheiko and Burney, 2013; Kowdley *et al.*, 2013; Liang and Ghany, 2013;Stedman, 2013) and a renewed push to encourage testing and treatment in the UK (NICE, 2012c; LJWG, 2012), together with increasing pressure on

resources, is paradoxically utilised both as a reason to *increase* treatment (to avoid future liver disease) and to *deny* treatment and support to some (i.e. injecting drug users). This reinvigorates the importance of calls for an exploration of, and further research into, the experience (and enactments) of treatment and post treatment (see Hopwood and Treloar, 2005; Treloar and Rhodes, 2009).

In recent work, Fraser and Seear (2011:138) describe 'want[ing] to unsettle the notion that treatment is always helpful'. My work takes this question further, asking whether treatment is always helpful, but also asking what else might be helpful. Interestingly, in exploring this question, Fraser and Seear (2011) use data from participants for whom treatment has not worked. In this thesis, the majority of the sample experienced treatment that *did* work, suggesting that even if the treatment is successful, it poses new and different challenges.

The importance of treatment

It is important to note that in challenging the dominance of the medical treatment response, I am *not* suggesting that treatment should not be offered to people with hepatitis C (including those who use drugs), nor would I want this research to be used as a means of justifying the current patchy and unequal distribution of treatment and support in the UK quite the opposite. However, this should not obscure the recognition that the sole focus on treatment and cure implicitly 'others' those living with hepatitis C and enacts them as abnormal and in need of 'fixing' (Marks, 1999). Similarly, in focusing on the enactment and materialisation of treatment in the lives of participants, I am not pathologising the experience of treatment or post treatment (Grinyer, 2009), or reducing participants solely to their hepatitis C treatment experience. I want to continue to break the silence and reduce the invisibility associated with these experiences (Persson, 2006). I wish to challenge the current focus on scientific progress (described by Fraser and Seear, 2011) because this enacts a silence around the needs of those on treatment and the context of their lives.

This chapter is intended as a call to wider professional disciplines and forms of expertise (including counselling, social work and peer support) to have an active, properly *funded* role in supporting those with hepatitis C (whether they are on treatment or not), to emphasise the importance of a range of options and support mechanisms for those on hepatitis C treatment and to push for more and new enactments of living with hepatitis C.

The shifting nature of treatment

Hepatitis C and its treatment have been recognised as ambiguous (Harris, 2005; Treloar and Rhodes, 2009; Harris 2010; Hepgul *et al.*, 2012), and difficulties and ambiguities around hepatitis C treatment will form a central thread of the chapter. The interrelated concepts of *'pharmakon'* and *'pharmakos'* will be used to explore the treatment experience. This marks an original contribution of this thesis, given that these concepts have not yet been used to explore the hepatitis C treatment experience. The concept of *pharmakos* also draws together the experiences of disabled people and people who use drugs, highlighting the intertwining experience of oppression.

It is important to note that all participants had (eventually) been offered and taken up hepatitis C treatment and all had ceased using illicit drugs at the time of interview. It is not unreasonable to assume that this is an enactment and material consequence (Fraser and Seear, 2011) of current institutional policies on candidacy for treatment (see Coupland and Maher, 2010), given that those participants who used drugs had ceased injecting drug use prior to beginning treatment. Professionals who I spoke to throughout the data collection indicated that current injecting drug users were not offered treatment (see also Harris *et al.*, 2012a) in their locality. Thus the views of participants who were either not offered, or chose not to take, the current recommended treatment have not been included in this study, and

this constitutes the experience of hepatitis C treatment in a particular way.[110] This perspective is consistent with my ontological position which follows Mol and Law (2002) in emphasising the intricacies and tangles of the hepatitis C treatment experience. The perspectives introduced here are necessarily partial and cannot be everywhere at once, and an attempt to provide an overview of hepatitis C treatments would necessitate trimming experiences in such a way that the rich ambivalence and ambiguity might be lost.

The dominance of medicine in hepatitis C

The pharmaceutical treatment of illness and disease is a central and widespread feature of contemporary healthcare (Persson, 2004). Van der Geest (1996) states that medicines are so powerful because they are tangible and have a visible effect. The origin of the term 'pharmaceutical' derives from the Greek word *pharmakon* (meaning both remedy and poison, elaborated on below), but over time the 'remedy' aspect of pharmaceuticals and pharmacology has been foregrounded and prioritised (Derrida, 1981; Gagnon, 2011).

Currently in the UK, the main response to hepatitis C infection is one of remedy those deemed eligible are invited (and expected) to embark on a course of treatment with the aim of eradicating the virus, or at least suppressing some of the virus for a short time. At the time of interview, recommended treatment (hereafter referred to as combination treatment) involved daily oral administration of Ribavirin tablets and a weekly injection of Interferon. However, Montagne (1996) posits that medication should be considered cultural phenomena as well as chemical the experience of hepatitis C treatment is shaped by beliefs about hepatitis C, evidenced by one of the Hepatitis C Trust[111] (2012) 'pros' for doing treatment: *'Knowing that you are no longer carrying an infectious and harmful virus may also*

---

[110] Although this is not through lack of trying when I advertised the study, I sent flyers to local drug services, advertised at local user forums and spent time with a local drug service in an attempt to recruit those who were using illicit drugs.
[111] UK national charity for hepatitis C.

help you to feel better about yourself'. Although presented as a means of improving current health and avoiding future impairment, descriptions of hepatitis C as a 'silent killer, as 'insidious' and 'sneaky' (see chapter six), and the association between hepatitis C and injecting drug use and infectivity (Harris, 2009a), also enact treatment as a solution and a means of avoiding these associations. These will be explored throughout the chapter.

Persson (2004) argues for a need to refocus on the ambiguous nature of medication, one which is not solely focused on remedy, but which also takes account of the unintended and often marginalised effects of treatment (and the discourses and beliefs surrounding it). This is constituted in the concept *pharmakon.*

Introduction to *pharmakon*

> *Andrew: 'So it was a good thing going on it. It felt horrible doing the treatment and but I had it in my mind...that it's only for a few months. I was actually clear after about three or four weeks, but you had to carry on eating your poison'.*

Andrew's quote above exhibits the ambivalence involved in taking hepatitis C treatment. It is both a *'good thing'* (the reasons for which are explored below) and *'horrible'*; indeed, Andrew makes reference *to 'eating poison'*. This ambiguity was heavily present across participant accounts and I argue, both opens up space to explore and explain the limited support given to those on treatment *and* reinforces the need for it.

The Greek term *pharmakon,* originally introduced in Plato's *Phaedrus* (and taken to mean remedy, recipe, cure) was explored and analysed by Jacques Derrida (1981), who critiques the persistence of dichotomies and polarities in western thought (Persson, 2004, Gagnon, 2011). Good *versus* evil, truth *versus* error, man *versus* woman, absence *versus* presence, poison *versus* remedy. Derrida (1981) maintains that the possibility of clear definitions and oppositions between these elements is actually an illusion one is always structured in

relation to the other (Johnson 1981) and they are thus messy and inseparable[112]. Derrida (1981) states that these dichotomies actually reflect politics of meaning the one that comes first is the one that has priority, remedy is prioritised over poison, non-disabled over disabled, healthy over ill. Derrida's (1981) use of *pharmakon* disrupts these binaries *pharmakon* is undecidable, simultaneously beneficial and detrimental. The meaning of the *pharmakon* is indeterminate and depends on context (Persson, 2004), commensurate with enactment rather than pre-existing anteriority. Thus, hepatitis C treatment can be both beneficial and dangerous to the same person at the same time, and can 'shape bodies and lives in both intended and unintended ways' (Persson, 2004:63). It is this shaping which we need to pay attention to and provide support for.

Treatment as a remedy

The severity of side effects and the sense of fear around treatment are outlined in the literature (see for example Munoz-Plaza *et al.*, 2008) however, the pervasive view of hepatitis C treatment as remedy was frequently invoked in participant narratives. The privileging of the remedy aspect and the dominance of scientific medicine is enacted though all participants in the sample having done treatment at least once. This is commensurate with Martin's (2006) observation that the ambivalent nature of medication does not prevent their consumption on a massive scale.

Participants described undertaking treatment for a range of reasons. Some participants accessed treatment because hepatitis C had begun to impact on their health, as JB, Boab and Morgan all described. This mirrors Harris's observations (2010) in relation to her own treatment experience she stopped thinking of treatment as a year of hell and started to imagine an improved life with hepatitis C. Others described taking treatment in order to

---

[112] See Persson (2006) for a more in depth discussion of health and a messy and dynamic concept.

avoid future liver disease (Manns *et al.*, 2007) or even a fatal outcome[113], and some participants presented this as paramount:

> *Steve: 'If you get diagnosed get treated …That is utmost. There is no reason why not-*
>
> *unless there are physical medical grounds why you can't be treated'.*

In stating that medical contra-indications would be the only reason not to do treatment, Steve's account reinforces the authority of medicine[114] (Marks, 1999) and temporarily[115] displaces the difficulties associated with treatment (and the need for attention to context such as housing situation, family circumstances, employment), in favour of prioritising medicine's capacity to restore health. Displacement is described by Martin (2006) as a process where the dangerous or negative elements are removed from direct view. For these participants they were 'hidden in plain sight' (Martin, 2006) all described being aware of the possibility of side effects by their consultant, specialist nurse or via their own research - but these side effects were frequently displaced through the invalidation of treatment effects as 'individual' (see below).

Given that Steve spoke at length concerning severe side effects and post treatment effects, I asked him why he recommended treatment so strongly:

> *'I want to live. That would have killed me and now I have a chance. I mean, I have liver*
>
> *damage but it's not that bad… I am fighting something on a level playing field…that if I*
>
> *do things right I can make it better. If [the treatment] don't work it don't work, some*
>
> *people it don't but I must say the majority of people are clearing no matter what they*

---

[113] These enactments as hepatitis C are part of what Fraser and Moore (2011) refer to as 'scaling up' hepatitis C in order to improve responses to it.

[114] Here treatment is enacted as a means of reasserting control (Jenner and Scott, 2008) over health and addressing the uncertainty Steve felt was associated with diagnosis.

[115] He acknowledges later in the interview he is lucky where he lives and to have a supportive family as did a number of participants.

are. I was geno [type] three...but whatever you are... if you let it get hold of you and if

you forget it and put it to the back of your mind it will have you – it will kill you'.

Here hepatitis C is enacted as a 'silent killer', as *pharmakos* (scapegoat, explored below). It is the disease itself, rather than responses to it (as discussed in chapter six), which needs addressing (and will kill) and treatment is the only course of action to avoid (certain) death. Even though Steve makes it clear he is aware that there are those who do not attain SVR, he invokes a narrative of scientific progress (displacing the uncertainty and limited effectiveness of combination treatment) to indicate that the majority of people are clearing, further emphasising hepatitis C treatment as curative and transformative (Fraser and Seear, 2011). However, the ambiguity of hepatitis C and treatment is also clear. Steve describes his liver damage as *'not that bad'*, but emphasises how important it is to treat.[116] Here personal responsibility (Crawford, 1994) to undertake treatment is emphasised and suggests that those who do not do treatment (or for whom it does not work) are not doing all they can *'to make it better'*.[117] This potentially places pressure on people living with hepatitis C to undertake treatment without any kind of attention to context, and places an additional psychological burden on those who do not have access to treatment, or who are not ready to undertake it. It perpetuates the centrality of treatment and virus eradication above personal health and wellbeing, and overlooks the role of other professions besides medicine.

Others made less reference to wishing to maintain their health. For Grace, medication as a cultural entity (Cohen *et al.*, 2001) is evident in her wishes to undertake treatment to clear the virus as a way of addressing feelings of stigma and contagion, and the (felt) judgements of others. At the time of her interview, she was on treatment for the second time. She

---

[116] This ties in with the ambiguity associated with hepatitis C degree of liver damage does not necessarily correlate with how long the virus is present.

[117] De Wolfe (2002) indicates that there is a deep rooted set of assumptions regarding the accepted (temporary) nature of illness and an expectation that those who can 'overcome' illness through treatment or intervention are expected and capable of doing so. This intra-acts with discourses of blame to shame and marginalise those who do not address it for whatever reason.

described receiving the news that she had not attained SVR at six months during her first treatment and starting treatment again:

> *'They [hepatology team] said, 'do you want to have this second lot of treatment, or you can have a year off'... and I said, 'No! I'll tick it right now' and I was at the hospital the next day starting the second lot ... And if this lot doesn't work, then I'll take that severe one that they do where you are literally bedridden for three months but it's a lot shorter treatment[118]. I mean I don't like being ill and apparently the side effects are a lot worse **but I do not want that on my death certificate.** That's something I do think about' (my emphasis).*

Grace could not face the possibility that she might die with hepatitis C and there may have been perceptions that she used drugs: *'I don't want people thinking I died from being a druggie'.* Here hepatitis C is enacted as a powerful stigma which would mark her out after her death, and affect friends and family perceptions of her. (This is not an unreasonable assumption given that during the course of fieldwork, I spoke to a pathologist who indicated that he assumes those who have had a history of injecting drug use have hepatitis C infection[119]). Thus, treatment is used as a means of addressing oppression and negative treatment, whilst simultaneously perpetuating it by re-producing normative assumptions about bodies (Rott, 2010); that they can and must be closed and clean (Treloar and Fraser, 2004). This is further compounded when Grace describes feeling *'blasé'* about her health, echoing Fraser and Treloar's (2006) findings regarding feelings of 'absolute contamination'.

---

[118] Grace indicated that she had heard about a trial in the USA where participants increased the frequency of interferon from weekly to daily. It is not clear whether she is referring to a combination treatment trial or a new therapy.
[119] Unfortunately a fuller exploration of this assumption and its implications are beyond the scope of this thesis.

Messy feelings about treatment

For other participants, reasons for undertaking treatment were similarly incongruent. Carl, Andrew and Brad all indicated that they did not necessarily feel unwell all the time of taking treatment. For Carl and Andrew there was a strong sense of ambivalence around the treatment, even having cleared the virus.

> Carl: 'I don't know how I did it or why I continued to do it. It was madness. It really was.

> Andrew: Well you did it because you knew it was going to do you some good and you weren't going to have to go looking for a new liver in another 10, 15 years or whatever.

> Carl: Yeah and that that's a plus. You know, today I don't go to bed... worrying that I'm going to die or I need a transplant or - and yeah maybe it's only added five or 10 years to my life but it's just nice to know I haven't got hep no more ... it's just a vile disease to have and a vile one to try and get rid of.'

This is a rich example of the ambiguity associated with hepatitis C treatment. Both Andrew and Carl had attained SVR on treatment, which might suggest that they can afford to be ambivalent about it in a way which others who have not cleared it cannot be. Yet their ambivalence regarding the treatment may also indicate their resistance to the power and authority of medical responses. At the end of the extract, Carl suggests that whilst his future health is indeed a concern, the most important thing is that he no longer has hepatitis C, implying that the social consequences of living with the virus are potentially as difficult, or even more so, than embodied impairment effects.

Here, treatment as *pharmakon* is enacted in that it paradoxically both creates and allays anxiety around hepatitis C. The availability of a pharmaceutical solution, with rhetoric of increasing effectiveness and eventual cure (see Grogan and Timmins, 2010; Kowdley *et al.*,

2013) is promoted, but this implicitly 'others' those with hepatitis C who have not accessed treatment. In addition, the promotion of pharmaceutical solution inhibits the development of other forms of support and closes down the possibility of supporting people to live well with hepatitis C (Harris, 2005). Similarly, the emphasis on starting treatment as early as possible to achieve maximum effectiveness, creates anxiety and pressure to access it:

> Andrew: 'And If I'd already had it for 15 years like I say, you don't know how much damage it's done or how much longer before it starts ripping into you properly'.

Here, hepatitis C is enacted as uncertain [mirroring Fraser's (2012) observations regarding the freighting of responsibility onto the virus or the person, rather than scientific development], and the treatment is enacted as certain solution (which it is not); a means of stopping hepatitis C *ripping into you properly'*. The remedy aspect is prioritised. However, later in the focus group the toxic nature of treatment comes to the fore:

> Andrew: 'But it is really odd innit? Like you say, you don't feel any symptoms from it until you're trying to get rid of it and then it does make you wonder why you do the treatment. If anything, you have it in your head, you think, 'you can't have it' so I better carry on trying to kill myself'.

In addition, the ambiguous nature of treatment is enacted in that efforts to remove hepatitis C have actually made it more visible (cf. Persson *et al.*, 2004). Andrew clearly states that he was not experiencing symptoms before he went on treatment and so, the concept of treatment in addressing health is challenged. Yet the prospect of deciding to live with it is so unthinkable (*'you can't have it'*) that Andrew keeps treating even if it feels like a form of *'trying to kill'* himself. This turns earlier comments from participants about the potentially

fatal outcomes associated with not doing treatment on their head: Here the treatment is

the killer not the virus[120].

Hepatitis C treatment effects

A major area of discussion in the literature and in participant accounts were the side effects,

and exacerbation of impairment effects, caused by hepatitis C treatments. The majority of

participants (20/21) described experiencing some side effects which had a serious impact on

their mental and physical health, working life, personal relationships, and feelings about

their body. The existing literature makes reference to physical and mental side effects

(Korner, 2010). Fried (2002) indicates that although severe side effects are rare (suicidal

thoughts and attempts, panic attacks, onset or worsening of autoimmune and heart

problems, loss of vision or hearing, strokes, acute renal failure), less severe ones, like

depression and insomnia, weight loss, anorexia, hair loss and joint pain were experienced in

over 30% of people, with 50% experiencing headaches, fatigue and muscle aches, which

contribute to discontinuation of treatment (Hopwood and Treloar, 2005). Participants in this

study described severe pain and aching joints, headaches, feeling cold, hair loss (even

eyelashes and eye brows), anaemia and neutropenia (low white blood cells resulting in

increased susceptibility to infections), severe weight loss, nausea and vomiting, depression,

rage and aggressive behaviour, feelings of isolation, being unable to drive (or driving with

dangerous consequences such as on the wrong side of the road), heightened fear and

anxiety, suicidal thoughts and attempts, rashes and itching, feeling weak, fatigue, difficulty

moving around (even in their home), burning scalp and skin, sensitivity to light and noise,

insomnia, feeling speedy and hyperactive, aversion to particular foods and irritable bowel

syndrome. In Daniel's case, a severe allergic reaction meant his treatment was terminated at

---

[120] There is also the potential here to interpret Andrew's comments that life with hepatitis C is not 'worth' living. There are links with ontological invalidation described in disability studies literature (see Reeve, 2012) and wider discussions concerning the 'value' of disabled human life (see for example Alison Davies, 1999).

week 13. The treatment as *pharmakon* is especially clear here. In order for participants to maintain their long term health, treatment materialised a form of embodied labour, with possible positive effects achieved through a gruelling process (Keane, 2011).

For some participants treatment was highly counter-intuitive. Charlie describes taking treatment for both hepatitis C and HIV:

> *'So they stuck me then on HIV treatments to try and sort my HIV out before I started the hep C treatment…I had felt ill for so long and then when I started to have the HIV treatment it was like 'wow I feel really well!' (Chuckles) I had that for about three months and then they put me on this horrible shit! (Laughs) And straight back down again.'*

As described in the previous chapter, participants regularly compared treatment with 'chemotherapy'. Both are *pharmakon;* counter intuitive medications which require further illness in the process of becoming well. Stacey (1997:81) describes:

> 'Radiotherapy destroys as it heals, chemotherapy pollutes as it cleanses. To kill the cancer cells the body is pumped full of poison…each chemical damages different parts of the body which are left in shock. All fast growing cells must die, benign and malignant, regardless of origin, regardless of purpose'.[121]

The ambivalent and ambiguous nature of hepatitis C treatment was clear across participant accounts. Treatment was described as *'horrible,' 'vile'* and *'awful'.* Carl stated *'I can talk about it for days but I can't say no good things about it.'* This was qualified, as Charlie's example indicates:

---

[121] The development of newer targeted treatments reinforces the chemotherapy comparison in relation to combination treatments.

'You know and saying to my friend, 'you know it's not going to be easy. It's going to be

horrible, it's going to be nasty, but it's a year and once you have got through it and you

have got rid of it you can get on with your life'.

The ambivalence surrounding hepatitis C treatment is evident in spite of the severity of side effects and the impact of treatment on participant's lives and wellbeing, participants frequently described the importance of doing it or supporting others to do treatment[122].

Morgan: 'Although the treatment for 80% of people is bad, it's not as bad as a lifetime

of liver disease...I mean even people who has been symptom free said that when

they've recovered from the treatment it's in really subtle ways that their quality of life

is much better... Some people clear it [spontaneously] but I think that must be fairly

rare you know, your viral load is going to increase and therefore your chances of

success are going to decrease so it is definitely worth being treated'.

Here Morgan invokes future health and subtlety as a way of encouraging treatment. Similar to Steve, she invokes the rhetoric of cure (in a different way) to emphasise the importance of treatment. Although, ambivalence in relation to treatment is enacted again when some participants described holding information back about the experience, indicating that they would not tell others for fear of deterring them.

Laurie: 'It (treatment) was hell for me, kicked the living sh*t out of me - from 1st

injection to the end. - Never really let everyone know how bad it was on forums - didn't

want to put anyone off'.

Laurie and Charlie described the need to strike a careful balance when talking about treatment, wanting to be honest but not wanting to worry others unnecessarily. This form of

---

[122] Similar to the comments made by participants in Harris and Rhodes' (2012a) exploration of the role of methadone diversion in protecting against hepatitis C. Methadone Maintenance Therapy was viewed with ambivalence, as a 'necessary evil'.

emotional labour, (Hochschild, 1979) managing their own and others feelings and reluctance to explain just how hard the treatment is, conceals the amount of work involved in being on treatment (Persson *et al.*, 2003) and validation of participant experience is inhibited. It is a reality made absent (Law, 2004). This may in turn be utilised as a reason for not developing support services.

Further, the ambivalent and difficult nature of treatment is also marginalised through reference to treatment effects as 'individual', which places responsibility for managing it at a personal level, rather than at a wider societal and structural level, the problem is not only that the treatment is difficult, but suitable supportive services do not exist.

This absorption of wider views that treatment must be managed personally was evident in participant's descriptions of treatment as *'individual'* and *'unpredictable'*:

> Morgan: *'I mean you know everyone is different and I would advise (people on treatment) to hang on in there and on the days when you can't see the wood for the trees you're going to feel totally different[123] the next day.'*

The erratic nature of the effects meant that participants found it difficult to plan things in advance, some managed their lives carefully to make the most of good days, others were unable to work or gain support, but repeatedly described the impact of treatment as 'individual'.

> Daniel: *'I think it's a very individual treatment. It affects people in different ways'.*

Whilst I am not suggesting that hepatitis C treatment does not affect people in a multitude of ways, this focus at the individual level further isolates those being treated for hepatitis C and depoliticises hepatitis C treatment (Persson *et al.*, 2003), placing responsibility onto

---

[123] Here Morgan lends strength to the position outlined in chapter three that objects, in this instance, treatment, do not exist prior, independent and singularly, but shift and change based on their intra-actions.

individuals to manage *their* illness (Race, 2001). Treatment becomes an exercise in self-management (Race, 2001) where the individual is responsible for their own outcome on treatment (Martin, 2006:274, see also Keane, 2011). Yet, vitally, the positive outcomes of treatment are reaped within wider society. People may stay in employment longer, having avoided serious health issues; pressure on health service resources and human organs are reduced and the overall prevalence of hepatitis C decreases. In the process, however, the individual and their support needs are overlooked.

Pharmakon, contingency and models of support

The difficult and unpredictable nature of hepatitis C treatment was acknowledged by participants as problematic in developing models of support:

> *Pixie: 'I don't even know if a hep C support line manned with 20 operators on - I mean*
>
> *know it would be busy - but who would fund that sort of support? It's not personal*
>
> *enough... for [some]. It's so difficult Heather to know what to do for these people really*
>
> *there is no sort of quick fix'.*

The lack of *'quick fix' means* there is a danger that instead of highlighting the need for *more holistic* support with social and emotional components, the needs of those with hepatitis C become *further marginalised* they are deliberately made absent, because there are no consistent side effects for everyone and, therefore, no clear model of support[124].

This resonates with wider observations from within disability studies. Sunny Taylor (2004) points to the heterogeneity among disabled people and Patricia de Wolfe (2002) indicates that it is much easier to advocate around issues which appear clear and stable. This acknowledgment of messiness, and the lack of stability, was described by Charlie as a reason for the lack of response to hepatitis C:

---

[124] There is the potential for this to be exacerbated given the development of new treatments.

'There is a great deal of uncertainty, the treatment for it is nasty, it's not a matter of simply giving someone a pill a day and the treatment is uncertain. It's only going to work with certain people... it's almost like it's too big to deal with.'

Here, the ambiguous and uncertain nature of hepatitis C treatment opens up an important gap to think about additional forms of responsive support and disrupt the dominant medical model.

Holistic and multidisciplinary support

The importance of addressing needs holistically for people with hepatitis C, especially those who use drugs, has been acknowledged in recent years. Treloar and Holt (2008) emphasised the need to pay attention to issues which may be inhibiting the uptake of hepatitis C treatment and Olsen *et al.*, (2013) refer to how poverty, unemployment and poor housing dominated the lives of the women who used drugs.

Similarly, participants in this study emphasised the importance of holistic support and the intra-active nature of the phenomena of hepatitis C. Participants found it difficult to separate out what was an effect of the hepatitis C, and what was an effect of the treatment or previous life experiences related to drug use.

Ken described not being sure whether the impairment effects he experienced (brain fog) was an outcome of the treatment, past drug use, additional health problems, or age (see Morgan in chapter five). Kerry described the *'multiple health issues'* she faced in addition to her hepatitis C and, as is discussed in chapter nine, participants often lived with numerous impairments and life circumstances which intra-acted, requiring a diverse range and form of support and information. A key finding of this thesis is that hepatitis C and its treatment are not standalone experiences or issues, but are intra-active and must be addressed as such. As Charlie states:

'It's that thing about linking into common agendas and not viewing things in a silo. People – everyone, doesn't matter what condition they have, has relationships with other people, has finances, has mental health, has housing, environmental, societal determinants to their lives and if you just try and pick off one of those and deal with it your rate of success is going to be appalling. You look at a whole health and welfare system then one of the reasons why it is not working the way it should do is because you siphon everything off, you compartmentalise everything and link everything together, you know, hep C - big time - very, very clinical view of hep C and there is no social input at all?'

Models of integrated support

In 2008 as I began this doctoral study, Foster noted, in an editorial in *Addiction,* that hepatitis C treatment for people who used drugs could be delivered successfully in the context of integrated services. Since then, a number of studies have borne this out. Brener *et al.* (2013b) recently evaluated a New Zealand integrated care clinic for people who had hepatitis C and/or who used drugs. The clinic was staffed by a full time nurse and a GP, as well as a part time social worker. Attendees reported that the clinic was helpful in getting them ready for treatment, as well as addressing health issues they experienced in addition to their hepatitis C. Health professional participants suggested that access to a range of professionals meant it was better placed to address the complexity of client need. Attendees suggested one of the main benefits of the clinic was access to digestible, current information, as well as the cultivation of relationships with professionals. As a result, Brener *et al.* (2013b) proposed that greater attention should be given to delivering hepatitis C treatment in community networks and settings.

In a rare UK based qualitative study, Sinclair *et al.* (2011) described feeling compelled to look beyond the current focus on the medical model, which dominates support provision (two of

the authors were working with the client group as psychologists), to explore support needs among co-infected gay men. They found that support focused only on treatment adherence, effectively overlooked participants' personal needs and priorities – echoed by participants below. In Scotland, the development of Managed Care Networks (MCN) have improved access to hepatitis C treatment and care for people who use drugs, who might otherwise not have engaged with healthcare. MCNs developed as part of the Scottish Hepatitis C Action Plans, acknowledge that people who use drugs often face daily challenges which require support from a range of agencies including health, social services, drug services and mental health services (Tait *et al.*, 2010). Recent research by Harris *et al.* (2012a) found that there were a range of issues which affected engagement with hepatitis C services, including negative perceptions of hepatitis C, difficulties with housing, the availability of social support networks, welfare benefits, caring responsibility and criminalisation. This very recent study (circulated publicly in 2013) is the first to explicitly address social support needs, though this (importantly) focuses on drug users.

This thesis shows there are other issues faced by people who are not current drug users, and who may not have contact with a similar level of support. One of the issues for participants in this study is that similar multi-disciplinary support services are patchy in their existence – it is the sheer lack of services providing support to people with hepatitis C which needs addressing first and foremost.

Forms of support

Participants most frequently described needing a clear point of support. A number of participants named the Macmillan Cancer Support service as a model they would like to follow:

JB: 'Yeah I mean if you had something like the Macmillan nurses for people on treatment [they could] call round see if they're alright, even if it was just a chat, making sure they are doing the treatment correctly, they are having their tablets with food which brings me back again to the benefits system if some poor sod's not got the money coming in he hasn't got a proper diet and is going to mess up his treatment because he is not eating right or taking the pills at the right time so I think if there was something like that then it would be a different show'.

Here JB makes reference to the interconnected nature of needs on treatment. Macmillan, aside from being a high profile organisation, take account of cancer treatment as *pharmakon* and crucially, acknowledge the illness involved in becoming well, as well as the nonlinear and contingent nature of recovery (explored in chapter eight).

When an initial summary of findings was offered to each participant, those that commented indicated that they would not want Macmillan nurses *per se,* but rather were pointing to the lack of existing social support infrastructure:

Richard: 'One of the really big ones is actually the complete total and utter lack of any kind of meaningful support that isn't entirely originating by self-help. I mean the support group in (city) doesn't get a penny from anyone'.

This lack of recognition further invalidates and de-politicises the experience of being treated for hepatitis C. Richard explained that he felt one of the main reasons for lack of support was the moral dimensions associated with liver disease and the culpability. This view was also shared by JB and Pixie who described liver disease as the *'two ugly sisters',* either as a result of alcohol or other drugs. This point is returned to in the discussion of *pharmakos* (scapegoats) below and in chapter nine.

Counselling

Other participants pointed specifically to the need for counselling support or the opportunity to talk things through. The importance of counselling support has been acknowledged in the literature, though a key criticism has been the ad-hoc and unequal nature of access to it (Ehsahni *et al.*, 2006; Swan *et al.*, 2010; Fry and Bates, 2012). Treloar and Hopwood (2005) refer to the vital role of counselling in managing the impact of side effects on mental health. Fry and Bates (2012) suggest that longer term support may be required as treatment may bring forth unexpected feelings and experiences as Morgan indicated, *'all this stuff from my childhood has been coming up.'* Peers were often cited as invaluable, but many participants referred to the need for formal support:

> *Boab: 'There's been no emotional support, no counselling or anything like that. My own GP - I've finally talked them in to allowing me to have counselling - they didn't offer that. I had to ask for it. The medical staff and the liver specialist staff made no mention of it all... the clinical care has been excellent, it's just the lack of psychological care, lack of emotional support'.*

In emphasising only the physical nature of the treatment, the biomedical model dominates the human body is a machine which requires fixing (Lupton 2003; Harris, 2005) and the emotional and social dimensions of the experience of hepatitis C and treatment are silenced, until Boab amplifies them. Boab stated earlier in the interview that because he lives on an island with only a small population, he felt that counselling was relatively easily arranged, but acknowledged that in areas with greater pressure on their resources this might not always be possible. A similar point has been made in an Australian context by Hopwood and Treloar (2005). Here, the silencing of the need for counselling could materialise in highly detrimental or even life threatening ways (i.e. suicide attempts). Shaun described participating in a six week group counselling workshop which provided the opportunity to

talk through his experiences with other gay men who had hepatitis C and HIV, and to explore the connections, experiences and wider structures which led to contracting the virus. However, this group had recently lost funding due to cuts, further reinforcing the silence around hepatitis C, the impact of treatment and especially the experience of living with co-infection (Owen, 2008).

Mental health support

The ambivalent nature of hepatitis C treatment is also clear from participant descriptions of the effect of treatment on their mental health. These effects are well documented in the literature (see Janke, *et al.*, 2008; Sgorbini *et al.*, 2009; Blacklaws *et al.*, 2011; Evon *et al.*, 2011; Sinclair *et al.*, 2011; Fry and Bates, 2012) and participants described these being taken seriously by their treatment team, with most participants being prescribed anti-depressants without psychological or emotional support. Pixie and Charlie made reference to the need for support beyond office hours, because of the impact of treatment and suicidal thoughts:

> Pixie: *'I think it would be the 24 hour helpline manned by people that know about hep C as an emergency thing... Because there is so many that try to commit suicide. You know I had one night in 2007. I had someone sat in bed crying with a knife who kept saying 'I just want to go through' and I talked to him all night and by the morning, 4.30am,he was starting to calm down the daylight was coming and it had sort of passed he has always said that if I hadn't been on the other end of the phone he would have done it. He would have killed himself so that's the sort of thing we need is just 24 hour not a 9am-5pm. I just hate 9am-5pm help lines for something like this'.*

This powerful example, where Pixie describes supporting someone through a particularly dark time on hepatitis C treatment (preventing him from seriously harming himself), enacts a treatment as a responsibility not only personally, but collectively shared by others with

hepatitis C. However, this collective responsibility, whilst it has the potential to be powerful, also involves intense forms of physical and emotional work (Thomas *et al.*, 2002) which may well be beyond a participant's capabilities. This simultaneously highlights the need for services which can provide emotional support and also the need for adequate funding, training and support of peer workers in supporting those on treatment.

Peer support on treatment

All participants I interviewed made reference to the importance of support from those who had experience of hepatitis C treatment (either in the form of a formal group, via the internet or from friends). This is unsurprising given the lack of support from services beyond the provision of treatment and the isolating experience of hepatitis C treatment (McCreaddie *et al.*, 2011). The importance of peer support has been documented in the literature review and in chapter five, and the importance of support groups in understanding illness experience is well documented for those with hepatitis C and with other chronic illnesses (Coreil *et al.*,2004; Mendelson, 2003; 2009; Schon, 2010; Travis *et al.*, 2010; Peterson *et al.*, 2012). Support from peers played a vital role in staying on treatment, as these participants made clear:

Kerry: 'It would be minutes after I'd pressed the enter key [on the internet forum] (support group leader) would be on the phone saying come on Kerry everyone's behind you keep going'.

Charlie: 'I have another friend (edit) who is just about to go on hep C treatment and he has always said he has had liver cancer and it was only when I went to [his hometown], I hadn't seen him for about 10 years and obviously he didn't know I had had hep C, and I mentioned something about, you know, actually going through the treatment and he went, 'you have been through the treatment?' And it was just like all of a sudden his

whole face just lit up it was like 'I have found someone I can talk to! Who knows what

it's like.'

As mentioned above, participants often felt that the hidden and unpredictable nature of the

treatment made it difficult to access support (discussed in chapters six and eight). Mirroring

the findings of Harris (2010) and other chronic illness literature (Charmaz, 2002; Wendell,

2002; Barker, 2005), participants made specific reference to the difficulties around asking

others for support or indicating how they felt:

> *Steve: 'There are times when I would get, not so much fed up it's like someone asks you*
>
> *if you feel okay the general English answer is like,' yes'. But you also get fed up of*
>
> *saying 'no I don't' so you just say 'yeah I am alright' leave me alone and go away'.*

The long term, rather than the acute, nature of the need for support also means that those

who provide support initially may become fed up and fall away. JB explained that families

might have a difficult time in understanding the experiences of treatment and thus pointed

to the need for shared experience:

> *'People aren't able to talk about it as much as they would like to about how they're*
>
> *feeling, about the symptoms, about what's treatment going to be like for me ... so*
>
> *thereby meeting people that have actually got it and are in the same situation as you.*
>
> *Yeah they open up and there's this understanding and this common bond'.*

Importantly, Charlie (who had also lived with HIV and been active in the HIV community for a

number of years) (cf. Persson *et al.*, 2003) referred to treatment experience as:

> *'A sister, brotherhood thing ... you have lived with it you know what you are talking*
>
> *about even though my experiences might be a million miles away from what your*
>
> *experiences are'.*

He described his experience as an HIV positive man as one he was proud of, partially because accessing the community and sharing experiences provided a means of identifying and combatting oppression suggesting a 'protective' or 'strengthening' element of identity. A full discussion of this is beyond the scope of the thesis, but constitutes an important area of further research.

Lois Keith (1996) has pointed to the value of the group setting as an important place for disabled people to share frustrations and difficulties, particularly regarding non-disabled people. The above extracts indicate that this also applies to those with hepatitis C. Participants' ideas concerning the best forms of peer support were wide ranging. Richard felt that these organisations should be within the community so that people can drop in and out of them, and Charlie made reference to providing more general blood borne virus support, which would support and raise awareness of co-infection as an issue. A key issue regarding peer support was appropriate and sufficient funding. JB and Pixie, who moderated an internet forum and phone line, were entirely self-funded and *'tried not to think about'* (JB) the cost.

Given that internet based support has been recognised as an important and cost effective way of providing support to people with hepatitis C (Richmond, 2008; Stewart *et al.*, 2012; Grogan and Timmins, 2010), there is a need for urgent funding to be provided here. As explore above, there was a need for out of hours support for when isolation and suicidal thoughts were particularly prevalent. Keith, Richard and Ken made reference to a 'buddy system' within their local hospital:

Keith: 'We tried to extend the support group to being like... when you go to the

hospital someone will approach you if you want to just to have a chat and this is what

we were trying to get for (town) whereby when you go through your clinic you can say

especially for the newly diagnosed, you can get someone who has gone through

treatment come down and 'say hold on a minute, it's not as bad as people make out,'-

you know what I mean?

Heather: Some kind of clear yeah, information from someone who has done it

Keith You know, it doesn't have to be a buddy thing, but there are people if that's what

they want it can be done its more of a collective, rather than this secret little

underground thing'.

The presence of a buddy at hepatitis C clinics, where participants could draw on support from peers if they wished, enacts hepatitis C as a disease with social consequences. The physical presence of buddies amplifies and materialises the need for social support and partnership with medicine.

The main point here is that needs related to hepatitis C cannot be extricated from the context of a person's life. Whilst other studies have made reference to the importance of multi-disciplinary support (Ehsahni *et al.*, 2006; Sinclair *et al.*, 2011; Stewart *et al.*, 2012; Deacon, *et al.*, 2013), a key finding of this thesis is that people with hepatitis C could be well supported by social work.

The need for social work support

Moffatt *et al.* (2010) note that within UK healthcare, it is frequently unclear who should take responsibility to support people with the social aspects of illness, given that boundaries are contingent and blurred. A key finding of this thesis is that social work (both in statutory and increasingly in third sector services) may be well placed to provide this. Social workers' daily involvement with circumstances and lived experiences which are ambiguous, cumulative, contradictory and difficult (Drayton, 2013), means they have transferable skills and capabilities to manage the challenging and cross-cutting issues raised by hepatitis C and treatment. Indeed, I have argued elsewhere that social workers are ideally situated to

provide a wide range of support and information ranging from harm reduction, to support through testing and treatment, as well as support for social issues raised by living with hepatitis C (Paylor and Mack, 2010).

In spite of this, there has been very limited academic engagement with the role of social work supporting those living with hepatitis C, exceptions being Paylor and Orgel (2004), Mack (2007), and Paylor and Mack (2010). Thus, this thesis makes a unique and important contribution in this area.

Interestingly, the role of social work in supporting people with hepatitis C has been regularly, if minimally, referred to in the literature for over a decade (Rowe *et al.*, 2000; Glacken *et al.*, 2001; Edlin, 2002; Hopwood and Southgate, 2003; Balfour *et al.*, 2004; Hopwood *et al.*, 2006; Ehsahni *et al.*, 2006; Hopwood and Treloar, 2007) and in policy (DH, 2002a; 2004), including some very recent policies and reports (Scottish Executive, 2008; Archer *et al.*, 2009; HCV Action, 2012). This brief, but regular, inclusion of social work, contributes to an (academic) reality where supporting people with hepatitis C is part of the remit for social work.

For participants in this thesis, faced with the everyday reality of hepatitis C, the opposite appeared to be true. There continues to be a severe lack of investment in education, awareness raising and dedicated funding within social work related to hepatitis C, likely to be exacerbated by the current constraints on funding and deep cuts to services. The development of integrated health and social care services proposed by the coalition government in the Health and Social Care Act 2012 may provide new opportunities for this, although this remains to be seen. Further to this, it has been suggested (Treloar *et al.*, 2011; ; Daddow and Broome, 2012; National Treatment Agency, 2012) that as funding becomes increasing constrained and local authorities set their own priorities for services, disinvestment in services becomes a distinct possibility.

Participants' accounts made visible, various junctures at which social work could have provided support. Social workers work across a range of client groups, all of whom have the potential to be affected by the issues raised in the course of hepatitis C infection, especially those working with disabled people, people who use(d) drugs and older people, given that an ageing population with hepatitis C is increasingly becoming an issue (Grogan and Timmins, 2010). Thus, a level of basic knowledge of hepatitis C, testing procedure, treatment availability and effects and the kinds of support required, should be rolled out across all social work teams. This should be linked with knowledge of contact points and services in the local area to facilitate referral and smooth communication (Paylor and Mack, 2010). A major challenge here is the patchy and inadequate hepatitis C services available.

In light of the support needs highlighted by participants throughout the thesis, and the ambiguous nature of the treatment, there is an urgent need for social work support for those with hepatitis C in the UK. However, discussions and observations with social workers on various teams during fieldwork (including a team working with learning disabled adults, one working with physically disabled adults and a team working with older adults), all indicated that they were not aware of hepatitis C as an issue which affected (or might affect) the people they worked with. This is clearly an area which requires further research, but in the meantime, a limited knowledge of hepatitis C coupled with increasing pressure on services and increasingly constrained eligibility criteria means that participant experiences and needs for social support on treatment are 'othered' and invalidated. One (cost effective) way of addressing part of this issue would be to extend the availability of the RCGP certificate in the management and treatment of hepatitis B and C to social workers, and ensure that ideally all, but at least one, social worker on every statutory team has completed it.

Participants in this study reported being unsure whether they could access support from social services. This may well be connected to not knowing which team to access, or concerns about being eligible for services, given that they struggled to meet the criteria for welfare benefits. However, participants should still trigger local authority assessment obligations under section 47 of the NHS and Community Care Act 1990 and at the very least, obtain signposting and information.

Participants described receiving no information about the social work support throughout their contact with services, most likely because such support is rare within the UK. Three participants did refer to receiving integrated multi-disciplinary support, including counselling, although this was in the context of a sexual health service. Here, hepatitis C *treatment* is enacted as a remedy for overstretched and under resourced NHS services in the longer term (i.e. a shortage of livers for transplantation), whilst the attention to the poison aspect (the creation of needs as a result of treatment) are othered. Participants are expected to go through treatment with little or no social support (relying on family and friends) which materialises them as threats to public health, rather than human beings with support needs.

For example, Morgan described a range of debilitating side effects on treatment:

'I mean I couldn't run a bath. There was times when I didn't have a bath for a week, I didn't have the energy to run myself a bath I certainly couldn't have had a shower, you know, I was vulnerable to falling over because I was sort of dizzy and weird a lot of the time. And, you know, you should have someone can help you with that and you should have someone who can cook you a meal because you haven't got the energy to stand and chop veg or stand up I mean I couldn't stand for very long at all'[125].

---

[125] When I read this in the transcript I was struck by how similar it sounded to the questions and descriptors on an application for Disability Living Allowance, suggesting that Morgan is trying to present herself as 'eligible' for support in the interview.

As a result, Morgan relied on existing social networks for help with shopping, preparing food, housework, supervision in the shower, to provide emotional and social support. Clearly this depends on the degree of disclosure and the strength of support networks for individuals. Similarly, the long term nature of treatment may mean that family and friends are unable to provide meaningful support for the duration of treatment (Hentz, 2002) and particularly post treatment (discussed in chapter eight). Recently Harris *et al.* (2012a) has drawn attention to the invaluable support that can be provided by family and friends during treatment, but indicated that participants in her study also referred to the need for practical support (such as housing repairs) and help with finances, for which very little support existed and which participants indicated drained what little energy they had.

Ken and Pixie referred explicitly to the need for childcare for parents on treatment, but made reference to the financial constraints as inhibiting greater social care involvement. For example, Kerry was caring for her three year old daughter at the time of being on treatment and described a partial and fragmented response, despite there being numerous professionals already providing support to her:

'I really did need [support with] childcare and I didn't get it. I rang them [social services] and asked them for an assessment at the beginning of the treatment and they said it was not in their remit...they already knew about my mental health problems and I said the hepatitis treatment will then be on top and the lady did ask me 'what's that going to entail?' And I tried to explain it in terms of basically like chemotherapy and there are very harsh side effects and I explained those side effects and I said obviously I don't know whether I will have those side effects yet, but fatigue and insomnia and stuff like that are quite common and as I already suffer from those symptoms it is likely they are going to be exacerbated and the same with my mental health, it could easily slip . My [mental health] team to begin with were not that sure about treating me

because they were worried I was going to try and kill myself or I might not be able to cope with the treatment. Luckily I get enough support from the mental health team that that hasn't happened. But I tried to explain to social services that because of my borderline - we are talking minutes between me being fine and me being in a complete crisis. And I tried to explain to social services, rather than calling the crisis team ten times, they might as well offer me ten weeks of help you see what I mean it hasn't happened I haven't had a major crisis, but I have been ill and my parents have had to take up the slack'.

This extended extract from Kerry clearly shows the intra-action between her existing health issues, her family life and the addition of the treatment for hepatitis C. Here, preventative intervention is not an option, which as Kerry points out could prove to be more costly in the longer term. Treatment as *pharmakon,* and as liminal (Rhodes and Treloar, 2008) and ambiguous, is visible here. Kerry describes receiving support from her mental health team, but struggling to access support to maintain her home life and care for her daughter. Hepatitis C treatment is enacted as very serious (the mental health team are concerned about treating Kerry, given her existing mental health issues and the possibility she might attempt suicide) and simultaneously not serious enough to warrant support from social work. This resulted in Kerry relying on family to support her and her daughter, further silencing the impact of treatment from a services perspective.

Harris *et al.* (2012a) in a report concerning the needs of people who use drugs on treatment, has also made reference to the need for social support and the lack of available services, thereby strengthening the findings of this thesis. The authors indicate that caring responsibilities made hepatitis C treatment more difficult and recommended that people should have access to subsidised home and care support.

It is here that social work as *pharmakon* becomes visible. Social work continues to occupy a position between enabling and disabling (Roulstone, 2012, Oliver, Sapey and Thomas, 2012). As explored above, social work intervention could make an important contribution to enabling participants to maintain employment, undertake caring responsibilities, live well and maintain their family relationships, before during and beyond treatment. In practice, it further contributes to the disablement of participants, with narrow criteria, lack of funding and limited awareness among social workers around hepatitis C marginalising and silencing their needs altogether. Ways this might be addressed include the embedding of hepatitis C and other blood borne viruses into undergraduate and post graduate education, together with the involvement of those with BBVs in modules and lectures (Clarke, 2010; Galvani and Hughes,2010). Roulstone (2012) points to the need for greater lobbying by, and with, social work in this case, in relation to support and awareness around blood borne viruses. Possible forms this might take include developing special interest groups,[126] expanding the remit of existing professional hepatitis C groups to include social work and people with hepatitis C, or developing a group of social care professionals and service users which crosses over with the remit to encourage joint working.

A key issue here is the development and maintenance of trust and rapport with social work professionals (Harris *et al.*, 2012a). Neale (2008) maintains that some people, particularly those who use(d) drugs, may be reluctant to engage with social work because of concerns about their children being removed (cf. Galvani *et al.*, 2013). Neale's (2008) participants felt that social services in intervention needed to be avoided, that social workers did not understand their problems, were unable to provide support and were not to be trusted. The negative perceptions surrounding social work are also being addressed more widely by The College of Social Work (2011) and, if adequately funded and supported, the development of

---

[126] A British Association of Social Workers Interest group does exist for alcohol and other drug use under which hepatitis C could be subsumed.

the social work role in hepatitis C support services might also help to change wider negative perceptions.

It is important to note here, that it is not my intention to write a thesis which is not orientated to the harsh realities with which it is intended to connect (Roulstone, 2012:144). It is likely that cuts to existing services will make engagement with hepatitis C particularly difficult at the moment increasing constraints on eligibility for services will mean that participants continue to find themselves (or indeed may even become) ineligible for support, along with many others[127]. It is vital to acknowledge that this is going to be very difficult, but that this is no reason not to make the need for support for people with hepatitis C (and those on treatment) very clear. Clearly, an area of vital research is the development of models of service within such constraints.

A key commonality (indeed intra-action) between people with hepatitis C and (other) disabled people is that both groups have received what Roulstone (2012) refers to as a 'Cinderella service'[128] – with both often treated as an adjunct within policy and practice. This highlights an important shared experience which could be used as a basis for organising together (see chapter nine).

Having explored participants support needs and the role of social work in addressing participants needs on treatment, the chapter returns to discussion of another dimension of *pharmakon,* the concept of *pharmakos.*

---

[127] The implications of the redrawal of these boundaries are explored in chapter nine.
[128] Services for hepatitis C have also been described in similar terms (see DH 2002) and the evidence presented in this thesis suggests that this is still the case.

An introduction to *Pharmakos*

Eschotado (1998, in Acevedo *et al.*, 2009), in his research into the etymology of the term *pharmakon*, found that the term *pharmakos* has been used to describe cleansing rituals (used in ancient Greece and Rome) in which a scapegoat is literally or symbolically scarified (see also Szasz, 1974). The *pharmakos* were often human beings (sometimes animals) offered to deities as a means of appeasing them, in turn alleviating a difficult situation within the community, removing personal and collective impurities, and avoiding plagues and famines (Szasz, 1974; Acevedo *et al.*, 2009). Szasz (1974) notes that the root meaning of words such as 'pharmacology' is not medicine or poison, but 'scapegoat'; it was only after these rituals of sacrifice had been abandoned, that the words took on the new meaning.

Writing from within disability studies, Bill Hughes (2012) discusses the enactment of disabled people as *pharmakoi*, maintaining that the main response to disabled people has been to either correct or eliminate that which is not tolerated. Hughes (2012:19) traces the rejection of disabled people through history, noting that those who were perceived as different were mocked and excluded he maintains 'disability was positioned as a moral and ontological pollutant.' Over the years the boundary between what is acceptable and what must be segregated has been drawn, and indeed maintained, by medicine that defines 'pathology', but who allowed entrance into the mainstream via corrective treatment (in this case hepatitis C treatment).

Interestingly, for the purposes of this chapter, speaking in relation to drug use and people who use drugs (but applicable to people with hepatitis C and (other) disabled people), Szasz (1974:27) states that we have moved from 'cure alls through human sacrifice to cure alls through chemistry', wishing to expel from the community those who use drugs and pollute

the community. When this is considered in relation to hepatitis C treatment, both the treatment and the people undertaking it can be considered *pharmakoi.*

Participants made reference to treatment administration as a kind of ritual, the ultimate aim of which is to expel the virus. Carl and JB described preparing their interferon dose as a ceremony which evoked feelings associated with using drugs:

> *'And it's that whole process of going through that injection every week because you have to set it all up and you have a sharps bin in your flat and it's like 'my god,' it's like I was still using. I had to go through a process. I got used to it after a couple of weeks but I would get it and set a little bit up and then have to sit down for 10 minutes and take deep breaths.'*

> *JB: it was strange because I had the Schering-Plough pen where you go through this ritual of getting it out of the packet, you click it together, you dial up your dose you screw on the needles - so there was this ritual that you went through, which took me back to my drug using days. And I was actually getting a little bit of an adrenalin rush.'*

Here, both the *pharmakos* ritual and treatment as *pharmakon* are enacted. The mode of administration of treatment both attempts to remedy the virus but evokes emotions associated with preparing to inject drugs and indeed, participants' identities as (former) drug users. Harris (2009b) also reported participant concerns about relapse to injecting drug use associated with interferon treatment, both in relation to preparing the medication, injecting it and the side effects associated with the treatment (see also Ogawa and Bova, 2009; Sinclair *et al.*, 2011). Further to this, it is possible to see the needle and injecting equipment (used in treatment) as symbols of the inherent potential for drug use (once a drug user always a drug user, see Lloyd, 2010) that must be expelled from the community.

Drug users as scapegoats

Scapegoats are most clearly mobilised in times of distress or unsettlement (see also chapter nine) and Szasz (1974) states that illicit drugs, those who use them and those who distribute them, have become scapegoats within society. He maintains that unlike those ancient societies performing a ritual, we no longer recognise when we use a scapegoat with the aim of cleansing or ridding society of things which do not conform to moral order. Now we use 'scientific' reasoning to explain it [i.e. the medicalization of drug use, drug users and hepatitis C (Fraser and Moore, (2011)].

Thus, both those with hepatitis C and the hepatitis C treatment are enacted and materialised as scapegoats. Hepatitis C as a virus which is transmissible (infectious), long term (a significant cost to the NHS if treated and potentially more so if untreated) and passed on via stigmatised practices (injecting drug use) does not conform to the order of society and thus, must be eradicated.

Moving on from hepatitis C

A significant number of participants enacted treatment as a way of 'moving on' (Daniel) from hepatitis C; of leaving negative assumptions and an 'abject' identity behind though consigning drug use and hepatitis C to the past, (explored below) was not always possible or desired by all participants. This focus on treatment as a part of 'moving on' re-produces the person with hepatitis C as someone who needs to take responsibility for their health (Harris, 2010) and, thus, provides an opportunity for a kind of scapegoating. This is particularly visible in Grace's telling of an encounter between her and someone who was not accessing treatment:

'He weren't on treatment he said 'there is no point in me having treatment because I don't have anywhere to live.' I goes 'that doesn't stop you having treatment' so it's all

self-inflicted, street druggie refusing treatment who was sitting there actively

contagious. At least I am doing something to stop myself being contagious. I don't

want to sit next to someone who is rife with it and who isn't doing anything. Mind you,

I was contagious for years and didn't know it.'

Here, Grace reproduces discourses around treatment ['get tested, get treated.' (NHS Choices, 2009)] with a lack of focus on the context of the man's life. Treatment becomes the rational response and those not doing it are irresponsible. Grace expresses scorn for *'active druggies'* (who become scapegoats) and not doing treatment is enacted as a personal refusal, rather than one which depends on taking a holistic view of the person's circumstances and treatment by health professionals (see Fraser and Seear, 2011), in the context of limited resources. There are parallels here with Anthropologist Murphy *et al.*'s (1988) observations of the way in which disabled people are treated as if they are 'contagious' and that ostracism is increased when there is a perception that someone is *responsible* for their impairment and disablement (revisited in chapter nine.)

The ambiguous nature of hepatitis C is also visible here. Grace describes the man as *'actively contagious'*. However, she later realises that it is impossible to completely separate herself from him and the disruption of separation and binary occurs again. Derrida (1981) explores the ambiguity of the *pharmakos* noting they are positioned on the boundary between inside and outside. He states that the ritual ceremony of purification, referred to above, allows the community to redraw its boundaries as closed, protected and cleansed of the threat (just as medicine positions treatment as cleansing the body). But, the *pharmakos* actually disturbs this. These scapegoats are both outsiders *and* insiders; the embodiment of that which must be expelled, but an integral part of the community for the role they undertake (Hughes, 2000, Kumari-Campbell, 2009). For example, the ultimate aim of pharmaceutical treatments is to eradicate hepatitis C and, as argued above, this sole focus on eradication works to

position people with hepatitis C as outsiders. Yet, in order to develop effective treatments, people with the virus (with increasingly complex life circumstances – see Swan, 2013) are required to participate in clinical trials and thus, are integral to its success.

Similarly, people with hepatitis C who undertake treatment are also on the border between inside and outside: there is evidence that both the participants and the treatment become *pharmakos* in their interactions with health professionals.

Treatment was referred to as a 'turning point' by professionals I interviewed, (e.g. specialist nurses and drug services workers) (see also Hopwood, *et al.*,2006 for examples within the literature), where drug users ceased using and accessed treatment, and this was often echoed by participants:

> *Carl: 'I did get to a place a couple of years ago where I went into a treatment centre and got clean and it kind of came back to haunt me in a big way as well because it was just an on-going thing for me was hep C . So there was a kind of a thing I had to deal with as well basically I did'.*

Here, hepatitis C and treatment are enacted as if it is something which participants face and decide to do once they enter recovery. However, there is evidence of the notion of recovery being co-opted to fit with organisational priorities (see Pilgrim, 2008; Morris–Colton, 2011; Stephenson-Turner and Mayes, 2011). The focus on treatment as something which is only addressed in 'recovery' obscures the power relationship between the person with hepatitis C and the professionals who do not offer treatment until they participants stop using illicit drugs. Here the concept of the 'turning point' narrative enacts drug use as being in the past and creates a false division between past and present, simultaneously marginalising the possibility of treating people who still use drugs.

As discussed in chapter six, this division is materialised in oppressive interactions with health professionals. For example, Kerry described being told at her first hepatologist appointment *'I'm assuming you're an IV drug user.'* This meant Kerry was forced to indicate that her drug use was in the past, before the interaction proceeded reinforcing drug use as 'other' and impacting on her emotional wellbeing.

This also enacts a false division between illicit drug use as 'bad' and treatment as 'good'. Recently explored in relation to methadone for people using drugs, as both a treatment for chronic pain and an opiate substitute, Keane (2013) highlights how the division between the two methadones is untenable. Nevertheless, this separation is visible in that participants described accessing support to manage and recover from 'bad' (illicit) drug use, but not to manage 'good' drug use (hepatitis C treatment); silencing the ambiguous nature of treatment.

Elsewhere, both hepatitis C treatment and participants are enacted as *pharmakos.* In an interaction with his orthopaedic surgeon, David describes being told that an operation would be postponed until after he finished treatment because *'the consultant [didn't] want to put his surgeons at risk'* (also described by Morgan and Ken). When David challenged this, the 'turning point' narrative (i.e. the division before and after drugs) is used to assuage David's anger:

> *'[The consultant said] we are leaving you here till we have done your shoulder. But then we'll do your neck before we operate on your knees. He had operated on my knees twice before but didn't know I had hep C then. I just had this bad feeling. Anyway when I went to see my GP and I said 'is it okay if I see another specialist?' She turned round and said 'it's mad you think this [of the specialist] because he has written a dead nice letter about you! Saying how you have turned your life around' and I did say 'well yeah he is really lovely and I feel a bit bad but he is definitely not sympathetic to people*

with this blood borne disease, and should he not be treating everybody in the same

category?'[By using universal precautions]

Here David is positioned both on the inside and the outside of the community (and the responsibilities of the NHS). Having 'turned his life around' he is a compliant, responsible citizen and no longer a drug user. However, he is positioned on the outside because his blood poses an infection risk to the surgeons.

In bringing this section to a close, the final point I wish to make is that the current emphasis on doing treatment enacts those with hepatitis C as scapegoats (*pharmakos*) and reinforces treatment as the only way forward with hepatitis C. Additionally, the *pharmakon* of treatment becomes a kind of *pharmakos,* enacted as the 'cure all' for hepatitis C, displacing the need for support.

As noted above, clear divisions between 'previous' lives which involved drug use and hepatitis C were not always desired or maintained by participants. Many participants felt that hepatitis C was an on-going part of their lives (even if they cleared it) – consistent with the concept of recovery described by Deegan (1988), Daddow and Broome (2012) and Pilgrim (2008). Recovery is recognised as a polyvalent concept which is concerned with living well with this does not necessarily mean being cured and moving on, but incorporating experiences into life (discussed in chapter eight).

Many participants challenged the notion that hepatitis C could, or should, be left in the past, by continuing to support people with hepatitis C and those on treatment. They did this by attending support groups, raising awareness in their local community, sharing their information and experience and acting as a kind of 'living proof' of life beyond hepatitis C and its treatment. Others indicated that it would remain part of their identity in their family life and in future work. At the time of interview, Kerry was writing her autobiography and felt that her experiences with drug use and hepatitis C would be central to this. Shaun and

Ben also indicated that their hepatitis C status could not be relegated to the past after clearing it, because negative judgements persisted about ever having had it.

Given this chapter's length, and the vital importance of participants' experiences post treatment, a short chapter follows which explores this in more depth. Similar to chapters three and four, this is not easily separated but is done to ensure important points are not overlooked.

Chapter Eight: 'It was an awful shock... to still feel like I did', experiences beyond treatment

Introduction

This brief chapter describes and explores participants' experiences *after* they had finished taking combination treatment, a phase usually considered (and enacted) as being beyond the boundaries of medicine (Fraser and Seear, 2011) and consequently poorly addressed in the existing literature (Hopwood, 2013). However, Van der Geest *et al.* (1996) indicate that medicines have a life after they are taken, specifically how they affect the wellbeing of the person who took them. This will be the focus of discussion. As has been explored throughout, medical treatment is a key response to hepatitis C in the UK. Current guidance recommends that participant blood is tested for the presence of the virus at the end of treatment (either 24 or 48 weeks), then at three months and then again at six months (Hopwood *et al.*, 2006). If the virus is 'undetectable' at six months following treatment completion, this is considered a sustained virological response (RCGP, 2007; NICE, 2006) in other words, the virus is supressed or eradicated and hepatitis C is 'cleared' (Pears, 2010; NICE, 2006) or even 'cured' (Dusheiko and Burney, 2013; Liang and Ghany, 2013).

Here, I am reminded of the words of Australian Sociologist Kane Race (2001:168), who, speaking in the context of HIV, maintains that the (viral load) test result functions as a measure of both individual and public health. He refers to the 'ability of medical technologies to determine truth and prescribe courses of action'. At present, if at six months post treatment the test no longer detects the hepatitis C virus, it is understood to be no longer causing damage to the liver and no longer transmissible to others. For people without severe liver damage[129], professional input in relation to hepatitis C stops. However, for many

---

[129] For people with Cirrhosis (permanent scarring of the liver, which cannot be reversed), monitoring and support from a liver specialist will continue even if the hepatitis C virus is cleared (RCGP, 2007).

participants, attaining SVR did not necessarily equate with improved health. Here the hepatitis C treatment, test and result organise and enact participant experience in ways which are commensurate with what medicine can offer, rather than paying attention to forms of support participants might need.

Race (2001) and Persson et al. (2003) also discuss the shifting contingent nature of health and how the HIV test enacts a person as 'healthy', or indeed treatment as 'successful', whilst the embodied experience may be very different.

In a recent question and answer session in partnership with The Hepatitis C Trust, Graham Foster[130] (2013) acknowledges that 'clearing' the virus is still a controversial area. There is still some evidence that traces of the virus can remain present in the blood (though he maintains that the virus is not transmissible or damaging). Foster (2013) explained that because it is impossible to be sure that the virus will not return, those who attain SVR are still barred from donating blood.

In Foster's (2013) response, the reality enacted at the end of treatment hangs together with the attainment of SVR (the virus is neither transmissible or damaging), whilst at the same time not cohering with regard to future blood donation (it is impossible to be exactly sure). In the same way, hepatitis C is enacted as 'cleared' in the reality of the PCR test but enacted very differently in participant descriptions. As Persson (2004) indicates, a virus may not be clinically apparent, but is very much present, socially and in participant's bodies.

The discussion of post treatment effects in the literature

Clinical studies researching the effectiveness of treatment have reported that quality of life, post treatment, improves both in terms of physical and cognitive impairment (Ware et al., 1999). Further, at six months post treatment there is no evidence of persisting impairment

---

[130] London based Consultant Hepatologist and Professor of Hepatology

compared with before treatment (Thein *et al.*, 2007). However, Hopwood (2009; 2013) points to persistent interferon based neurotoxicity among people treated for hepatitis C, which results in a wide range of impairment effects, both physical and psychological.

A small number of qualitative studies have explored the on-going impact after treatment ends, and post treatment and support remains an under researched area (Fraser and Seear, 2011). To date, Hopwood (2009,2013) and Paterson *et al.* (2006) are the only published studies which explore post treatment experiences and these are in an Australian and New Zealand context. Some studies exploring qualitative experiences of hepatitis C treatment briefly mention the post treatment experience without elaboration. For example, Janke (2008) reports that participants felt that the anger they had experienced whilst on treatment did not dissipate as they had expected, and Sternhell *et al.* (2012) refer to the persistence of mental health needs after treatment. Similarly in a study carried out in the Republic of Ireland concerning patient satisfaction with specialist nursing support, Grogan and Timmins (2010: 2871) surveyed patients six months after treatment, stating that they did not wish to 'burden' patients on treatment and implicitly acknowledging a six month recovery period (though they make no justifications for this time period in the study.)[131]

Loveday and Dore (2009) indicate that the immediate period post treatment may require additional support, due to on-going treatment effects and coming off treatment. They maintain that clinical contact should be on-going and that this should not solely be provided at the six month confirmation of SVR. In the UK, the only acknowledgement or explanation of the post treatment experience, to date, exists in the form of a survey conducted by The Hepatitis C Trust (2010b) (discussed below); thus opening up significant space for exploration of the post treatment experience and support needs in the UK.

---

[131] Though this might also be interpreted as an attempt to gain an 'overview' (Mol and Law, 2002) of the treatment experience given that participants in this study described their needs altering from day to day whilst on treatment.

It is important to note that not all post treatment effects that participants experienced were negative. A small number of participants in the sample who had finished treatment at the time (three of the 16) described feeling better after treatment. This is what Hopwood (2009) refers to as a sense of renewal. As Charlie indicates he experienced a burst of energy:

'As soon as I came off the treatment within two or three days it was like someone switched all the lights on this amazing feeling of energy and almost feeling hyperactive really and that lasted for months – feeling... really, really excitable really, really good and I knew it had gone.'

However for many participants, attaining SVR did not necessarily equate with improved health. Participants referred to 'post treatment effects' and the need for greater attention to this period was raised as a specific issue:

JB: 'I think there are lots of issues post treatment which still need to be researched – not only emotional but physical, and people are still depressed even if the treatment is successful'.

In the most extensive qualitative exploration of post treatment to date, Hopwood (2009; 2013) found that although a minority of the participants he interviewed did feel better, most did not, and some felt worse after the treatment than before it. This finding was also supported by a recent Hepatitis C Trust survey (2010b) (of 500 participants) which found that 90% of the respondents experienced on-going side effects and symptoms for longer than 12 months post treatment. Only 31% of respondents reported feeling better 40% actually felt more unwell, irrespective of SVR. The survey found a low correlation between attaining SVR and feeling better, and pointed to the need for further research in this area.

My purpose in this chapter is to explore participant experiences of post treatment and their support needs but also the way in which post treatment is effectively made absent, or 'othered' (Law, 2004), from hepatitis C treatment realities, via specific social and cultural beliefs and processes. This leads to the invalidation of participants' experiences and impacts on their psycho-emotional wellbeing (Reeve, 2002; 2004; 2012a).

Drawing on the suggestions of Hopwood (2009), and given the links to cancer already outlined within this thesis, cancer survivorship literature is drawn upon in order to derive some lessons for the development of post treatment services. The application of the concept of recovery is also briefly explored.

Defining post treatment effects

Post treatment effects are defined as impairments which continued, or became visible, after participants finished the course of treatment. Of the participants who had finished treatment at the time of the interview (16), 12 described post treatment effects. The duration of post treatment effects ranged from 14 weeks to five years. It is acknowledged in some patient information that treatment can take up to six months to recover from (Porter, 2008). However, many of the participants I spoke to described being unaware that this would be the case, or did not believe that it would happen to them.

Participants described a range of impairments after the end of treatment, including fatigue, joint pain, brain fog and memory problems, low mood and depression, gastrointestinal issues, rashes and feeling *put through the wringer* (Laurie). Carl explained that for three and a half months after treatment, he experienced both physical and psychological effects:

'I felt really low and I felt really shit and I felt really just the same ...It was just a relief

when I used to wake up on a morning and put the kettle and get the milk out the fridge

and yeah oh there's no injection. And that was the only way I could tell for the first few

months that I wasn't still on it, the side effects were still there'.

Although the treatment may be physically absent from his fridge, it continues to be present and working in his body. Others reported much longer post treatment effects, for example Andrew stated *'sometimes I feel like I'm still on it and that's from two years ago'*.

All but two of the participants who reported post treatment effects in this study had attained SVR. Keith had attained SVR at the time of interview, but did not feel well enough to return to work due to on-going treatment effects. Morgan and Steve also described feeling they could not return to work due to difficulty concentrating. Morgan was self-employed as an alternative health practitioner and described how feeling physically well, and present in her own body, was a vital part of her job. Freda worked all through treatment, but in our last correspondence, having finished treatment, she was seeking support for depression. Pixie experienced the onset of rheumatoid arthritis. All participants felt these effects were connected to long term effects of hepatitis C and treatment:

> *Pixie: 'It's like I have been diagnosed with rheumatoid arthritis[132], I finished treatment*
>
> *three years ago - so a lot of people will just say well, maybe you were just going to get*
>
> *it anyway... But being as it is an autoimmune disease I also feel that it could have been*
>
> *treatment that set this off because what I am getting is what other people I see all the*
>
> *time the joint pain and stuff like that so I think we need to be looking far more at post*
>
> *treatment. [People] need to be looked after'.*

JB described being initially sceptical of the long term effects of treatment (explored further below), but had taken an overdose in recent weeks whilst waiting for his six month post treatment SVR:

---

[132] Ferri *et al.*, (2012) discuss rheumatoid arthritis as an extra-hepatic impairment resulting from hepatitis C infection, again making the division between impairment related to hepatitis C, treatment and post treatment untenable.

'It wasn't till I had fallen in that black hole and attempted suicide that I thought there was something in this.'

It is in JB's example that hepatitis C treatment as *pharmakon* is readily apparent; JB cleared the virus but also experienced serious mental distress alongside.

Participants who experienced post treatment effects described being placed in a similar liminal (Turner, 1966; Treloar and Rhodes, 2009) position to that they inhabited prior to their diagnosis, where they knew that they still required support, but were disabled by existing structures of services (no medically authorised 'label' which validated their experience, no clear information and limited support) and subsequently found a lack of awareness and recognition (see Jackson, 2005 for a similar discussion in relation to people living with chronic pain). Furthermore, there was even less support available than when participants were on treatment, as they felt medical support was no longer an option.

There is a further parallel between hepatitis C treatment and cancer treatment here. Stacey (1997) also reported falling into a post treatment gap. Once her cancerous tumour was removed, it was unclear whether she had cancer or not. A good example of this was present in the group interview:

Andrew: ' I find it hard they [specialist team] said it [hepatitis C test result] was clear, said it was clear after the first month and 6 months, then a year or so after... The results tell you you're clear and that and then it says you're less that 30 parts per million which counts as you not having it. Does it mean you haven't got it [hepatitis C] or does it mean there may still be a little fraction of it there?

Brad: ...They count down as far as 30 parts... They have no idea whether it's there or not. It could be 29 parts or there could be no parts there, yeah, anywhere from nought to twenty nine.

Worker: ...It's because you don't get a definitive answer as to you haven't got it isn't it?

It's the way it's actually measured and there has got to be some sort of line drawn as

to how it's measured and that's how they do it.'

The worker's comments at the end of the extract regarding the lack of *'definitive answer'*

make the fluid boundary between having and not having hepatitis C visible. Stacey (1997)

discusses how cancer narratives never offer a complete resolution and Harrow *et al.,*

(2008), in their study of partners of women with breast cancer, similarly describe

difficulties and feeling 'in limbo' following treatment, wondering how and when to move

on. Schmid-Buci *et al.* (2011) in her study of the needs of people with breast cancer and

their relatives, found that after treatment patients did not return to the state of health

they had been in prior to illness onset, but had a specific set of needs (see also

Hodginkson *et al.,* 2007). Others referred to on-going impairment such as 'chemo brain'

(Abel and Subramanian, 2008). Those living with different types of cancer have also

highlighted the need for greater information and support (see also Thomas *et al.,* 2001).

Among these was the need for support with treatment related impairment and future

health, as well as emotional support, practical assistance and financial advice. Post

treatment, people with cancer reported feeling depressed, uncertain about the future

and worried about recurrence (Oxlad *et al.,* 2008). Whilst these problems are not exactly

the same for people with hepatitis C, they do make a wider point concerning the impact

of a long term health condition and a difficult treatment. Both of these groups [part of

Frank's (1997) 'remission society'] share common experience regarding disabling

structures and barriers, and as such provide a potential point of identification for joint

work and activism.

Feeling prepared for post treatment effects

A key finding of this research was the variation in the degree participants felt prepared for post treatment effects and their long term nature. As Brad described:

> *'Yeah [the effects] went on for ages afterwards months … I assumed the week after I'd had that treatment that I was going to feel on top of the world. It was an awful shock after 48 weeks to still feel like I did'.*

Similarly, although Laurie described experiencing support and encouragement from the specialist nurses, the only post treatment information he was provided with was the duration of the wait until his PCR test (to see whether the treatment had worked):

> *Heather: And no one spoke to you about this?*

> *Laurie: NO! - Not a word, just 'x weeks to your PCR test'. The nurses were excellent, wished me all the best, told me how hard I had battled, hugged me, but counselling and advice on post-TX (treatment) didn't exist.*

Here, in the lack of information and support, the remedy aspect of treatment is given priority, re-enacting the 'heroics' and authority of medicine (Fraser and Seear, 2011; Marks, 1999.) The cure aspect of *pharmakon* is maintained. Laurie finishes treatment and is congratulated by the staff, but should only return to confirm that the virus is cleared, no further support is offered and the toxic aspect of treatment of *pharmakon* is silenced. Other participants reported a lack of information from their specialist team until near the end of treatment, and only knew about it from their own research.

> *Morgan: 'Actually I knew how long it took to get over treatment, you know, because of the research I'd done, but they don't tell you till the end of treatment - and that can come as a horrendous shock to people. I mean my specialist - I knew it was going to*

take three to six months to recover from the treatment - but the specialist didn't tell me that 'til my last session'.

As indicated above this raises a number of pertinent issues. It mirrors Hopwood's (2009) findings that consent forms for treatment do not adequately cover the experience of post treatment and raises ethical questions about offering treatment without alerting participants to the possibility of long term treatment effects. There are also implications for the relationship between Morgan and the consultant, and about how likely she is to return to him for support. The lack of information, advice and recognition also has very serious consequences for those participants who may be expecting (and expected) to (return to) work at a pace shared by colleagues, and raises questions concerning seeking and receiving accommodations or financial support (see chapter nine).

The failure to acknowledge post treatment effects further undermines the experiences of those who experience them. Participants may not be aware that these are post treatment effects when they do occur, which may cause unnecessary stress or anxiety, and may place further strain on relationships with friends and family.

It is important to note here that it may be that participants *were* informed of the possibility of post treatment effects at various points. Indeed, both Brad and Andrew reported feeling that they had been given ample information and yet still not anticipating the effects, suggesting that more than information is required. As mentioned above, this could be connected to participants believing that the post treatment effects would not happen to them [what Hopwood and Treloar (2008) term 'unrealistic optimism']. Yet it is also possible that the post treatment effects were not fully absorbed or considered by participants *because they were not enacted and materialised as serious in the provision of formal support services.* Information indicating that post treatment recovery may take some time is difficult to absorb if it appears that in practice, no further support is required.

Grinyer (2009), in her research exploring the longer term support needs of young people who survived cancer, states that provision of information concerning the possibility of post treatment effects is a difficult balance to strike. She highlights the dilemma of informing participants about the possibility of longer term treatment effects which they may not experience, potentially producing anxiety in the process or, alternatively, leaving them ill prepared and unsupported in the event they do experience late effects. Grinyer (2009) resolves this dilemma by recommending that professionals emphasise it *is one possible outcome* paying attention to the multiple nature of treatment. Here, Mol and Law's (2002) observations regarding the 'overview' of experiences are pertinent. It is difficult to make wide ranging recommendations without losing the nuanced nature of post treatment. Observations are partial, contingent and dependent on a range of factors, thus recommendations should accommodate this contingency where possible (see appendix one).

Experiences of invalidation

The lack of recognition and validation of their post treatment experiences, coupled with the expectation of a clear division between being ill and being well (Frank, 1997) has implications for participants sense of entitlement to peer support. Pixie and JB described forum participants feeling that they could no longer post after attaining SVR. This led to the development of a 'post treatment' section on the forum, explicitly acknowledging It as a specific phase of the hepatitis C experience:

> Pixie: 'Lots of people feel guilty, because they have cleared the virus and there's no
>
> reason why they should be feeling like they're feeling - you know still tired and that.
>
> They are wrestling in their minds of whether or not it's themselves and they're just lazy
>
> and that they should be better motivated and stuff like that they do tend to feel a bit
>
> guilty so I'd like to see at least that they could go and discuss symptoms after

treatment without fear of being dismissed that they should really be getting on with

their lives. Just a little bit more care'.

Here, Pixie makes reference to the possibility that forum participants have internalised the idea that they are lazy or weak, rather than unwell (also described by Glacken *et al.*, 2001; Dunne and Quayle, 2001), and this is explored more in chapter nine. She further indicates that in contact with others on the forum, she has found post treatment effects dismissed or not taken seriously by professionals. This highlights the need for further longitudinal research into the experience of post treatment and for clear information and training produced by governmental or charitable organisations regarding the possible longer term effects of treatment, which could be updated as more information becomes available, and which should be tailored and disseminated to GP's, DWP workers, family members and employers. The liminal status of participants' post treatment experiences also had serious implications for participants' own sense of self and social relationships, as Morgan describes below:

'Well I think, well once you've finished the treatment you should be fine, you know,

you've got rid of the virus, you've finished the treatment, what's your problem?... Why

you aren't fine now, get back to work what's wrong with you? (Laughs)'

Here Morgan's comment *'get back to work, what's wrong with you?'* hints that she has absorbed wider perceptions that she is somehow acting dishonestly by not working post treatment, explored in chapter nine. Importantly, Morgan described a lack of support from some friends post treatment, describing a sense that she was somehow acting deceptively or manipulatively in experiencing on-going impairment when she was told to *'stop milking it'*

This is potentially linked to wider cultural beliefs and values around illness as outlined by Harris (2009a). Wider society is less tolerant or accommodating of illness which extends beyond a period of time or does not have a clear or discernible end point. There are

some commonalities here between hepatitis C experience and the grieving process explored by Patricia Hentz (2002). Hentz (2002) found that the non-linear experience of grief and its unpredictable nature was difficult for others surrounding the grieving person both to accept or address (Hentz, 2002). For the person grieving, these experiences were subsequently silenced or hidden.

Further to this, participants interviewed as a couple described initially being sceptical about the presence of post treatment:

> JB: 'I would diss it [post treatment effects]. I would say 'oh that's a load of rubbish it's because of their lifestyle. They should get out and get a job, get up and do something you know get off their arses and get their head in gear', you know –

> Pixie: I'm not just trying to say it's drug users - what I'm trying to explain is the people who had been drug users, I always feel that you know - in a way - they have always got issues and that's why they went down that road. There is no getting away from it they had issues. So part of me wondered just because they have done the treatment and cleared the hep C whether these issues were still there in their heads...Then I got more and more into it and I would ask them how they got hep C or we would discuss that'.

Pixie explained it was only when she realised the post treatment effects were experienced by people who 'got up every day, went to work, came home, didn't have any problems' that she and JB took it seriously. Here the post treatment effects intra-act with participant's life histories, circumstances, wider cultural and societal values and assumptions related to hepatitis C and drug use, to enact them in persistently negative ways. The connection [or conflation, Harris, (2005)] between hepatitis C and injecting drug use intra-act with wider public perceptions of people who use drugs, as weak, unproductive and deceptive (see Lloyd, 2010). Thus post treatment effects are enacted (and dismissed) as an inherent personal fault,

rather than an iatrogenic impairment. Similar observations have been made by Spandler and Calton (2009) in the context of impairment effects caused by mental health 'treatments':

'Patients' complaint about the secondary mental illnesses caused by medical intervention (iatrogenic harm) are frequently interpreted as a facet of their putative 'disorder', arising from a 'lack of insight' or a 'symptom' of the underlying disease' (Spandler and Calton, 2009:247).

Here treatment as *pharmakon* is made visible again. It enacts those who experience post treatment effects as *pharmakos* (scapegoats) for the 'failures' of medicine. The lack of information and support silences post treatment issues and relegates them to the individual domain. Further to this, in the context of hepatitis C, the mode of transmission enacts those who use (or used) drugs as *pharmakos* (scapegoats) amplifying the connection to drug use and silencing the widespread nature of post treatment effects among those who have done treatment. There is a need for wider acknowledgement and responses to the post treatment period, although as Steve stated in relation to support post treatment:

'It sort of stops, it was about four days to a week and I felt like I could run a marathon. Basically I was full of energy but you're left on your own and after that initial spurt, you're left in a bit of a void there. It was' yes you've done it yes you've cleared the virus, and now it's a matter of three months, six months and you're clear'. There is none of this 'in between you might feel a bit down or you might feel a bit up, or in-between you could feel totally depressed between here and there, you have been on a long course of heavy drugs.' It was just... 'you have done it, well done.'

Here, Steve describes the initial euphoria of finishing treatment and then feeling as if he was in a void (see also Hopwood 2009) without any kind of support from the professionals, or any indication of how he might feel, further enacting hepatitis C treatment as a public health measure rather than a personal one. With successful treatment, the long term possibility of

needing a liver transplant or experiencing liver cancer or failure is reduced. However, this focus overlooks and marginalises Steve's current experiences and needs.

This kind of response fails to recognise the impact of the treatment on the person, their social network and their wider life circumstances. Steve stated he had a support network around him post treatment. Although support networks should have constituted an area of assessment and discussion with the specialist team (see Treloar and Hopwood, 2008 and Rolland, 2008) prior to commencing treatment, the lack of acknowledgement of post treatment effects by services, described above, raises issues about how well prepared support networks are for the post treatment period, and points to the need for information and support for the individual and their wider social network.

Nursing scholar Barbara Paterson *et al.* (2006) suggests this lack of post treatment support is indicative of a bigger issue concerning the structure and delivery of medicine: Three of the participants in Paterson's study indicated that even though they had cleared hepatitis C spontaneously or through treatment, they still felt that they had a chronic illness. Here the ambiguity between health and illness is enacted; there is not a clear division (Race, 2001; Persson *et al.*, 2004; Harris, 2010) between being healthy and being unwell. Paterson *et al.*'s (2006) participants described how they felt they were unable to access support from doctors and specialists, both because they felt that they did not wish to return to the clinic environment (Grinyer, 2009; Hopwood 2009) and also because they no longer had a tangible impairment to 'cure' the restorative power of the medical profession is muted (Persson, 2004) and therefore, medical support is withdrawn. A similar phenomenon was reported by Abel and Subramanian (2008) in their study of women who experienced post treatment effects following breast cancer, and also by their partners (Harrow *et al.*, 2008), which suggests it is perhaps not only about the 'high profile' nature of the disease (cancer), as

posited by participants in chapter six, but wider expectations concerning the dominance and authority of medicine.

Paterson *et al.* (2006) (see also Harris, 2005) describe how this results from the medical model of the body as a machine in need of fixing and the fragmentation of the body into particular areas of specialism. Thus, unless there is monitoring of a liver or mental health condition required, limited support can be offered – especially in the context of limited services. This leads to fragmented care and support which does not take account of the whole person. Although in my view, Paterson *et al.* (2006) go on to undermine their own observations, by indicating there may be some 'need for psycho-social adjustment' to life after hepatitis C. This focus on 'adjustment' implies that it is the individual who needs to adjust rather than the surrounding structures.

Within disability studies, scholars have drawn attention to the medical professionals only being interested in those people they can cure or fix (Oliver, 1990), referring to the vast amounts of money provided to state of the art technological cures (Marks, 1999). Those who cannot be 'fixed' are not the recipients of funding or support. In a 2004 paper, Reeve refers to this as a form of psycho-emotional disablism, enacting those who cannot be cured or effectively treated as being of limited worth.

Similarly, a hierarchy of disease prestige has recently been reported by Album and Westin, (2008; see also Norredam and Album, 2007). The authors reported that higher prestige was afforded to impairments which primarily affected younger people, were centred on vital organs in the upper part of the body and involved technologically innovative intervention. Hepatitis C's conflation with injecting drug use, blood borne nature, impact on the liver, association with an older (and increasingly ageing) population, and until recently, relatively limited technological innovation, potentially explain its lack of prestige.

Interestingly, the increase in the profile of hepatitis C [recent features on hepatitis C treatment have appeared in The Wall Street Journal (Whalen, 2013) and the Financial Times (Knight, 2013)] may be connected with the increase in new treatments (and profits!) maintaining the authority of medicine and its power to cure, further marginalising the need for social care funding and obscuring the differences in funding provided to social care compared with the NHS (Roulstone 2012).

Post treatment support models

In addressing their post treatment needs, participants indicated that they required written digestible information and advice on addressing the after effects both physically and mentally, along with support and validation from professionals that this was part of the treatment experience:

> Laurie: 'Explanations on how long it would take to get the chemo out of the system advice on cleansing the chemo, explanations and help on the symptoms of post-TX (treatment). Lots of people finish and go straight back on the bottle or drugs, swapping one chemical (chemo) for another addiction It happens - frequently. Happened to my brother big time'.

Here Laurie raises concerns regarding a return to drug use following treatment after he witnessed this happen to his brother. Similar concerns have been raised by Harris, (2009b) - discussed in chapter seven - suggesting that support post treatment also needs to incorporate drug service professionals.

The treatment as *pharmakon* is again made visible when Laurie and Morgan highlighted the need for advice on *clearing the treatment* from their bodies. Laurie's request for information on *'cleansing the chemo'* acknowledges the medication effects may feel worse than hepatitis C itself(Jenner and Scott, 2008). Morgan described needing to know how long this would

take, as well as advice and information concerning the itching and rashes she felt were caused by the seeping of toxins through her skin.

Here the messy and unbounded natures of participant bodies, and of the treatment, are made visible. This links with Hughes's (2012) work, which draws attention to the dominant understanding of disabled bodies (and bodies with hepatitis C) as unruly and unpredictable - the opposite of the ideal (but illusory) clean, contained (hepatitis C negative) body (see Shildrick, 1997; Shildrick and Price 1999). The extent of this illusion is made visible in that in attempting to achieve bodily cleanliness and closure, bodily leakiness and mess become more apparent.

Other participants referred to the need for post treatment counselling *'[because] after treatment you feel in a way you feel like you should be well and no one understands'* (Morgan). Here, Morgan refers to the tentative nature of the wellness achieved through treatment and the wider cultural expectation that medical treatment encourages wellness rather than further illness. Counselling support would recognise the commitment involved in treatment and looks beyond the treatment as a medical response, to treatment as something which can affect a person's life in a much wider way.

Given the on-going need for support, Hopwood (2013) has suggested that this might be addressed via a post treatment protocol within the liver clinic. Steve suggests that post treatment support could be provided via a GP:

'I think there should be an aftercare, it should come through the GP -not through the hep C nurse, through the GP. They should give you maybe even a weekly check, just to make sure you're alright. They're not psychiatrists, I know that, but just to make sure. They can get to know the person they're treating and make sure there are no subtle changes that they can see. That refer from there. It might be fine, the person might finish treatment and not want to go but there, but there should be the option'.

This clearly this depends on GPs having adequate knowledge of post treatment issues, which further reinforces the need for training and information.

It is important to note here that this thesis has been written in the context of rapidly developing treatments and it is likely that interferon-free treatments will be widely used within the next five years (Jensen, 2011; Rice 2011; Dusheiko and Burney, 2013; Kowdley, 2013; Stedman, 2013), which may ameliorate some of these post treatment effects. Indeed Hopwood (2009:2) states:

> '..*Either* the development of a more efficacious and tolerable treatment is required, *or* significantly more resources need to be allocated toward increasing the range of supports and health care services that are available to people during and after treatment for hepatitis C infection' *(My emphasis)*.

As has been indicated throughout the thesis, the availability of new drugs should not be used to obscure the needs of those with hepatitis C. There is a need for both newer treatments *and* adequate post treatment support for those who have been or will go through treatments in the future. In the context of severe funding constraints, this might be incorporated into existing hepatitis C services, via the addition of a post treatment service to an existing clinic, the expansion of a specialist social worker role or referral pathways to local blood borne virus organisations.

Models of support post treatment: inspiration and starting points

In developing post treatment support, Hopwood (2009) indicates that cancer survivorship programmes may provide a good model. The next section of this chapter will explore the features of such models which could be applied to the hepatitis C treatment experience.

Attention to cancer survivorship has increased in recent years following criticisms concerning the lack of support after cancer treatment (Macmillan Cancer Support 2012b; Thomas *et al.,*

2001; Abel and Subramanian, 2008). The development of survivorship programmes and initiatives recognises that there are increasing numbers of people surviving cancer, together with the need to develop integrated sustainable care and support in the context of limited resources. Goytia *et al.* (2009) recognise post treatment as a distinct stage in the experience and this was reflected in their development of a cancer survivorship programme in the US. They described a link between the specialist services and the GP (a shared care arrangement), so that a range of services and information could be provided and easily accessible. Although this clearly depends on the relationship with the GP and clear communication between the specialist team and the general practice.

North American literary critic Emily Bartels (2009) traces the history of what she terms a cultural shift in understandings of cancer specifically the rejection of the simplistic division between 'sick' and 'cured' and the development of the concept and movement communicating the experience being openly impaired (and disabled) after cancer. She acknowledges the usefulness of the 'cancer survivor' concept in highlighting the on-going impact of cancer, but indicates that this too has potentially become oppressive, extending the reach and authority of medicine (and pharmaceutical companies), with serious implications for attaining insurance and employment, and creating a long term identity as a person who has had cancer.

Thus, it is not my intention to extend the reach of medicine or pathologise the experiences of post treatment. Insights from disability studies are useful here in highlighting that previous impairments and experiences of disablism, may mean that even when 'cured', a person may still experience disablism (see Beauchamp-Pryor, 2008).

In the UK, the National Cancer Survivorship Initiative, launched in 2010, is developing a support pathway specifically for the post cancer treatment experience. The 'Recovery Package' comprises of a structured holistic needs assessment, and review, provision of a

treatment summary (DH, Macmillan Cancer support and NHS improvement, 2012; 2013), as well as dedicated patient support and information (Health and Wellbeing Clinics) (DH, Macmillan and NHS improvement, 2013). It is based on two key principles of multi-disciplinary working and supporting patients to self-manage (explored below). Of particular value in the context of this discussion is the recognition that 'the nature of cancer treatment means that the subsequent consequences vary significantly between patients in frequency, timing, severity and impact on quality of life – the level and nature of support that patients require will therefore vary' (DH, Macmillan and NHS improvement, 2013:9).

Thus, some important lessons could be gleaned from the existing framework and piloted in relation to hepatitis C, and some brief suggestions are offered as starting points.

An end of treatment discussion and assessment process could be developed with those on treatment (to meet occurring needs there and then for instance, with housing or childcare as Keith and Kerry indicated) a specialist social worker attached to a team could help facilitate. This could be revisited post treatment to accord with participant experiences. This discussion could be multi-disciplinary in nature involving input from the medical team (including information on follow up, and on possible post treatment effects and how these can be managed, together with appropriate pathways for re-accessing support), as well as input from other involved professionals (such as substance use services and mental health where applicable). Importantly, this would include key contact, local service details and referral for social, emotional and financial support, as well as how to re-access the clinic if necessary. This post treatment discussion might also include discussion with family members, information on what to expect, plus attention to any needs that they have, including out of hours support (National Cancer Action Team, 2010; National Cancer Survivorship Initiative, 2013).

Each of these areas has been shown to be an issue for those on hepatitis C treatment. Whilst some of this may already occur in part (i.e. provision of contact details of the specialist nurse), there needs to be an easy way to re-access support in the event this is not provided.

There are also parallels here with Marlize Moulton's (2011) study of social workers who identified the needs of people on hepatitis C treatment, (though social work did actually exist as part of a multidisciplinary team in this study). In the UK, social work could assist with clear information, signposting a referral to emotional and financial support (support groups, peer support initiatives, Citizens Advice Bureaux), as well as providing enabling support during and after treatment.

The role of self-management

Much of the discussion around post treatment in the National Cancer Survival Imitative framework and increasingly, longer term support for people with hepatitis C (see Groessl, 2011) is based on patient self-management. Expert Patient Programmes have been used in the UK since 2002. The programmes are based on the chronic disease self-management programme (CDSMP) developed by Professor of Medicine, Kate Lorig, at Stanford University. Lorig (2002) maintains that the person living with the condition should be regarded as the expert though they may need education and training to fulfil this role .

The CDSMP aims to equip people living with long term conditions with the skills and knowledge to manage it. Lorig (2002:814) goes on to state that the programmes are intended to develop partnerships between patients and doctors (potentially challenging the dominance and authority of medicine):

'Self-management programmes are focused on the problems experienced by patients, and disease-related problem-solving is a key self-management skill; learning to solve one's own problems is very different from having health professionals do it'.

Although this suggests that it is possible to address the challenges of living with a chronic illness alone, and links to responsibilisation.

There was little discussion of Expert Patients Programmes in the context of this research (perhaps connected to the barriers to participation outlined below), other than one participant indicating that he *quite liked the idea* (Keith) as part of a wider discussion of the integration of peer expertise into formal services. Yet, these are increasingly being used to support people with hepatitis C. A recent grant to develop the programme in Bristol states:

'The courses are delivered by two trained facilitators who are also living with hepatitis C and/or another long-term health condition. Run over seven weekly sessions, each lasting three hours – they are designed to improve quality of life, reduce feelings of isolation, depression and stigma. They help deal with pain and fatigue, improve eating habits, understand how the condition can impact on your life, job and your relationships, reduce visits to health care professionals and help people understand how to manage their illness and the effects it has on their day-to-day life' (Expert Patient Programme, 2012).

The press release quotes the Hepatitis C Trust who state: 'Those living most successfully with the virus are those who have reached an accommodation with the virus in terms of treatment, diet and lifestyle but do not let it restrict them from the life they would otherwise choose to live.'

The above extract evokes some of the concerns expressed by Medical Sociologist, Mike Bury, in 2010, who questions why those considered experts in managing their condition would

need to develop skills and training in this area. Furthermore, the focus on individual self-management is firmly rooted in the medical model where individual skills and abilities are invoked in managing problems which are seen to be *solely caused by impairment* rather than attention to the wider context in which the person lives with a chronic illness. Indeed, the last sentence of the above extract refers to the *virus* restricting participants, rather than wider social or structural barriers, such as the low profile of hepatitis C both among public and professionals, poverty, lack of flexibility in employment or lack of formal support services.

Whilst there may be a number of important benefits derived from such a programme, not least meeting others with chronic illness, (which may highlight commonalities in experience) and improving communication and confidence with health professionals (which Zickmund *et al.*, 2006 have noted as an issue for people with hepatitis C), the overall intention is to manage expectations and reduce pressure on resources. Indeed, John Chisholm (2012), chair of the self-care forum, referred to the need to reduce 'dependency' on services, although Bury (2010) and Paterson and Hopwood (2010) note that this may not necessarily be the case and that Expert Patient Programmes may actually increase pressure on services.

In a recent review of self-management programmes, Paterson and Hopwood (2010) indicated that EPPs attract and retain those who are already motivated to self-manage and thus, who may not be as in need of such a programme. There are also additional barriers attracting those from culturally diverse backgrounds or from lower socio economic groups. Vitally the authors found that reasons for leaving or not attending the programmes were closely related to the barriers already identified in this study, including the costs of attending, lack of transportation, practical and family commitments. In short, although EPPs may be considered a pragmatic response to severely reduced resources, rolling out these programmes locally for people with hepatitis C would not necessarily address the needs and

challenges identified by participants in this thesis, indeed it may ingrain them and would further reinforce the individual focus on managing impairment.

The application of the concept of recovery

A pertinent difference highlighted by the widespread nature of post treatment effects is the important differentiation between recovery 'from' and recovery 'in' (Davidson and Roe, 2007). Recovery 'from' is based in a medical framework where a person's impairment, mental health or drug use progressively improves before reaching a clear endpoint. This is the current model of support which hepatitis C treatment is based on. As the chapter - and indeed the thesis - has shown, recovery 'from' has limited relevance. In contrast, recovery 'in' recognises recovery as a process which accumulates meaning within the context of a person's life. It does not necessarily mean being 'cured' (Deegan, 1988), but refers to living well in the community.

Vitally, within the context of this thesis, Deegan (1988) maintains that recovery is not narrowly defined, and does not fit easily with existing frameworks. Recovery is not a linear process but is fluid, contingent and back and forth, accommodating multiple enactments and the contingent nature of the hepatitis C experience. Importantly, Davidson and Roe (2007) acknowledge the two forms of recovery can exist and intermingle. It is possible to recover in some areas but not necessarily others. This would create a space to recognise that although blood tests denote SVR, an individual might still face on-going impairment effects or disabling barriers.

However, this is not to say that issues are not raised which need to be further researched. For example, recovery has been described as a vague and polyvalent concept (Pilgrim, 2008), used differently by different interest groups. It becomes different objects in different practices (Fraser, 2011) and thus, there are criticisms that recovery is becoming increasingly

colonised by services, especially in terms of getting people on Incapacity Benefit (now ESA) back to work (Pilgrim, 2008; Morris-Colton, 2011; Stevenson-Turner and Mayes, 2011).

'Recovery in' developed from the service user/civil rights movements of the 1960s and 1970s and is influenced by the recovery frameworks developed by Alcoholics Anonymous. The connection to the civil rights and independent living movements are particularly important given that these recognise that the barriers faced by those in recovery are not *caused* by impairment[133] but rather structural and social responses to it, and that the right to participation is realised not through improved impairment but by challenging disabling barriers (Davidson, 2008). Furthermore, the central role of peer support in supporting recovery (Corrigan *et al.*, 2005; Davidson *et al.*, 2006; Schon, 2010) has also been emphasised. Here new intra-actions between hepatitis C, recovery, disability studies and drug use (given the government's widely publicised focus on recovery) become visible. Clearly this is an area for further research.

Thus, I suggest that the concept of 'recovery in' might be a useful way of accommodating on-going impairment effects and barriers related to hepatitis C and its treatment – and the on-going need for support. If people on hepatitis C treatment (regardless of drug use) were recognised as being 'in recovery' this would open up a space where they felt entitled to continue accessing support and address the impact on their psycho-emotional wellbeing without pathologising them. Given the current focus on recovery within both mental health and drug services, this might also open up a space for the development of services both within the hospital and within the community. Clearly these possibilities and ideas need to be explored further.

This chapter focused on experiences, support needs and social and cultural position of participants after they had completed the prescribed course of treatment. The next chapter

---

[133] The presence of impairment in mental health at all is disputed by some (see Plumb, 1993, 2011), though as indicated in chapter six, impairment may be intertwined with specific forms of disablism.

builds on those preceding it by exploring the experiences of welfare benefits and employment.

Chapter Nine: 'And you're thinking, am I ill enough?' Working and claiming welfare benefits with hepatitis C

Introduction

This final data chapter explores the experience of living with hepatitis C in relation to welfare benefits and employment. This is a major gap in existing literature and is highly pertinent, given the extensive and on-going welfare reform and the global economic recession. Cuts to welfare benefits and public services - including social care provision - will impact heavily on disabled people (Soldatic *et al.*, 2012). This may further marginalise the experiences and needs of people with hepatitis C, given the need for wider social support outlined in chapter seven. This chapter looks at how political forces, social and cultural beliefs around hepatitis C, disability, welfare benefits and drug use, intra-act and constitute hepatitis C and people with it, and the material consequences. The financial impact of living with hepatitis C and the process of applying and being found eligible for welfare benefits are addressed first, with the second half of the chapter dedicated to participants' discussion of employment.

Context

In the social research literature which is available, living in poverty and lack of access to financial support is entwined with the experience of living with hepatitis C. Among people who use drugs, lack of financial resources can contribute to hepatitis C transmission via the need to share injecting equipment or drugs in the context of relationships (Bourgois *et al.*, 2004) an area of increasing academic interest (Dwyer *et al.*, 2011; Seear *et al.*; 2012, Fraser 2013). Limited finances frequently intra-act with other aspects of living with hepatitis C, which make life more difficult (see Copeland, 2004; Banwell et al., 2005; Ogawa and Bova, 2009; Olsen *et al.*, 2013). In addition, pressures of living in poverty can affect ability to actually address hepatitis C or care (Crockett and Gifford, 2004), given the potential for

increased expenses related to accessing medication and support (Norman *et al.,* 2008). In a US context, accessing hepatitis C treatment has been documented as leading to debt problems (Blasiole *et al.,* 2006). Money has also been highlighted as important in facilitating stable accommodation and the purchase of appliances and equipment to assist with hepatitis C treatment (fridges, bedding, cooking equipment[134]) (Hopwood and Treloar, 2008; Harris *et al.,* 2012a).

As outlined in the literature review, information on financial and employment status is often collected as a context (Balfour *et al.,* 2004; Crockett and Gifford, 2004; McNally, 2004; Banwell *et al.,* 2005; Harris, 2010; Sternhell *et al.,* 2012), but there is little focus on participants' feelings about applying for welfare benefits, their experience of the process and the impact it has on their sense of self. Given the crossover between welfare policies in Australia – where the most extensive body of literature around hepatitis C exists and in the UK (Grover and Soldatic, 2012), this chapter makes an important contribution in an area of research where there has been limited academic engagement to date. The chapter uses social policy and disability studies literature to explore the views of participants around welfare benefits. It covers how hepatitis C was enacted in interactions with DWP staff and on welfare benefit applications, along with participants' and workers' knowledge and understanding of hepatitis C and benefit entitlement. In addition, it explores how increasingly restrictive criteria constitutes people with hepatitis C as being outside the boundaries of support.

The enactments and arguments within this chapter are necessarily situated and partial. They are made possible and visible in what Barad (1998) terms a 'cut' - a temporary halt of the

---

[134] However, it may be difficult to access such support given Community Care Grant provision ceased on the 1st April 2013, Crisis Loans have been dissolved (with alternatives for both provided by Local Authorities, suggesting that they will be provided to varying degrees) and Budgeting Loans depending on duration of income related benefit claim (Gov.uk, 2013).

process of enactment and re-enactment, which makes it possible to look at things more closely.

At the time of generating data, Employment and Support Allowance (ESA) had recently been introduced. As the thesis has taken shape and been written, major reforms to welfare benefits (and services) have been announced by the coalition government; notably, for the purposes of this chapter, to Disability Living Allowance (DLA) (the introduction of Personal Independence Payment – PIP), Housing Benefit and the limiting of contributory ESA for those in the WRAG[135] to 12 months. In addition, newer treatments for hepatitis C are being trialled or have been approved (Hopwood *et al.,* 2010; Rice, 2011; Jensen, 2011, Stedman, 2013), so enactments of hepatitis C, its treatment and people living with it, will alter in the coming years.

Following the exploration of welfare benefits, I discuss the impact of hepatitis C treatments on participants' bodies and working lives. To date, much of the literature has focused on how hepatitis C has affected participants' ability to work. Accounts of obtaining adjustments in the workplace are scarce and little reference is made to the coverage of people with hepatitis C under anti-discrimination legislation. This thesis thus makes a vital contribution here.

Interviews with participants were conducted between late 2009 and early 2011. In May 2010, a general election took place and a coalition government (Conservative and Liberal Democrat) came to power. It announced that given the UK deficit and global economic crisis, there was a need to drastically cut spending and services, and during the period of writing this thesis huge reforms to the NHS, reduction in welfare spending and cuts to services as well as mainstream public services (Williams-Findlay, 2011) have occurred. The government maintain that they intend to reduce the economic deficit whilst protecting those who need it

---

[135] Work Related Activity Group .

(HM Government, 2010.) In reality, as discussed below, the result appears to be the opposite. Williams Findlay (2011), writing on behalf of the campaign group Disabled People Against Cuts (DPAC), indicates that the cuts will increase the disablement of those who receive services. He maintains that the cuts are ideological, rather than concerned with addressing the deficit and will further oppress disabled people (among others), hindering their abilities to expose disabling structures and barriers.

Welfare benefits in the UK past and present

The next section of the chapter briefly explores some aspects of welfare provision in the UK, beginning with the 1601 Poor Law and tracing to the present day. This is because some have argued (see Grover and Piggott 2012; Patrick, 2012; Garthwaite *et al.,* 2013) that current enactments of welfare provision represent a return to the division between 'deserving' and 'undeserving' poor. In tracing these enacted divisions between deserving and undeserving, the contingent and shifting nature of disability and disablism is exposed. it does not pre-exist, but is brought into being though specific practices, depending on time, place, social and cultural beliefs.

The Poor Law: enacting and materialising the 'deserving' and 'undeserving' poor

The Poor Law of 1601 required local parishes to bring up orphaned children, provide work for the 'able bodied' poor and support the 'aged' and 'impotent' (Borsay, 2005). The elected 'overseers of the poor' in local parishes were charged with putting the 'able-bodied' poor to work (the 'undeserving poor'), and punishing them if they did not comply, whilst providing outdoor relief[136] to the 'deserving poor' (those deemed unable to work). Borsay (2005)

---

[136] Money, sustenance and clothing without the requirement to enter a workhouse (referred to as indoor relief).

indicates that a postcode lottery existed in terms of support and enforcement, which was further impacted by the lack of definition as to what constituted 'deserving'.

The Poor Law Amendment Act of 1834 was built on concerns that the provision of relief would deter families from taking responsibility for their relatives and thus, reduced support to such a degree to ensure it would be sought as an absolute last resort. It introduced the principle of 'less eligibility' (that those receiving support should receive less than the worker earning the least) and ensured that the only form of support available for 'able bodied' poor was in the workhouse. Borsay (2005) maintains that these reforms were based on the imagined abuses of the system (always a small minority). Further to this, concerns about increasing expenditure on outdoor relief led to a stringent 'workhouse test' (creating a place for medical assessment, discussed below) applied to everyone, which determined which people should be eligible for outdoor relief.

Grover and Piggott (2012), and Garthwaite *et al.* (2013) maintain that similar principles are visible in *current* government rhetoric and policy, the stance that no one will be better off on benefits than working, increasingly stringent tests (the WCA and PIP criteria) and high profile claims concerning fraudulent benefit claimants (Campbell *et al.,* 2012). It is important to note that being determined to be 'deserving' of support under the Poor Law did not entitle the recipient to a comfortable life. It was intended as a deterrent to others to prevent further claims. Similarly, those in receipt of current benefits are by no means comfortable. Borsay (2012) and Patrick (2012) indicate that claiming benefits today continues to carry with it a set of assumptions that even as a 'deserving' claimant, a person is a 'lesser' citizen.

Yet, it is important to note that disabled people have not always been positioned as 'undeserving' (Bambra and Smith, 2010). Indeed, Van Oorshot (2006), in his study of the Swedish public found that disabled people closely followed elderly people in being perceived as deserving of state support. Until the 1970s disabled people were provided with means

tested assistance in the same way as other non-disabled people who were unable to work. However, in the 1970s, disabled people were distinguished from other claimants upon the introduction of Invalidity Benefit (IVB). This was replaced by Incapacity Benefit (IB) in the mid-1990s and eventually by ESA in 2008 (Grover and Soldatic, 2012).

Where being on sickness benefit was previously viewed by the Thatcherite government as preferable to claiming unemployment benefit (Garthwaite et al., 2013) [and used by government to obscure high unemployment levels (Foster, 2007)], at present the opposite is true (Garthwaite et al., 2013). Unemployment is enacted by the government as preferable to receipt of IB/ESA (see also Bambra and Smith, 2010), and policies and claimants are infused with conditionality - with the receipt of benefits based on fulfilment of specific obligations and responsibilities. This has its roots in Workfare, developed by the Regan administration in the US and furthered by Clinton in the 1990s (see Soldatic and Chapman, 2010).   Now, instead of seeing disabled people as deserving of state support, claimants are further divided into those who are disabled but able to work ('just disabled') and those who cannot (the 'really' disabled) (see also Grover and Piggott, 2010). Implicit within these processes and divisions is the assertion that those claiming incapacity benefits 'are able to be somewhere else' (Garthwaite *et al,*.2013;2).

These perceptions are augmented by media and wider societal discourses around benefit claimants 'scrounging' (Garthwaite, 2011) from the state indeed, the official Conservative Party website outlines their principles and refers to people 'languishing on the dole' (Conservative Party, Undated) and George Osborne, in an interview with BBC Radio 4's *Today* programme, ahead of the Conservative conference in 2012, invoked the image of a neighbour on benefits having their blinds drawn as others go out to work (see Sparrow and Owen, 2012), implying that recipients are lazy (see also Kingfisher, 1998). De Wolfe (2012) challenges the perception that benefits amount to taking the 'easy option', maintaining this

obscures the constant stress, anxiety and pressure that people who need to be on benefits experience, as well as structural barriers to employment. As will be discussed below, there is evidence that the language used in relation to benefit claimants (Garthwaite, 2011), and the negative perceptions, had been absorbed by participants.

An introduction to Employment and Support Allowance

Employment and Support Allowance (ESA) was introduced by the Brown Labour government in October 2008 (the same time as I began my PhD and made tentative contact with potential participants). ESA is an 'income replacement benefit' (Burchardt, 1999) as it supposed to provide financial support for those people deemed incapable of working. The intention of ESA was to move claimants off Income Support and Incapacity Benefit, which was perceived as 'too easy' to get on and stay on (Grover and Piggott, 2010), and attach work related conditions to receipt of benefits (DWP, 2008). In 2010, the Coalition government announced their plans to move forward with ESA and to move all IB claimants onto ESA by 2014 (Patrick, 2011). The introduction of ESA in October 2008 has been described as a major change in how individuals experience claiming (Houston and Lindsay, 2010). In order to be eligible for ESA, claimants need to be sick and/or impaired to the degree that it affects their ability to work for two or more out of seven consecutive days (Department for Work and Pensions 2010). On application for ESA, claimants undergo a 13 week assessment period (paid at same rate as JSA), which comprises of three mandatory stages: a work focused interview (WFI), a work focused health related assessment (WFHRA), and a work capability assessment (WCA). The WCA is intended to focus on individual capabilities and will be discussed in greater depth below. Based on this information, claimants are then assigned to either a Work Related Activity Group (WRAG) or a Support Group (SG) (DWP, 2008; Grover and Piggott, 2010). Those assigned to the WRAG are expected to participate in further work focused interviews and in the development of a

personalised plan of employability activities. Recipients are expected to participate in work related conditions and activities or risk losing their benefits (Patrick, 2011). In return they are provided with tailored 'support' to return to the workplace, though Patrick (2011) questions the suitability of this. Those people who are allocated to the SG have been assessed as being too impaired to work. ESA is soon to be replaced with the single benefit Universal Credit which is intended to simplify the benefits system (Department for Work and Pensions 2011).

According to Houston and Lindsay (2010), this major reform is premised on some key (false) assertions; first, that there has been a decline in work ethic, so that people must be forced through mandatory measures in order to gain employment. Second, that most people currently on incapacity benefits are not sick or disabled 'enough', so a medical test that toughened the eligibility criteria was deemed necessary and introduced. Third, that it is the demand side, rather than the supply side, causing major issues within the labour market. It is individuals who do not want to work, rather than the work not being available.

The organisation of work

ESA has been criticised for its individualist focus on the person claiming and Patrick (2011; 2012) maintains that the model the government works from in developing policy and reform is rooted in an individual model of disability. She maintains that sanctions are problematic, given that the barriers to participation in employment are primarily structural, but rarely mentioned (cf. Soldatic and Chapman, 2010). Patrick's (2011) participants also described a strong sense of motivation to work and although some indicated their current impairment effects prevented participation in the workplace, they emphasised that focusing on increasing claimants' employability was misguided, given the issues that face disabled people (including people with hepatitis C) concerning the structure of work, negative and discriminatory treatment and issues around access (Roulstone and Barnes, 2005; Patrick, 2011).

Key to this (but under addressed in current policy reforms) is the configuration of work. Barnes (2003a; 2003b) maintains that disabled people are disadvantaged as a result of the value-base on which employment is built - including expectations of speed, productivity and regular contributions - and notes that during the period of the Second World War when employment was to some degree, built on reciprocity, there was more of a place for (some) disabled people (see also Borsay, 2005). As disabled artist Sunny Taylor (2004) indicates in her discussion of *not working,* it is important to recognise the inherent value of disabled people (see also deWolfe, 2012) and not to measure them by their financial contribution. Taylor (2004) maintains that current government responses place the value of citizens on their employment and represent it as the path to financial freedom, despite the available employment often being low paid, part time and insecure. There is also currently a limited understanding on behalf of the government about what exactly constitutes 'work'. A recent consultation undertaken by Disability Activist Sue Marsh (2012) on her Diary of a Benefit Scrounger blog, indicated that there was a need for a much more flexible definition and forms of work, including increasing working from home, a work bank for those who are able to work at unpredictable times and support to develop micro businesses for those whose hobbies have become more (see Marsh 2012 for full details). Patrick's (2011) participants described fulfilment through unpaid work, such as volunteering and childcare, which links to a wider discussion by Barnes (2003b) that for some disabled people work is constituted in personal care, shopping or indeed explaining their experiences to others (cf. Keith in chapter six).

In the context of this study, participants who were not working described providing support and information to others via support groups, telephone, or online support. Thus, people with hepatitis C and (other) disabled people make contributions for which they do not receive wages, but which are still highly valuable. Indeed, awareness raising activities and the development, and maintenance, of support groups were self-funded by participants and

were described as key to getting people though treatment, or to accessing testing – thereby saving vast amounts for the government and public services.

Introduction to Disability Living Allowance and Personal Independence Payment

Disability Living Allowance (DLA) is an 'extra costs benefit' (Burchardt, 1999) intended to help disabled people meet the additional costs that often comes with impairment and disability. The benefit is not affected by employment status and has been recognised as highly valuable in enabling disabled claimants to stay in employment (Thomas and Griffiths, 2010). In spite of this, the government have repeatedly represented it as an out of work benefit and, indeed, as an impediment to work (Campbell *et al.,* 2012; see DWP, 2012).

The coalition cited huge increases in claimants as need for reform, claiming there has been a 30% rise in DLA claimants, even though the figure is actually 13% (Campbell *et al.,* 2012). The statistics used included those under 16 and over 65, who will not be affected by changes brought about by PIP. Further to this, under claiming is recognised as being greater than over claiming (Macmillan, 2004; Campbell *et al.,* 2012), which is related to limited knowledge concerning entitlements and a dearth of advice and support from formal services. In 2010, the government announced plans to replace DLA with PIP and cut spending by 20%. This means some existing claimants will go from being defined as disabled to non-disabled overnight (Soldatic *et al.,* 2012), having experienced no change in the level of impairment or experience of disablism. The very system meant to enable people who are impaired is further disabling them (Malacrida 2010).

The effect of the increasingly stringent criteria for ESA (and PIP) is that the category of disability is redefined, forcing some groups into a 'netherworld...not knowing whether they have classified as genuinely disabled, being encouraged to go for jobs but in the absence of jobs they have this strange paradoxical situation of not fitting into normal or disabled

categories' (Roulstone, 2011). This redrawn boundary (as explored below) and subsequent liminality, is likely to disproportionately affect those with fluctuating or hidden impairments (Bambra and Smith 2010).

Although the coalition government maintain they are committed to supporting disabled people to 'lead independent lives and exercise choice and control' with the introduction of PIP (Department of Work and Pensions, 2011:2), Campbell *et al.* (2012) maintain the opposite is true. Consultation respondents felt that the withdrawal of support would significantly disable claimants further, including being unable to meet costs for care, support and even food and fuel impeding access to social life. Further, many were concerned about the removal of Motability[137] vehicles upon reassessment and the impact on access to employment (Young *et al.*, 2013)[138].

Personal Independence Payment will still be a cash benefit available for the same age group of applicants (aged 16-64) and payable to those both in and out of work, and the government emphasises that it will provide a much simplified process[139]. Specific reference is made to the social rather than the individual model of disability in establishing eligibility for the benefit and ensuring disabled people's independence, though this appears to be superficial and insincere. First the depth of understanding of social model principles is doubtful, given that the press release refers to the 'individual disability' (rather than impairment). Second, the proposed system of descriptors which focus on level of functional ability 'end up being a proxy for the level of impairment rather than a meaningful measure of barriers to participation or an indication of how assistance in the form of PIP could facilitate greater independence and inclusion' (NAT, 2011: 3). Critics maintain that the language of

---

[137] The Motability Scheme enables disabled people to use the mobility component of DLA to lease a new car, scooter or electric wheelchair (Motability, 2013a).
[138] As this thesis was being proofed, Motability announced a package of transitional support (see Motability 2013b) to combat some of the difficulties for those who may no longer be eligible for the Motability scheme after reassessment for PIP.
[139] The current system has been criticised for being arduous and complex, see Banks and Lawrence (2005), Shildrick and Price (1999) and Reeve (2002) – revisited below.

'independence' has been co-opted to fit with government priorities (Morris, 2011; Patrick, 2012).

PIP criteria are even more stringent which means it will be more difficult to qualify and for those that do, the level of financial support will be much lower (Soldatic *et al*, 2012). This is exacerbated by an increased timescale for eligibility. In order to be found eligible for DLA, participants must have been disabled for the last three months and be likely to be disabled for the next six months. Recent guidance notes on PIP (DWP, 2011) state that the retrospective eligibly test will mean that a person's impairment must be expected to last a minimum of 12 months, before they are eligible for PIP, moving even further away from the provision of support at the point of diagnosis enshrined in the DDA and the EQA (Campbell *et al.*, 2012).

The reform of the eligibility criteria was almost unanimously opposed in the government's consultation (Campbell *et al.*, 2012). While those who responded to the consultation for PIP supported the proposition that DLA should be reformed, they felt this should happen to the *existing benefit*. Campbell *et al.*,(2012) point to the costs of development and implementation of the new benefit when the money might be more appropriately spent on improving support. The shifting from three rates of eligibility to two will mean some people no longer receive any support. One consequence of this will be the additional pressure placed on Social Services, given that components are currently used to self-fund for some aspects of care, and receipt of even a low level of benefit can be beneficial in promoting health and preventing crises (Campbell *et al.*, 2012).

The experience of financial support

Initially, the experience of accessing welfare benefits was not included as a topic for exploration on the interview schedule, but rather, it was raised by participants during the course of the interview [thus giving strength to the finding as this area was not directly enquired into, but was enacted in discussions between myself and the participants (Conrad et al., 2006)]. JB described benefits as a *'hellish road'* and Ken described the need for support particularly on treatment:

> *'I'll tell you what does need addressing big time, that's the Department of Health and Social Security, whatever they're called now…You should get extra support… they will not recognise DLA for that and that's wrong because you're incapacitated, you can't do very much for yourself you have to have help to get your shopping done - just about everything really – you need support and that includes financial and they (DWP) won't recognise it.'*

Given that realities are multiple, it was necessary to make political decisions to bring specific ones into being, paying particular attention to those which are 'othered' both in Law's (2004) sense of being unthought and in the sense of being defined as different and marginalised (Johnson, 2004) .

The need for welfare benefits when living with hepatitis C, or on hepatitis C treatment, is mostly absent from wider discussion in the existing literature. In addition, the rapid development of new treatments and the forward-looking rhetoric of treatment discussions (both in print and online, see for example Chung, 2012; Lok et al, 2012; Swan 2013) means there is the potential for the financial and employment impact of current treatments to be obscured, or side-lined, as no longer important in the face of increasingly effective treatment.

This data does not attempt to generalise the findings to the population in the UK, or even in England, living with hepatitis C this would be particularly difficult given the widely

documented 'postcode lottery' in services (All Party Parliamentary Group on Hepatology 2008) however, there is evidence to suggest that welfare benefits and financial support are important issues for those living with hepatitis C. The January 2013 newsletter from the Hepatitis C Trust reported a vast increase in calls made to their helpline concerning welfare benefits (Hepatitis C Trust, 2013a) and recent reports, both from Harris *et al.,* (2012a) and NAT (2012), also point to the vital role of financial support.

Why do people with hepatitis C need financial support?

Participants frequently made reference to the additional costs associated with living with and being treated for hepatitis C. Ken described the importance of diet and fresh fruit and vegetables. Loveday and Dore (2009) indicate that diet is an area of self-management that can improve health for those living with hepatitis C. Crockett and Gifford (2004), in their interviews with women living with hepatitis C, also found that in spite of knowing that a healthy diet was important, participants were unable to afford it and relied on cheaper fast food. In their recent response to the PIP consultation, The National AIDS Trust (2011) also emphasised the importance of diet and drew attention to, the increased costs of fresh fruit and vegetables, stating this was not fully recognised in the PIP guidance[140]. Participants also described the additional costs of alternative therapies. Morgan described using her savings to fund support for the treatment and to manage the side effects, and felt that alternative therapies should be more freely available. Some participants did describe accessing some of these therapies from a multidisciplinary service which maintained strong links between the hepatitis C treatment team. Scottish services 'C-Plus' (C-Plus, undated) and 'C Level' (now Waverley Care, 2013) offer complimentary therapies and healthy eating programmes, although this was not available across the UK, as Morgan describes:

---

[140] In addition the emphasis on food preparation, or the ability to plan a meal, overlooked the difficulties associated with physically shopping for a meal. The emphasis on being able to prepare a small meal by any means also means that if claimants could prepare a 'ready meal' (which would be more expensive and less healthy) then this would mean they would score less points (NAT, 2011).

'I mean I'd been using my savings and all in all it's been quite an expensive business because I've chosen to have healing and I've chosen to have massage and I choose to eat really well but they are all the things you should do to support the treatment.'

Additionally, Freda makes specific reference to raised fuel costs whilst on treatment (her lack of knowledge around what she could claim is also returned to below):

'I don't know about benefits and I would love to know although I am working if I can get anything for extra heating as I am so cold'.

Costs associated with heating and diet are consistently named as the main ones DLA recipients spend their benefits on (Berthoud 1998). Recent research by the Papworth Trust (2011) found that survey participants felt food and bills would be areas most affected if they were not found eligible for PIP or had their payments reduced. Similarly a few participants made reference to severe fatigue and difficulties with public transport, travel to hospital appointments and hospital parking which incurred additional costs and were a source of stress.

Participants frequently referred to DLA and ESA. At the time of interview, two participants reported receiving Job Seekers Allowance (JSA), one as a result of being found fit for work after applying for ESA and the other as he felt he did not require ESA. Two received Incapacity Benefit (IB), two reported receiving ESA and being placed in the WRAG. Eight participants were employed and six participants reported applying for Disability Living Allowance. Two other participants were already in receipt of DLA, related to other impairments. Three participants described being found eligible for it on appeal, one participant ceased their appeal and two were too ill to pursue it. One participant with HIV reported choosing not to claim DLA. Finances were not discussed extensively with five participants, though two of these indicated a lack of knowledge concerning what they might be entitled to.

Meeting the eligibility criteria

A significant problem for participants was that hepatitis C did not appear to fit the criteria for ESA and, particularly, DLA. The ambiguous, contingent and difficult nature of hepatitis C as a chronic illness, is at odds with the processes required for gaining support or welfare benefits. Participants often experienced their impairment as variable. Boab stated it 'depends *on which day of the week you get me on*' and Grace stated that treatment effects 'come *and go.*' Others described having *'good days and bad days'* (JB) which were exacerbated on treatment, or not being able to tell what was an effect of hepatitis C treatment, or existing impairment or age. Here, hepatitis C is bound up with other aspects of their lives and experiences.

There is evidence in social research literature to suggest that people with other chronic illnesses experience difficulties claiming benefits. Cathie Hammond's (2002) research into DLA claims for people with ME, found that there were particular types of impairments which were awarded less often, including blood disorders. Though this data is some years old, the impairments shared a number of common characteristics which are particularly relevant for people living with hepatitis C. Benefits were less likely to be awarded if impairment effects were difficult to articulate under the categories on the DLA form, fluctuated or varied widely from person to person. For people with hepatitis C, this fluidity and contingency was difficult to articulate to others[141] and was exacerbated by brain fog and cognitive impairment.

In a Canadian context, Lightman *et al.'s* (2009) research with people with 'episodic disabilities' who had been refused welfare assistance, found that the fixed vocabulary of the process invalidated participants' claims to financial support (see also Shildrick, 1997) and led to feelings of illegitimacy. Echoing Hammond (2002) Lightman *et al.,* (2009) point to the

---

[141] McFarland *et al.*, (2009) have indicated that metaphors help to bring into being that which is difficult to express, hence the cancer and chemotherapy metaphors.

need to acknowledge the fluid nature of benefits and disablement, that individuals may move back and forward between being more or less impaired, disabled and able to work (consistent with being 'in recovery'). Interestingly, one of Lightman *et al.'s* (2009) participants lived with hepatitis C and described how the hidden nature of her illness meant she was frequently not recognised as a disabled person. She too made specific reference to the lack of understanding of social services and the difficulty in accessing support.

Yet, this lack of fit between experience and process has an express political purpose the 'othering' of that which is difficult, intangible, or which does not easily fit (Law, 2004), enacts people with fluctuating illness/impairment as non-disabled, ultimately resulting in a reduced number of people on benefits.

The restrictive and disabling assessment process

For others, the process of assessment did not fit with their experience:

> Daniel: 'Well it was all physical it was touch your toes – do your lace up, do this and do
>
> that and it was stuff that didn't relate to my illness, can you make a meal for yourself,
>
> can you take a shower, can you walk to the shop, can you use the telephone I was
>
> going 'yes, yes, yes, yes'. So all 'okay you're fit for work' it was nothing that related to
>
> the hep C treatment or the drugs I was on.'

Though guidance states clearly that the assessment is not dependent on condition, but how it affects the person (DWP, 2013). Daniel explains how the WCA enacted a reality where his experiences of the effects of treatment were not taken account of. Given that Daniel is referring to the WCA here, it is important to note that concerns have repeatedly been raised about it. NAT (2010) in their review of the WCA (for people with HIV, but which is also applicable to people with hepatitis C) state that the assessment does not account for some of the major impairment effects including fatigue, fluctuating symptoms, treatment side

effects, pain and mental health issues. The Citizen's Advice Bureau (2010) question whether the WCA is fit for purpose given that seriously ill people are called for assessment, no account is taken of the barriers or discrimination that people face in looking for work and there are concerns about the number of people being found fit for work, who then go on to successfully appeal the decision. The Harrington (2010; 2012) reviews of the WCA acknowledge these concerns and note that some health conditions are more 'subjective and evidently more difficult to assess' (Harrington, 2010: 6) and that some of the descriptors may not fully capture the complexities of health conditions in establishing fitness for employment. At the most recent review, progress with addressing these descriptors is on-going (Harrington, 2012). Patrick (2012) notes that in spite of these reviews, the government have not paused to implement any recommendations and further to this, that real change may not be seen for three years (Campbell *et al.,* 2012). The result is that relationships between claimants, staff and the government are fragmented and characterised by mistrust (Patrick, 2012).

As explored above, eligibility criteria for ESA and DLA are becoming increasingly restrictive. Houston and Lindsay (2010) state that the eligibility criteria has been set increasingly high and one of the major concerns regarding the welfare reform is that the bar for entitlement is now set impossibly high (The Broken of Britain 2011). The move to a face to face assessment for PIP suggests that these problems outlined in relation to the WCA, will persist in relation to PIP. The assessment criteria for PIP does little to suggest that the government are aiming to move away from the culture of *'box ticking',* which Daniel experienced during his assessment given that it contains a range of very specific and rigid descriptors, with highest scores attributed to those with the 'greatest need'. In reality, this equates to those with the most visible, clearly understood impairment effects. There is little to suggest any shift in the way disability is understood - as called for by Roulstone nearly ten years ago (2004). NAT (2011) draw attention to the lack of open questions within the assessment criteria which

does not give people the opportunity to define their own needs, but forces them to be defined by others (i.e. the ATOS[142] assessor). Daniel recounted his frustration at the irrelevance of the assessment to his experience of treatment, echoed by the evidence of a second year review of the WCA put forward by the UKDPC (2011). Daniel was subsequently found fit for work[143] and moved onto Job Seekers Allowance (JSA).

Others referred to not fitting into the 'disability category':

Morgan: 'I think it's too rigid. I think if you don't fit into their boxes and there isn't a box for you to tick, then there's no space for your own individual process. I don't think it's a particularly fair system, because I know people who are far healthier than I am who are on DLA'.

Morgan's observation regarding 'fitting into a box' is particularly interesting in light of Stone's (1986) work, which situates disability as an administrative category determined by the government, which affords particular privileges to those deemed disabled. However, it also has a severe impact on those who do not meet the category, simultaneously outlining what impairments and barriers individuals will be expected to live with unsupported. Stone (1986) maintains that the boundary is enacted in combination with the political and economic climate. In periods of high unemployment there is a restriction on benefit eligibility and the boundaries are drawn tighter to include less people, to create a reserve army of labour (Grover and Piggott, 2005; Grover and Soldatic, 2012).

---

[142] At the time of writing ATOS was the private company commissioned by the government to undertake independent medical assessments on behalf of the Department for Work and Pensions. They have since ceased to provide them. These assessments determine eligibility for welfare benefits in particular Employment and Support Allowance, Disability Living Allowance (ATOS Healthcare, 2011) and PIP in some parts of the UK.
[143] Another parallel with cancer is that people on chemotherapy are also being found fit for work, thus facing similar problems (Soldatic et al., 2012). Although the third WCA review notes that support and provision for people with cancer is improving (Harrington, 2012).

Multiple hepatitis Cs

It is important to note that the enactment of hepatitis C treatment in the WCA as not having an extensive effect on the body or ability to work is very different from the one enacted by the hospital staff who advised Daniel to use two forms of contraception during treatment and for six months after, due to the possibility of teratogenic effects in pregnancy. This enacted treatment as serious with long term effects.[144] These two enactments overlap for the person on treatment, but are kept separate or rationalised (Law, 2004) by the professionals involved (i.e. the DWP and the Specialist Nurse), meaning that both realities are maintained[145].

Other participants found that they occupied a similarly liminal and contradictory position, where they were enacted as *too impaired* to undergo routine surgery but *not disabled enough* to be awarded DLA without an appeal. Participants suggested this was likely to be connected to concerns regarding infection, despite existing policy on the use of universal precautions. In being denied surgery until treatment was over, participants experienced exacerbated impairment effects, as well as increased psycho-emotional oppression, as David described in chapter seven.

Psycho-emotional disablism and feeling entitled to benefits

As well as the obvious financial implications of not fitting into the disability category, not being found eligible for welfare benefits impacted on the way participants felt about themselves. Indeed, Bambra and Smith (2010:8) indicate that being 'sick but able to work' is

---

[144] The same advice is given both to women and men. This also raises a wider issue concerning advice against the creation of a potentially disabled foetus but a fuller exploration of this issue is beyond the scope of the thesis.

[145] The enforcing of the separation between these realities is also visible in the recent advice to GPs not to provide written support with welfare benefit applications unless requested by the DWP (see Bro Taf, 2013; Birmingham Local Medical Committee 2013).

a particularly stigmatised status. Others have made reference to the negative perceptions associated with claiming benefits more generally [see Green and Shuttleworth, (2010) and Moffatt *et al.*, (2010)]. Both are visible in Steve's extract:

> '*So on that side of things when someone says they can't go to work they really can't go to work and you find a lot of people that are on treatment that are ashamed of not being able to support themselves when they are so they don't need the stigma and the disbelief from the social security'.*

Here, Steve refers to people made to feel dishonest by claiming, or that they have morally failed. Interestingly, Steve (who was not working at the time) does not indicate that *he* feels ashamed, but rather than *others* do. Here, he is possibly participating in the interview for a political reason, raising awareness of the experiences of others beyond himself and resisting oppression by distancing himself from negative perceptions of benefit claimants. Beatty *et al,.* (2010) found that participants were embarrassed about claiming benefits. Grover and Piggott (2007) also make reference to the perception that the majority of claimants who are impaired are somehow playing the system (cf. Malacrida, 2010) (returned to below).

These moral undercurrents are visible in this information contained on the website of The Hepatitis C Trust. While the trust have a part time benefits advisor and provide information concerning specific benefits on a section of the website (see The Hepatitis C Trust, 2011b), the generic nature of this means that there is little indication of how this might apply to people with hepatitis C. Whilst this may be connected to the individual and variable nature of the virus, it contributes to the enactment of a reality where people with hepatitis C should not be claiming benefits. On the page providing information on welfare benefits they state:

> 'While access to financial assistance via the benefits system *may be essential at times,* it is worth considering that *becoming dependent* on benefits can, in some cases, not work to your overall advantage. Naturally if your ability to work is severely hampered

by your health then there may be *little choice about whether to apply*. However, *becoming dependent* on benefits can be part of a *vicious cycle of dependency*. For some people this can lead to lowered self-esteem or feelings of lowered self-efficacy. In these instances it may be wise to consider whether *depending on* benefits is in your best interests overall...If you are diagnosed with hepatitis C this does not automatically give you entitlement to benefits from the Benefits Agency. However, if your condition affects your ability to carry out day-to-day activities, continue to work or the condition is having a significant impact of your physical or mental health *then you may be eligible* for certain disability benefits.' (The Hepatitis C Trust, 2011b - *my emphasis*).

Here, the assertions that benefit claiming may be essential for those living with hepatitis C is undermined with rhetoric around welfare 'dependency' - a term which is overwhelmingly present in this short paragraph. Benefits are enacted as a trap. Rather than facilitating participation, preventing crises and reducing the impact on formal services (Corden *et al.*, 2010) or promoting health through providing support to do treatment[146]. The act of claiming benefits is enacted as something which should be avoided or accessed only as a last resort. References to lowered self-esteem and self-efficacy imply that benefits are damaging to the rational autonomous human being, who is ideally earning a wage and thus independent (Stone, 1986; Fraser and Gordon, 1994).

Following on from the exploration of metaphor in chapter six, and the way in which words used actually help to constitute hepatitis C and people with it in specific ways, Fraser and Gordon (1994) indicate the same is true for use of the word 'dependency'. They state that it is an ideological term which reinforces the focus on the individual, without focusing on the structural or economic aspects which both create the need for financial support and maintain it.

---

[146] Which, given the content of the website, the regular updating and explanation of available treatments would appear to be (rightfully) highly important.

It could be argued that the use of the word 'dependence' by the Hepatitis C Trust has some echoes of drug dependency, although this is not made explicit. Fraser and Gordon (1994) indicate that perceptions and understandings of welfare dependency are built on and intertwined[147] with beliefs about drug dependency. Those receiving welfare support are assumed to be drug users, which enhances negative perceptions. Indeed, they indicate that dependence is perceived in solely negative terms – as an encumbrance or a drain. There are similarities here in discussions of dependency in the disability studies literature - dependence is often understood negatively to be synonymous with 'burden', but this ignores that everyone is (inter)dependent on others to some degree, in provision and receipt of support or services (see Thomas, 2007). Further to this, the 'dependency' of pharmaceutical companies, medical staff, substance use workers, DWP staff, policy makers and researchers on people with hepatitis C is rarely discussed.

Indeed, many of the participants described requiring financial support for a short time whilst on treatment, in order to save NHS funds in the longer term. Bambra (2008) indicates that the shift to ESA does not acknowledge that participants claiming it are actually sick and disabled, and may be in recovery. She indicates that addressing health should be prioritised over return to work. Vick and Lightman (2010) similarly maintain that in regard to welfare benefits, the demand for productive bodies is prioritised over the reality of participants' changing and unpredictable bodies. This marginalisation of what participants actually need, together with the absorption of beliefs about benefit claimants as workshy, is illustrated in the extract below from Grace. She reports taking a job after being found fit for work:

'I have always worked. Not at the moment because I am still on treatment. Been on

treatment for the last year and a half. Last time I spoke to you I had just started a new

job hadn't I? Part time, five hours a day. I lasted three days on that one, I was so

---

[147] Fraser and Gordon (1994: 325) actually use the term 'infect' to describe the way perceptions about drug use shape perceptions of receipt of welfare benefits, pertinent in the context of hepatitis C.

physically sick I couldn't do it after three days. I realised I can only do so much, but

mentally I am ahead of my body if you know what I mean?... I got to the point where I

was physically pulling over in the car and throwing up. So I had to give it up, I was just

doing too much, but I just presumed I could because I needed the money.'

Despite having done a difficult treatment for 18 months (she described going *'straight back on the treatment'* as soon as it became clear the first course of treatment had not cleared the virus), Grace is mandated to attend a Pathways to Work programme but finds that she is unable to work, even part time. When she states *'mentally, I am ahead of my body'* this can be taken as a sign that Grace is motivated to work (often understood as a barrier to employment), but her impairment (and the type of employment made available) prevent this. She positions herself as someone who is 'genuinely' ill when she says ' *I have always worked'* and *'I did try and work'* she is aware of the 'benefit scrounger' rhetoric which permeates the media (Grover and Piggott, 2010) and how people who receive benefits are labelled and portrayed (Garthwaite 2011).

Lastly, Grace states *'I just presumed I could because I needed the money'.* Grace indicates that a need for financial support coerced her into work though she was not fit. NAT (2010; 2011) draw attention to the processes of applying for ESA (and also potentially PIP) which forces people who are sick and/or impaired through a system which actually worsens their impairment effects, whilst simultaneously reinforcing the idea that they are not 'ill enough'.

Grace described actively resisting the perception that she was not entitled to benefits or time off to recover during treatment, because she had paid national insurance contributions. For this reason, she described being honest in assessments, although this turned out to be counterproductive due to the fluctuating impairment and treatment effects:

'I told them - I said - I don't feel too bad today, I goes, I haven't for the last couple of days but last week I felt this, I felt that...I told them everything, so you know I have horrendous back pain. I don't know if that's got worse or if it's nothing to do with what I've got (hepatitis C)'.

Grace's assertion that she doesn't *'feel too bad'* echoes Banks and Lawrence's (2005) findings that people had a tendency to describe their situations more positively than they actually experienced them [see also Wilson and Amir (2008)], but which led to them being refused welfare benefits. De Wolfe (2012) (see also Reeve, 2008 - below) indicates that in order to make a successful application, the reverse approach is necessary. This was echoed by a number of participants who stated that being honest about the impairment effects and experiences of disablism was ineffective. Participants referred to needing to 'play the system', including dressing in certain ways or using particular words or vocabulary on application forms, enacting themselves as impaired and 'disabled enough' for the process in ways that fit the category. Paradoxically, this forces them to be dishonest and makes them feel as though they are stretching the truth, perpetuating the perception they are 'not really' entitled to benefits (Reeve and Soldatic, 2012).

Applying for welfare benefits is described by Reeve (2002; 2008; Reeve and Soldatic, 2012) as a key site of psycho-emotionally disablism, given that claimants are forced to define themselves using a deficit model, describing what they cannot do, rather than what they can. Reeve (2002) and Shildrick (1997) highlight how the process of applying for benefits is an exercise of disciplinary power. Using Foucault's (1977) work on the Panopticon (an ideal institution where prisoners regulated their own behaviour as a result of incorporating the belief that they were being watched at all times by prison guards) the concept of self-surveillance developed. Self-surveillance, where the individual polices themselves and their own behaviours, rather than being policed by an external body and which Reeve (2002) links

to ideas around responsibility for personal health, operates to construct applicant's bodies as 'disabled enough' or not. In order to access benefits such as DLA, participants are forced to become their own oppressors through turning the surveilling gaze on themselves (Shildrick, 1997) and describing in detail the physical limitations of their own bodies in order to qualify:

> *Morgan: Because you're feeling incredibly ill and you're thinking am I ill enough?...while you are really ill you're trying to be really positive and then you have to do this thing where you're showing the worst side of it all.*

Being forced to question if she is 'ill enough' to qualify for support, is both anxiety producing and psycho-emotionally disabling for Morgan. This experience can be described as 'sapping the strength' (Reeve, 2002:494) of disabled people beyond the presence of structural barriers.

Enacting a hierarchy: reinforcing perceptions of hepatitis C

Not meeting the criteria enacts participants as non-disabled. Grover and Piggott (2010) state that ESA claimants (like Daniel and Grace) are subject to social sorting (Lyon, 2003) which leads to the development and maintenance of hierarchies of entitlement, where only severely impaired people will be entitled to benefits and others will be consigned to living in poverty. This is likely to worsen further given the recent announcements that no ESA will be paid during a period of 'mandatory reconsideration' (which must be gone through prior to appeal). Though claimants can 'choose' to claim JSA or Universal Credit during this time, (Freud, 2013), this presents distinct challenges for those who are not fit for work, forcing participants into a liminal space where they can neither work, nor access support. This further marginalises the needs of those with hepatitis C, and subsequently affects the opportunities available to them, determining their life chances (Lyon, 2001).

Identifying as disabled

Being found fit for work (like Grace was) simultaneously undermines participants' feelings and knowledge of their own bodies, enforces a feeling of being undeserving of support and reinforces stereotypical notions of disability. For example, that impairments are static, visible and unchanging – see Grewal *et al.*, 2002; Mueller *et al.*, 2010). This drives a wedge between people with hepatitis C, (other) disabled people and the non-disabled population. Indeed, Grace later stated *'if I was an immigrant I'd get everything.'* Here, I am reminded of the observations of Peter Beresford at the Lancaster International Disability Studies Conference in 2012, that the welfare benefit reforms encourage division rather than unity, which weakens collective political power. Despite clearly facing structural disadvantage in terms of access and participation, experiencing psycho-emotional oppression (chapters six and seven) and living with an impairment for which they undertook gruelling medical treatment (see Shakespeare *et al.*, 2010), a small but significant number of participants explicitly referred to not seeing themselves as disabled:

Heather: *'I was going to say, do you see hepatitis C as a disability[148]?*

Grace: *No not in that way, I think disability to be is having a limb missing that sort of no I don't think of it as a disability. I think while you're on the treatment you've got - do you know what I mean? You're limited what you can do while on treatment but with it generally no it's not a disability it's a blood disorder. I wouldn't even take away. I wouldn't compare myself you know people have limbs missing, blown up, blindness, but then again maybe. I don't know anyone who has died from it'.*

---

[148]Here I follow Thomas (1999) who used the commonly understood term 'disability' instead of referring to impairment and disablement with participants, given that they may not be familiar with the differentiation.

Here, Grace alludes to visible and stereotypical notions of impairment and disability (Grewal *et al.*, 2002) whilst at the same time acknowledging the disabling effects of treatment, before revealing the extent to which she has absorbed the oppressive views around hepatitis C and disability. Even to the extent that a person would have to be severely impaired or even dying before she thought of herself or others with hepatitis C, as disabled.

That being said, the concept of not being 'ill enough' to qualify for support is materialised in the condition related information on hepatitis C on the DWP's website, which indicates that there are few symptoms prior to the onset of cirrhosis or fibrosis (which participants in this study contested). Further support is only indicated in progression of cirrhosis :

'Even those known to have progressive disease (chronic hepatitis C) may have few symptoms with minimal disabling effects for up to 20 years or more. *With the development of cirrhosis and progressive impairment of liver function* functional restrictions may be attributable to severe fatigue, weight loss, muscle weakness, jaundice, anorexia, ascites etc. Help may be needed with personal care, moving around, rising from a chair, preparing food etc. and walking may be restricted.

The side effects of the drug treatment for hepatitis C can be debilitating. They may increase the degree of functional restrictions experienced by someone who already has clinical features of liver damage. People with hepatitis C of moderate severity however may have few symptoms or functional restrictions when drug treatment commences. In these cases any resultant care need, or difficulties in walking attributable to drug side effects such as fatigue, flu like symptoms etc. should be carefully evaluated. *In many cases they will not be sufficiently severe to affect personal care or to restrict mobility, and will only persist for the limited duration of the treatment'* (DWP, 2009, *my emphasis*).

Here the emphasis is on people experiencing 'minimal' impairment effects prior to the onset of cirrhosis (permanent liver scarring and reduced liver function). However, Sutton and Treloar, (2007) and Thein and Dore, (2009) indicate that there may be little correlation between impairment effects and degree of liver damage. Further to this, the information concerning treatment is the *opposite* to what participants in this study described, particularly around the severity of treatment effects and their persistent nature post treatment. Whilst treatment (and post treatment) effects are not inevitable -Pixie reported not experiencing any - this is vastly different to the reality enacted in the DWP information[149]. This information should be updated as a matter of urgency, including links to more detailed guidance. This information enacts people with hepatitis C as not very impaired until they have cirrhosis enforcing its own kind of hierarchy and disabling barriers.

Further to this, the information on the DWP website about hepatitis C, begins with a brief description of the virus, genotype and symptoms, and then moves onto transmission routes and prevalence, with long term impacts on the left hand menu of the website. The presentation of this information, aside from being highly individual and medicalised, *enacts transmission route as more important than the effects.* It raises the question as to why DWP staff would need to know about transmission route in detail, given that a description of its blood borne nature and the need to avoid exposure prone procedures (i.e. deep cavity surgery) in employment would be more than sufficient. This is revisited below.

Returning to Grace's example above, the absorption of oppressive ideas about what it means to be being 'genuinely ill' or 'really disabled', could in part, be explained by public perceptions around what is covered under disability legislation or what disabled people look like Grewal *et al's.* (2002 study) found that participants perceived impairments as physical or sensory, static and permanent. Mueller *et al.* (2010) found that visibility was also associated

---

[149] Another overview where the nuance and contingency is lost also for a political reason.

with perceptions of 'legitimate' disability. Watson (2002) found that many of the people he interviewed would not define themselves as disabled, either because their identities were shifting or they just thought of themselves as 'normal' and Grue (2012) maintains that even though one billion people live with impairment, only a small percentage are likely to define themselves as disabled people this often depends on the benefits of doing so. Furthermore, Watson (2002) indicates that there may not be benefits in the same way as there might be for a gay man to be explicit about his sexuality[150].

For Grace, being enacted as fit for work and receiving no financial support compounds the negativity she feels around having hepatitis C. In addition, the push towards treatment and the possibility of eradicating hepatitis C may mean not only that participants are less likely to identify as disabled people, but that living with hepatitis C is marginalised as an experience.

This is not to say that every participant rejected a disabled identity. Ken indicated that he thought of himself as disabled, *'I am anyway'*, due to existing impairments. A significant number made specific reference to being defined as disabled either in relation to legislation, for example, coverage under the Disability Discrimination Act, or as a result of receiving Disability Living Allowance. Banks and Lawrence (2005) state that receiving DLA may be considered a sign that an individual is disabled as defined under the Disability Discrimination Act (1995), although the DLA claim form itself indicates that individuals do not have to identify as disabled in order to claim or qualify (Disability and Carers Service 2011). There is a need here for dedicated information which enacts people with hepatitis C as entitled to apply for welfare benefits in a way which does not promulgate ideas about dependency and which makes clear that an individual may not necessarily need to self-define as disabled. Although an engagement with wider disability issues may well encourage those with

---

[150] Although this has been problematised by Fraser (2008).

hepatitis C to identify as disabled and thus, recognise the oppression faced by them and other disabled people.

Drug use and identifying as disabled

Reeve's (2012a) observations that cultural understandings of impairment are intimately linked to the experience of psycho-emotional disablism, and that impairment and disablism are interwoven, are particularly pertinent to the discussion that follows. Briant *et al.,* (2011) indicated that impairment type affected how deserving benefit claimants were perceived to be in relation to the type of impairment they had. People with physical and sensory impairments were more likely to receive sympathetic treatment by the press, whereas those with mental health conditions were mentioned far less in the 'deserving' stories [people with mental health issues in particular are seen as 'fakers' Bambra (2008)]. Individuals with impairments which were less visible, or to which society was 'unsympathetic' (Briant *et al.,* 2011: 12), were more likely to be seen as unworthy of the benefit, with serious implications for individuals who have contracted hepatitis C through drug use.

It has been documented in hepatitis C social research literature that people with hepatitis C may accept or absorb negative views about themselves specifically in relation to infectiousness and injecting drug use (Butt, 2008a; 2008b; Harris, 2005; 2009a). This, combined with issues of blame and responsibility (Lloyd, 2010), work to constitute hepatitis C and people with it in specific ways.

In Copeland's (2004) study, participants who used drugs described feeling unable to claim or access support feeling they were not entitled to call themselves 'sick' in the same way the general population might, because of the sense of personal responsibility they felt for their hepatitis C status. Similarly, Herek *et al.,* (2002) in relation to HIV, and Sgorbini *et al.,* (2009)

in relation to hepatitis C, have referred to the lack of support from others for illnesses that are perceived as 'self-inflicted'.

Participants in Mueller *et al's.* (2010) study, indicated that substance use, including alcohol or drug dependency, should not be covered under the Americans with Disabilities Act (as is currently the case) and that the more likely a person was perceived to have some role in their impairment (emphysema, HIV, obesity), the less likely they were to be seen as protected under the ADA. These individualising responses ignore the wider structural forces which lead to hepatitis C transmission (e.g. poor treatment by medical staff which leads to disengagement, lack of policy and service response, inadequate needle exchange coverage). Nevertheless, there is evidence that participants have absorbed these wider views. These issues were brought into sharp focus in the group interview with Carl, Andrew and Brad, when I asked if they would see hepatitis C as a disability:

Carl: 'In fact I can even say I have tried this one on with the benefits system when I have gone for medicals and things like that the reason can't work is because I am an addict and I've got hep C and it doesn't come under their...it's not recognised as a disability.

Worker: Do think that is because they don't actually understand and haven't had it like we were saying before unless you have had it, you don't understand how debilitating it is?

Carl: No I think it's because it's self-inflicted. The way they look at it and the way this addiction is. And because you're not born with it or you haven't contracted it through what's the word?

Andrew: No fault of your own

Carl: Yeah and they kind of say you know what and they don't let you use it as a

disability. Because I always thought it would be a good one that 'who is going to

employ me with hep C? Of course, I need to be on the sick. And I am a heroin addict as

well – I'm really ill.' I kind of got thrown off the sick and they wouldn't accept the sick

notes and the reasons on it... they still classed me as fit for work and although I'm

physically fit they don't - the benefits system don't look at the mental side of things - so

physically yeah, mentally no. The government and such people don't recognise things

like that.

Worker: It [the hepatitis C experience] doesn't fit in a box though does it?'

In this extract, Carl describes being found fit for work (though it is not clear which benefit he

is claiming*). 'I have tried this one'* and *'I always thought it would be a good one, that'* implies

that he has absorbed the belief that past claims may not have been 'genuine' and that he

may not have 'deserved' benefits. However, later on Carl indicates that his experiences of

mental distress were not adequately recognised in the benefits process[151] (Bauld, 2010;

Rethink, 2013). When challenged by the worker present, Carl indicates that he does not

identify as disabled with hepatitis C due to the 'self-inflicted' nature of the virus.

Here, hepatitis C intra-acts with social and cultural beliefs about drug use it is an individual

issue which must be personally managed rather than something which is connected to wider

structural forces, and given that the individual is to 'blame', they are not entitled to support.

The link between hepatitis C and drug use is particularly pertinent here. The UK Drug Policy

Consortium (UKDPC) (2011) refer to the way in which people with drug problems are heavily

stigmatised or treated differently than other claimants. They are targeted to fulfil special

requirements (see Grover and Paylor, 2010) but not afforded protection under legislation

and are specifically excluded from the definition of disability under the Disability

---

[151] Though Beresford *et al.,* (2002) indicate that for some experiencing mental distress, obtaining
welfare benefits depends on subscribing to medical model views of 'illness', which not all wish to do.

Discrimination Act or the Equality Act 2010. The idea that participants were responsible for hepatitis C permeated the narratives of many participants[152]. This affected their sense of entitlement and, implicitly, the degree to which they felt it was their responsibility to clear the virus.

In addition, just as Simmonds and Coomber (2009) found that drug users operated a hierarchy of comparisons depending on the method of drug administration, (i.e. injecting was further down the hierarchy than smoking, participants internalised (incorporated into their self-beliefs) a hierarchy in relation to the method of transmission of hepatitis C – as evidenced in Pixie's comments in chapter eight. Carl's status is intertwined with his (previous) heroin use. Here, there is evidence of the comparison of two different forms of hepatitis C: the kind acquired through 'no fault of your own' (Andrew) - what Duffin (2004a) associates with the 'innocent' form (blood transfusion) - and the 'guilty' or 'self-inflicted' form (injecting drug use). These separate enactments of hepatitis C could have serious impacts on the material circumstances of people with hepatitis C, particularly if they do not claim based on perceptions that they do not feel they qualify for or *deserve* support (Bauld, 2010).

There is also evidence that this division by transmission route is being perpetuated by the provision of services which are provided based on method of transmission. In October 2011, The Hepatitis C Trust announced that it would facilitate counselling for individuals who contracted hepatitis C via contaminated blood from the NHS (The Caxton Foundation 2011). Whilst this is an important step forward in the recognition of the needs of people affected by the NHS contaminated blood, there is an implication that those who do not contract hepatitis C through contaminated blood, do not require access to counselling. Seear *et al.* (2010) in their exploration of emotion and hepatitis C, maintain that emotions in this context

---

[152] Both Holli and Morgan actively resisted this (though it may be significant that they were both unsure how they had contracted the virus).

obscure the structural factors at work specifically the link between poverty and problem drug use (Seddon, 2006), which the moralising responses of the welfare benefits system may perpetuate (Grover and Paylor 2010).

The disabling process of applying for welfare benefits

Another disabling barrier (both structurally and psycho-emotionally) was the poor levels of knowledge and understanding of the experience of hepatitis C and treatment from those making the assessments:

> Daniel: 'I couldn't have gone and done a day's work when I was on that treatment... Basically what they were saying to me was 'you're fine - you just have a virus in your blood', so that really annoyed me....I have just been through a punishing treatment... so the benefit agencies could do with knowing more about this illness and the way it affects you.'

Grace also highlights the apparent lack of knowledge and information around the impact of treatment on impairment effects:

> 'When it comes to hep c they [staff making the assessment] can't see what it is - or they are not told what the treatment is. All it ever says on the paperwork is 'they have hep C, they have liver damage'...It only ever says 'and is receiving treatment'... That's the problem because to them it could be Paracetamol. It names it, but no one knows what it is. ... it says has usual symptoms, has aches and pain but that could be old age, they don't seem to have enough information maybe some people do get really bad, but if stopped taking painkillers I can't walk I tell you that'.

Here the hidden nature of hepatitis C and the lack of information provided to staff making the assessment have serious consequences for Grace and others, especially given the information provided about hepatitis C on the DWP website. Further to this, 'has usual

symptoms' is particularly worrying in a treatment context, given that the symptoms can be variable. Similarly, Grace feels that the *'usual aches and pains'* does not accurately describe her embodied experience of the treatment. At the end of the extract, the shifting and contingent nature of living with hepatitis C, and how Grace feels about living with it, are made visible. By stating *'maybe some people get it really bad'* she implies that her experience is not 'bad enough'. However, at the same time she indicates that she is unable to walk without high doses of pain medication. Her health is therefore described in contradictory terms (Persson *et al.,* 2003).

A similar sense of uncertainty and contingency is evident in Richard's extract it too begins with a limited understanding on the part of the assessor:

> *'I tried to get DLA and the doctor who came to do the medical examination quite*
>
> *clearly knew absolutely nothing about liver disease. I didn't get it and I was too ill*
>
> *appeal at the time... I'm pretty sure over the last couple of years I was in a state where*
>
> *I certainly, arguably should have had it'.*

Richard uses the terms *'certainly, arguably'* as though he is not entirely sure of his footing or entitlement. He indicates here that he is not *'desperately hard up'* and he talked about giving up work and experiencing some serious post-transplant and treatment effects. Just as Richard was too ill to appeal the decision concerning his DLA application, Hammond's (2002) participants also stated that they were too ill to attend the tribunal to appeal, or even to fill in the form. Paradoxically, the more unwell they were, the less likely they were to (be able to) make a claim.

In addition, when asserting their entitlement to benefits, other participants made reference to the disabling nature of the medical – including the exacerbation of treatment effects and worsening impairment (see also de Wolfe, 2012). JB specifically highlighted the lack of

knowledge and the dangers of forcing claimants with hepatitis C to travel to assessments which, given their weakened immune system, might put them at risk of infection:

'you know people who are on treatment with low neutrophils, low white blood cell counts being made to go for medicals, who should not be out and about because they're at risk of catching infections'.

Interestingly, this same point is made by Macmillan Cancer Support (2011a) who indicate that there is a lack of awareness or understanding associated with expecting individuals who have compromised immune systems to travel to assessments.

Anecdotal evidence from an informal interview I carried out with a welfare benefits advisor, suggests that the overall numbers of participants claiming DLA in relation to hepatitis C (and disclosing it) is only small - so small that it is not included on the list of conditions in the DWP statistics. However, this may not be because few people with hepatitis C require financial support. Rather, it may be that individuals do not know they can claim benefits and that they have limited knowledge about the process and little support, as a significant number of participants reported (see also Bauld *et al.,* 2010 and Moffatt *et al.,* 2010). Further, the UK Drug Policy Consortium (2011) draws attention to people who use drugs not being included as a specific statistical category in DWP statistics, rendering them (like those with hepatitis C) as an invisible group. This can have serious material consequences in that it could be used to justify a lack of support services in times of financial pressure.

It has been well documented that the system of applying for benefits is complex and confusing (see Lawrence and Banks, 2005) and constantly changing. As described in chapter six in relation to Macmillan Nurses, Morgan describes the difficulty in filling out the forms which requires a lot of effort when unwell (de Wolfe, 2012) and may worsen impairment effects (see Reeve, 2008 and Shildrick and Price, 1999) Malacrida (2010) reported how even

participants who had worked in benefits advisory roles were unsure what they could claim and what they were entitled to.

Morgan's experience of contacting the Disability Benefits Unit to stop her DLA appeal bears this out in practice. Morgan experienced severe post treatment effects which significantly impacted on her wellbeing and would have meant that she may have been eligible for DLA however, a lack of professional support meant she stopped the progress of her appeal. Keith's experience highlights the importance of professional support when he states:

'I know I was surprised the length of time they gave it (to me) anyway but I mean I

mentioned that to (local welfare rights organisation) and they turned around and said

'Oh no you don't know how long it's going to take you to recover from your medication

– I wouldn't give it back until you know you're going to be fine – because of how hard it

is [to claim].'

Malacrida (2010) states that disability benefits policies are written for an 'ideal' individual who is confident, literate, who has time to go over the forms and few other responsibilities or demands on their time - or indeed their health. Concentration was highlighted as being key when completing benefits forms successfully, and completing the form in short bursts could be detrimental and lead to inconsistencies (Banks and Lawrence, 2005). Thus, for individuals with hepatitis C who experience fatigue and 'brain fog', the process itself is disabling. A few participants reported receiving support from friends or peers with regard to benefit applications, although Keith does later describe approaching formal services. Moffatt *et al.,* (2010) found that people with cancer also had limited knowledge of the benefits system, no one alerted them to what they could claim and they only described finding out either from specialist nurses or online forums.

Hepatitis C and employment

For many participants, an area which was significantly affected was employment most commonly during and post treatment. A few participants described either stopping work prior to beginning treatment, due to increasing hepatitis C impairment effects or intra-action between hepatitis C, recovery, other impairment effects and parenting responsibilities. Participants who were working, or looking for work, described the impact of the impairment and treatment effects on their ability to work (Patrick, 2012), intertwined with structural barriers within the workplace.

This part of the chapter makes an important contribution in a number of areas. As was explored in chapter two, accounts of employment experience with hepatitis C are scarce, particularly within a UK context where few qualitative studies are available. Two standout areas of discussion in this chapter are the degree to which individuals felt protected in disability legislation (i.e. the Disability Discrimination Act, 1995, 2005, now part of the Equality Act, 2010) and their experiences of receiving reasonable adjustments in the workplace. It has been noted that in exploring disability discrimination legislation, much literature focuses on the perspectives of employers and not employees (Foster, 2007), thus this chapter makes a contribution here. It is an important time to document participant experiences, given the reported low rates of impairment disclosure in employment (European Human Rights Commission, 2012) and the current instability in relation to the labour market (Patrick, 2012).

As was explored above, employment and making an economic contribution is understood as a key marker of citizenship (Taylor, 2004). Employment plays a key role in developing economic and social status, and exclusion from the labour market means that some groups continue to be marginalised (Kitchin, 1998; Zucker, 2006). Paid employment has been recognised as beneficial (Wendell, 2001; Roulstone and Barnes, 2005), not only financially

but in terms of an increased sense of self-worth, structure in daily life and connection to the local community (Platt and Gifford, 2003). I follow Edwards and Boxall (2012) in recognising that both impairment effects and disabling barriers affect the experience of employment and contribute to experiences and enactments of disablism - and that many of the experiences documented here have commonalities with the experiences of other disabled people.

Negotiating work and treatment

All participants who were working on treatment (or started treatment while working) described needing to adjust working hours and patterns of work. This depended on disclosure to employers to varying degrees (discussed below). Freda was the only participant who continued to work the hours she did before treatment, despite experiencing severe treatment effects, including debilitating fatigue and emotional instability. She described managing these effects by sleeping during her lunch hour with her office door closed. She explained that her reasons for non-disclosure related to her perceptions of her manager whom she felt *'couldn't hold his own water, let alone a confidence'.* This echoes Roulstone *et al.*'s (2003) findings that reasonable adjustment negotiation depend on relationships with line managers.

Shaun, who was on treatment for the second time at interview, described taking the final weeks of his 24 week treatment off work:

'I was doing okay for the first half... Then I started (laughs) – I'm laughing, it's not funny – I started picking fights with people at work, and that's when I thought it's time to back off... There would be days when I'd go in and I'd just be like a zombie: I'd stare at the screen, I couldn't talk to anybody...I was getting aggressive and snappy...Ordinarily I'm someone who's very, very motivated... I have to be very astute. I have to talk a lot of directors. So, that felt horrid because... over a period of time I'd

avoid people, I'd avoid meetings, I wouldn't take phone calls because I thought, I haven't got the energy to think about what you're telling me or asking me. The other thing, I'd describe it as my brain wading through treacle ... Typically I would go into work eight, nine o'clock in the morning, but by two o'clock I was toast; I just couldn't function after that time.'

Shaun's rich description of the effects of treatment on working makes visible not only the embodied experience, but the impact on wider relationships. He described raising a grievance against his employer on treatment. Whilst Shaun indicated that he probably would have raised this grievance in due course, he felt that treatment exacerbated this. Holi also described reducing her hours to part time in her role as a counsellor, whilst on treatment. Ben, who was treated for hepatitis C infection twice, reported reducing his hours on both occasions – but this was affected by his employer at the time.

Redundancy

Two participants described being made redundant whilst on treatment, possibly a marker of the time period during in which this data was generated. Whilst it is unlawful to make someone redundant due to disability, it is questionable whether this occurred for Laurie (discussed below). Both Keith and Laurie described taking voluntary redundancy when their respective companies needed to make savings. Keith indicated that redundancy was part of a range of options, (although the degree to which these were meaningful or suitable is debatable, as one option was to take an 18 month sabbatical unpaid). The uncertain nature of the treatment meant that Keith took redundancy:

'I decided I was going to take redundancy so they gave me a big fat cheque and I walked away and basically I have been on a holiday since. So I am not – my doctor keeps signing me off anyway so I am not due to go I have been signed off until the end

of September. But I need to go back to work anyway because I quite fancy earning some money. But I don't really care what I do... Because I think the importance of a career is gone.'

Whilst Keith spoke positively of his employer (see below) and described his changing views on the importance of a career as a good thing, he later described finding it difficult to survive on the redundancy payments given that he had parenting responsibilities. This also had knock on effects for his housing. Keith reported that eviction procedures were started when he informed his landlord he had lost his job. This was only resolved with the involvement of his MP, his local council and his liver consultant. Here hepatitis C treatment intra-acts with a number of areas of his life and paradoxically, obtaining support actually required that Keith put in a great deal of 'work' whilst on treatment. The 'work' required is also likely to increase for those subject to the size criteria or benefits cap (DWP, 2013a, 2013b) where individuals find they can no longer afford to live in their home and have to move away from social networks and incur additional financial expenses and the stress of moving.

Laurie described a particularly difficult experience of being made *"redundant"* (his use of parentheses) from his job in a legal environment:

'I had to drop my working week to 3 ½ days, then my company made me redundant 1/3 way thru - blessing really cos I couldn't cope at that point and my health was getting progressively worse...Work-wise - totally started to strip me of ability to function. Aggressive, absent-minded, short of breath - couldn't sleep, obsessive at times'.

When I later clarified this arrangement with Laurie, he explained:

'Going part-time for me was basically my employer allowing me a half day for the chemo shot, and a half-day recovery the following day - so part-time of one day off.

The chemo laid me so low that this was problematic. Being slightly naive I relied on their generosity on this issue and didn't request under the Disability Act. They made me "redundant" two months into chemo.

Laurie indicated that although his employers provided him with a generous redundancy payment, and the time off gave him the opportunity to recover from treatment, he felt their specialised legal knowledge had enabled them to make him redundant despite this being unlawful under the DDA (1995, 2005, now under Equality Act 2010).

Laurie indicated that he did not think to ask for reasonable adjustments under the DDA, although his employers, given their profession, might perhaps have suggested this to him. This could be interpreted as a lack of knowledge on Laurie's or his employer's part suggesting the need for greater information, training and awareness around applications of disability discrimination and equality legislation. It is possible that the impact of the treatment on Laurie's cognitive ability, and the increased stress he experienced on treatment, might well have influenced his willingness to pursue an adjustment. It is also possible that Laurie's employers were unsure about his entitlement to an adjustment under the act given the contingent and shifting nature of the treatment effects and duration. Further, Laurie's phrasing suggests that his employer determined how much time he needed to recover from treatment, rather than asking Laurie, which proved inadequate for Laurie's needs. This echoes Roulstone's (2003) observation that power to apply the DDA rests with professionals.

Voluntary work

David, who was in recovery at the time of interview, described working as a volunteer with a substance misuse organisation. He was also working towards professional qualifications at the time and reported that participating in the interview with me was an important part of

367

his recovery. He indicated that the voluntary nature of the position functioned as a *'safety net'* regarding the effects of treatment:

> *'I sometimes think morally I am having...an easy time of it [on treatment]. How can I be reliable to be working on a daily basis if I don't even know if I am going to be able to get out of bed in the morning?...That's like my worst fear. That's why I have it [inject interferon] over the weekend so if I need to recuperate I am alright. I have to have this safety net of 'its ok if I am not able to do it' and being a volunteer that's great I don't have to worry about losing my job or letting people down'.*

There are a number of important points here. In spite of the voluntary nature of the role David works in, he reports taking actions similar to those completing paid work, i.e. injecting interferon over the weekend to minimise impairment effects in the working week. His observations about the need to avoid *'letting people down'* or losing his job, overlook his own commitment to his recovery (both in the context of hepatitis C and from drug use) and to the organisation. Though David is working in a voluntary, academic and recovery capacity, this is enacted as 'lesser' than paid work (Ferguson, 2013). It also implies that David has absorbed beliefs that sickness in the workplace 'lets people down' and enacts those with hepatitis C as potentially unreliable rather than highlighting the need for reasonable adjustments from employers. For David, his concern with not *'letting people down'* (i.e. being reliable) may also intertwine with his awareness of oppressive assumptions associated with drug use; *'morally I know I am having an easy time of it'*, implies that since he contracted hepatitis C through drug use he should be experiencing more difficulties on treatment.

Obtaining reasonable adjustments in the workplace

Some participants did describe receiving reasonable adjustments under the Disability Discrimination Act (now under The Equality Act 2010). The DDA requires employers to make 'reasonable adjustments' under section six of the act to facilitate the employment of disabled people in the workplace, including: providing equipment (chairs, laptops, software), making adjustments to the workspace or to the structure and timetable of work (working part time, working from home, working a different routine) (Crooks 2007; Foster, 2007; Crooks *et al.*, 2009). However, as Crooks (2013) notes in a Canadian context, even though these rights are enshrined in legislation, adjustments may be unevenly available and the concept of reasonable adjustments remains vague (Bruyere *et al.*, 2004).

Keith described receiving a formal reasonable adjustment and a very positive response which he felt was related to the national reach of the company and the size of the organisation he was employed by:

> *'They installed a broadband line in my house; they gave me a computer...so I could work from home. All I had to do was go into the office on a Friday, they insisted on that because they didn't want me to be isolated from the team – which is fair enough...they were wonderful, absolutely superb but they are a big company. They can't be seen to discriminate'.*

Here Keith is provided with equipment to work from home a mechanism which, if expanded, could increase access to the labour market for many disabled people (Foster, 2007; Marsh, 2012). This experience fits with a survey by Bruyere *et al.*, (2004), who found that equipment provision was the most easily accommodated adjustment.

Similarly Shaun reported a positive response, which he felt was connected to the informed and specialist nature of his role and his employer being in the public sector:

'I've got a good job. I've got a good employer as well because they're a public sector organisation they're very good about things like people with HIV and other conditions...they've been fine about giving me time off. During the initial part of my treatment they said they would give me a reasonable adjustment, so I explained how I could work best and they worked around me. So, from that point of view I can't complain. But I could well imagine there are loads of other employers who would say: what's wrong with you, well on your bike if you can't perform'.

As Shaun indicates, this positive response is perhaps connected to the large nature of the organisations, and the size and specialisms of their HR and legal departments, who may be better informed than smaller organisations. Although as Richard's example (below) shows, this is not always the case.

Charlie described a positive response which he too felt was related to the nature of his employer and the type of work he did, which made adjustments relatively straightforward:

'Because (my employer) is a [blood borne virus organisation] they had a fuller understanding of what was going through. It would have been impossible in a physical type job for me to carry on... There was a huge amount of flexibility. I luckily had an employer who rather than restrict that actually expanded that. So things like being able to work from home was a major bonus because sometimes if I couldn't get out of bed I could turn the computer on and just go through my emails.'

Charlie makes an important point here about the forms of work that are amenable to adjustments of this type, indicating that this may have been more difficult if it involved physical work or attending somewhere every day[153]. Those working in roles which are

---

[153] This raises issues regarding recent proposals to require claimants to look for work 35 hours a week in order to receive benefits (Citizens Advice Bureau, 2013).

insecure and low paid - the current nature of available employment (Garthwaite *et al.,* 2013) - may find this is much less the case.

Similarly, Daniel, who was training to be a counsellor, described his college tutor making adjustments to enable him to continue to participate, which he felt was related to his strong relationship with his tutor and the flexibility of the course and the college.

It was perhaps no coincidence that most of the participants who received a reasonable adjustment were well informed of their rights, either through working in a disability advisory role or working for an organisation which provided some advice and training on these issues (cf. Roulstone *et al.,* 2003).   However, for Richard, specialised knowledge (both on his part and on the part of his employer) did not lead to a positive experience when employed by his local authority. He described disclosing both his liver transplant and the second course of hepatitis C treatment (and the impairment effects and adjustments needed) at the interview, and was offered the job. Despite this honesty Richard reported:

'[The employers were] absolutely diabolical. They tried to sack me when I became ill and eventually I won but it was like, you know, unions and it dragged on for about three quarters of the year … exactly what I didn't need because at that time I was going through treatment…if I had been slightly higher up the organisation, I guess my union might have thought it worthwhile suing them, because I would have loved to have done that. I didn't regret leaving it but its put me off my local [authority] for life…they just could not understand that they were dealing with someone who had a disability and they refused to accept that…They saw me as someone swinging the lead…even when Unison quoted the discrimination act at them they still refused to be impressed by that and it got really nasty. It took over my life for some months …And at the end of the day it wasn't just the shit of a line manager I had I was dealing with - I didn't speak to her for about nine months - I was dealing with their HR who should

know something about this! They tried to get rid of me without even referring me to –

they actually ended my contract at one point, I got a letter saying I was no longer

employed by them without having gone through occupational health.'

This extended extract highlights the difficulties Richard faced and the intra-action of these difficulties which materialised him, and his impairment, in both directly and indirectly psycho-emotionally disabling ways. The extract makes visible the lack of clarity around hepatitis C and liver disease and the coverage of the DDA. Although it is difficult to see how a person recovering from an organ transplant would not be considered disabled for the purposes of the act. It also highlights the stressful and long term nature of the process of challenging this using the DDA, which became even more disabling (Roulstone, 2003). Whilst Richard described resisting and challenging this, there is evidence that others do not (Edwards and Boxall, 2012). There are also serious implications given that Richard indicates that he would be deterred from seeking local authority support, potentially affecting how much he engages with regard to social work support and information in future.

As Fry and Bates (2012) have noted, responses from employers can be uneven and contingent. Ben described two very different responses. When he underwent treatment the first time, he disclosed his HIV status and eventually his hepatitis C status to his line manager, with whom he had a positive relationship, and came to an arrangement where he went home if he felt unwell. Ben described that he felt this was a result of the size of the organisation which could temporarily absorb his work responsibility during difficult periods of treatment. However, after the company was sold to a smaller organisation, Ben reported a less proactive response from employers, deterring him from seeking a reasonable adjustment:

'Yeah, the first time round they were supportive because I suppose when you're a big HR team you know the rules and everything else. The second time around the onus was put on me to go and get the information. I thought 'well I'm not going to have the wrangle, I'm not making myself any more ill by trying to do all the homework'...I just thought, 'I don't need any more at that point'...I was four months into the medication and I was tired. And of course on top of that the company had been taken over and I don't need any more stress, trying to hold onto our jobs and everything else.'

Here, Ben indicates that he did not pursue reasonable adjustments under the DDA because he would have had to research and negotiate this with his employer. He described seeking advice and support from a national charity, who explained that adjustments need to be negotiated on a personal basis. Ben described not feeling well enough to do this due to the effects of treatment. Crooks *et al.,* (2013), in their study of Canadian academics seeking employment adjustments, similarly found that participants did not ask for reasonable adjustments, because they expected it to be stressful and felt too ill to take on the additional work they felt it would entail. There is a parallel here with participant experiences of accessing welfare benefits, where participants reported being too impaired and disabled to pursue an appeal paradoxically, this means that those who are the most in need of support are the least likely to access it. I am reminded here of Barnes' (2003b) observations that anti-discrimination legislation and support should be highly visible, its implementation adequately funded and that responsibility for enforcing it should not be left to disabled people themselves.

Further, Ben indicates that he had concerns about the stability and security of his employment if he was to have made his hepatitis C status clear in his workplace. He described shredding his personal file, which disclosed his HIV status, out of concern that this

may well have affected the way he was treated and his career trajectory. Similar sentiments were echoed by untenured academics in Crooks et al.'s (2013) study.

Coverage under legislation

Hepatitis C was described in the context of disability legislation in Australia fifteen years ago, (Crofts et al.,1997) and in the US Grace Moore (2009) makes explicit reference to coverage of people with hepatitis C under the Americans with Disabilities Act. In the UK, Mack (2007) and Paylor and Mack (2010) have suggested that those with hepatitis C (and on treatment) should be protected under disability legislation, but there has been no exploration of the extent to which people with hepatitis C felt they were covered. A person is covered by the Disability Discrimination Act as if they have 'a physical or mental impairment which has a substantial and long-term adverse effect on the person's ability to carry out normal day-to-day activities'. For the purposes of the Equality Act (2010) the wording is very similar (HM Government, 2011).

The Disability Discrimination Act, which most people referred to in their interviews, has been criticised for being based on a medical model (Pearson and Watson, 2007). Although recent efforts have been made to cover fluctuating impairments in the Equality Act, many participants described feeling uncertain about whether they were covered with hepatitis C. Ben described feeling that people with hepatitis C *were* covered under disability legislation, but that the difficulties he faced in employment were a result of hepatitis C not being *explicitly* included under legislation from the point of diagnosis in the same way HIV is; which contributed to its enactment as unimportant. Though Ben acknowledged the contingency of hepatitis C experiences, he described how acknowledging hepatitis C from the point of diagnosis would be validating and helpful:

'And I know hep C is kind of short term, for some people it's short term, for some

people it's long term, but I thought for that period of medication it would be helpful if

it was classified because then it makes it easier, because my employer, they just didn't

know. Even when I asked at the hospital they said it's between you and your employer,

they didn't know either'.

Though it is important not to reinforce the medical model by stating that those with hepatitis C should be covered on the basis of impairment alone, the structural and psycho-emotional barriers described by participants in this thesis suggest that they should be included explicitly under the Equality Act (2010). This contributes to a reality where hepatitis C is not depoliticised and individual, but a responsibility shared by employers and wider society.

As was explored above, significant work may be required on the part of the person claiming under the act. Making increased reference to the DDA in wider information, campaigns and training is not intended as a panacea, especially given the findings of a recent National Aids Trust (2009) survey which indicated that even with legislative protection, one fifth of people with HIV questioned felt they had experienced discrimination in the workplace. Further, recent cuts to legal aid may also impact on the possibility of bringing cases to court and could entail further difficulties for participants, contributing to the silence around rights for those living with hepatitis C. However, in spite of the problems with it, the DDA has enacted the needs and rights of disabled people as important (Roulstone, 2004) and the Equality Act represents a step forward regarding recognition of the cross cutting nature of oppression. Though the DDA (2005) incorporated people with fluctuating impairments from the point of diagnosis - including HIV, Multiple Sclerosis and Cancer - there has been limited acknowledgement of the rights and entitlements of people with hepatitis C under the Disability Discrimination Act, and later under the Equality Act (2010). NHS Choices (2012d) and The Hepatitis C Trust (2011b) only briefly mention legislation, indicating that employers

'may have' an obligation under the DDA. Only NHS Health Scotland (undated) explicitly and firmly acknowledges that those with hepatitis C are disabled and are entitled to reasonable adjustments. Thus, there is a need for greater attention to employment, reasonable adjustments and coverage under the DDA.

'Work life' (2010), as discussed by Boyd (2011), provides employment support and guidance for people with chronic and fluctuating conditions, including MS and HIV. Work life's remit could be widened to include the experience of hepatitis C, enabling people with hepatitis C (and those with co-infection) to garner employment related information and to be able to signpost others. In addition, specific information could be developed for employers to explain the impact of hepatitis C and treatment, and their obligations, such as the toolkit developed by Macmillan Cancer Support (Macmillan Cancer Support 2011b).

Being self employed

The final area where there were specific issues raised around employment was the experience of self-employment. Both Morgan and Grace reported being self-employed and giving up their businesses due to treatment effects. For Morgan, having to give up her business was cited as the major impact of hepatitis C treatment as she lost clients and her working premises.

> *'No matter how positive [you are] and how much you do for yourself I think it is going to take time for my body to recover, so financially, and, who I am and what I do is affected very definitely by it [the treatment]'.*

Here Morgan's comment *'no matter how much you do for yourself'* resists the pervasive position that what those who are not working need is 'motivation'. The treatment effects impair her body and the unpredictable nature means that she needs to recover before she can begin practicing again and building her client base back up. Grace, described selling her

business due to a combination of information she had read on the internet concerning difficulties on treatment and beginning the treatment itself:

> *'I didn't understand it or I couldn't take it in what they were telling me, because I still didn't have a clue what it was, and I'd read so much on the internet that I was struggling to take any of it in. Only the highlighted bad bits were the bits jumping out at me which I supposed would happen if you're not feeling well. It was all sort of people you know saying 'do the treatment, don't do the treatment' and now - it was just a horrible drug - I couldn't even think straight. That's why I sold my business, sold my work and I totally regret that. I feel stupid for doing that...that was all scaremongering I got off the internet'*

Here the need for clear and accurate information about the treatment, the implications for her self-employed status and the opportunity to discuss it with a business advisor or within a hepatitis C support group (which Grace did not find unit much later in her treatment), may have prevented Grace from making the decision she later regretted. Later in the interview, the complexities of being on treatment and having to survive financially after being found ineligible for welfare benefits were made visible. Grace used the profits from the sale of her business to survive on treatment. This echoes her earlier comments regarding being *'in limbo'* she did not fit the eligibility criteria for welfare benefits, but was too impaired work.

Ben and Charlie described the importance of continuing to work because of the structure and distraction, and the sense of purpose afforded by the working day. Whilst this has been recognised in the literature (Platt and Gifford, 2003), and other participants described looking forward to going back to work, Ben's extract indicates how this sidesteps the issue of their entitlements under legislation:

'[The Consultant] said if you sign yourself off, for six months or three months, he said at the end of it you've got to go back to work and you've got to build all that strength up to go back to work, he said for some people that's quite hard. He said you're better off staying at work so I did in the end. I just gave a mental two fingers to my head office, and 'I'll just get through it and stuff you'. So I did'.

Here the idea that Ben will eventually have to return is used to encourage him to continue to work. Whilst it is important to acknowledge that return to work after a period of absence may be difficult, this advice is divorced from Ben's specific circumstances and appears to be highly variable (i.e. Keith referred to his doctor signing him off).

This chapter has explored participants' experiences of living with hepatitis C and the impact on welfare benefits and employment. This is a vastly under researched but timely area of exploration, given the current reforms. The next chapter draws the thesis together and presents conclusions.

Chapter Ten: Concluding thoughts

Introduction

This final chapter draws together the main findings and discusses how the thesis addresses the research aim and questions. It also describes the unique and original contributions that this thesis has made. Recommendations for practice are made in appendix one.

Originality of research

The thesis makes a number of novel contributions to knowledge, above and beyond that which I anticipated at the outset. Vitally, the process of fieldwork with all its difficulties was discussed honestly across chapters three and four. Specifically, how this challenged the way I saw the world and hepatitis C within it. It has made visible how and why the realities presented in this thesis have come into being and in doing so, opened up the possibility of change. Specific theoretical concepts have intra-acted with participant experiences to contribute to theoretical discussion *and* make contributions to practice.

The thesis explores the experience of living with and being treated for hepatitis C in a UK setting, particularly within England, where literature remains scarce. Social research which does exist is authored by academics and practitioners in medicine (Copeland *et al.,* 2004; Grogan and Timmins, 2010; McCreaddie *et al.,* 2011) and whilst this is both highly relevant and valuable, attesting to the central role of healthcare, it further enacts and materialises hepatitis C as a medical issue. In contrast, writing about hepatitis C from within applied social science - specifically social work - enacts hepatitis C as an issue which has significant social consequences, which social work can and should be addressing.

This thesis has added to areas of research which have been largely overlooked in academic literature to date, specifically the social and cultural implications of living with the virus and

being on treatment. The post treatment experience, the implications for employment and participants' views and experiences around welfare benefits have also been addressed.

Where existing literature around hepatitis C in the UK (vitally) focuses on harm reduction and on encouraging those who use drugs to access testing and treatment, the sample of participants in this study provide an important insight into the support and information requirements of those who have been assumed to be relatively well supported by existing services (ACMD, 2009) finding that in practice, this was far from the case. The inclusion of data generated from men with co-infection made visible a reality in need of urgent research and service attention, adding to the value of this work.

A unique aspect of this thesis is its exploration of living with hepatitis C as an area of interest for disability studies, and its explicit acknowledgement that people with hepatitis C experience disablism. It highlights the intra-active nature of needs of participants, noting that the oppression experienced by participants related to their (former) drug use, intra-acts with the disablism experienced in relation to hepatitis C with serious consequences for participant wellbeing and in terms of structural barriers.

This thesis intersects with a number of bodies of work. It contributes to the literature which explores participants' use of metaphor to describe experiences of illness and disease, and to an emerging body of work which investigates how hepatitis C is materialised through social and political forces (Fraser and valentine 2008; Fraser and Seear, 2011). It applies research and theory which had only previously been applied to hepatitis C in an Australian context, to a UK setting. It illuminates in new and important ways the experience of living with hepatitis C (and its treatment) in the UK, including how people with hepatitis C see themselves, how culturally prolific diseases (Weiss, 1997) are made and remade depending on context, the people they affect and material conditions.

It contributes to calls (Harris, 2005; Suarez, 2006; Paterson *et al.,* 2006) to treat hepatitis C as a chronic illness. The context and time period during which this research was completed is bound up with, and augments, the important contributions it makes, particularly in relation to employment and welfare benefits.

The diverse nature of the chapters, the broad range of experiences and the use of a number of bodies of work evoke and enact the contingent, multiple and complex nature of living with hepatitis C. This explains (in part) the difficulty in responding to hepatitis C, but also the highly political and ideological way in which services are constituted. The thesis has a distinctly political aim, to call for greater response to hepatitis C in the UK (including co-infection) and in making comparisons with other experiences of impairment and disablism, to emphasise the commonality of experience and service requirements among (other) disabled people and those affected by wider welfare reforms.

Disciplinary contributions

The thesis makes a contribution across a number of different disciplines, which for clarity, will be addressed in turn. However this is not to suggest that these disciplinary contributions are discrete.

The thesis makes a contribution to disability studies in exploring both the structural and psycho-emotional barriers people with hepatitis C face in everyday life. It begins a conversation which explicitly includes people with hepatitis C within disability studies and flags this up as an area for further research and discussion, as well as potentially providing an opportunity for identification and organisation among people with hepatitis C and (other) disabled people.

In exploring the experience of diagnosis, treatment and post treatment, as well as the use of metaphor and liminality in participant accounts, the thesis makes disciplinary contributions

to health research – specifically that concerned with the social, qualitative aspects of health. Social needs related to health, (among those with hepatitis C and others) are an area which has historically been marginalised as a result of the blurring of boundaries between professions and a lack of clarity about which services might address which needs (Findlay, 2014). This thesis embraces this lack of clarity, in arguing for greater use of multidisciplinary and holistic support.

In light of this, the thesis also makes a number of bold disciplinary contributions in relation to social work and hepatitis C in the UK. It, for example, argues for both the expansion of specialist hepatitis C social workers and the integration of hepatitis C support and information provision into wider social work teams. It recognises the uniquely beneficial role that social work services could play in supporting people with hepatitis C and maintains that this marginalisation of social work and social needs cannot continue.

The thesis also makes important contributions within social policy, specifically around social security benefits and employment. There are important insights for those working within human resources and employment studies. The lack of fit between the needs of people with hepatitis C and (other) disabled people and the current social security benefit system are highlighted together with the needs of those with hepatitis C in relation reasonable adjustments in the workplace.

Main findings

The aim of the research was to explore and address the (professional) support needs of people with hepatitis C and the understandings, experiences and social implications of living with the virus.

Whilst the research has fulfilled this aim, I found that in undertaking the research, the *exploration* of the experiences of living with hepatitis C was far more complex, nuanced and

worthy of discussion than I had initially anticipated. The process of undertaking the research itself co-constituted the findings and their materialisation in the thesis, both on a micro level (i.e. in the interaction between myself and the participant) and macro level, in terms of raising and discussing issues that both my participants and I felt were important.

With this co-constitutive nature in mind, the research questions are reiterated:

1. What are the support and information needs of people living with and being treated for hepatitis C in the UK[154]?

2. What do participant accounts reveal about the cultural position of hepatitis C in the UK at present and how can this improve our[155] understanding and response?

3. Do people with hepatitis C experience stigma and discrimination?

Each chapter includes elements of all three key research questions and cannot be viewed in isolation. For the sake of clarity, I have addressed each of the key research questions in turn, with an emphasis on cross-cutting themes.

Research question one

What are the support and information needs of people living with and being treated for hepatitis C in the UK?

This research question was developed in response to the consistently documented 'low profile' of hepatitis C within the UK (particularly within England) and the accompanying lack of political and adequate service response (Copeland, 2004; APPGH, 2006; Agarwal *et al.*, 2007; Frazer *et al.*, 2011b). The period during which the research was carried out and written up (2009-2013) was one of considerable economic and political change, proved to be

---

[154] 20/21 of the participants resided and received treatment in England so this is the main focus. Particualrly given the service development and responses to hepatitis C require serious work and invigoration.

[155] As academics, professionals, members of the public and family members/friends who may live with, or have to support someone with, hepatitis C.

a particularly fertile time for the development of new pharmaceutical drugs, and was accompanied by renewed calls for greater numbers to enter testing and treatment (LJWG, 2012). It was against this backdrop that the research question took on renewed importance.

Succinctly stated, the main finding relative to this research question is that current enactments of hepatitis C have a much wider range of social consequences and participants have a much wider range of support and information requirements than are currently recognised, in the literature and in service provision. Participants' needs both intertwine with, and diverge from, the medical focus which dominates current responses to hepatitis C. The experiences and participants' lives are much messier than is currently recognised and hepatitis C cannot be understood in isolation, requiring a multi-disciplinary response. Participant support and information needs identified in the thesis are now revisited.

Awareness and representation

A key finding is that a low level of awareness around hepatitis C persists. Participants who described being aware of hepatitis C prior to diagnosis were those who had contact with drug services or worked in the blood borne virus field. Other participants described a vague or partial knowledge of hepatitis C, prior to diagnosis. Whilst some of the vagueness can be explained by the time period during which they were diagnosed (1990s or early 2000s), there is evidence that even those diagnosed later (mid to late 2000s) had minimal awareness of hepatitis C. Overall, participants described an absence of representations of hepatitis C in everyday life and a subsequent lack of awareness about its effects and implications, from family, friends and professionals who were not specialists (i.e. GPs social workers, Department for Work and Pensions staff, welfare benefits assessors and housing staff). This absence of hepatitis C in public arenas enacts hepatitis C as an illness which only concerns particular proportions of the population (i.e. people who access drug services), not

something which should concern wider society, materialising in limited services, with adverse consequences for those diagnosed.

Though the current information focused on exposure and accessing a test is important (DH, 2004b; Hepatitis C Trust 2010a; NHS Choices, 2012a), there is a lack of visibility of the experience *beyond* diagnosis and treatment initiation. This both constitutes and mirrors participants' own experiences in this study. The (limited) resources currently expended on hepatitis C focus on surveillance, testing and treatment, with far less focus on those living with the virus or going through treatment.

As well as a general lack of awareness and profile in public, the men living with co-infection indicated that hepatitis C was frequently ignored or silenced in gay and HIV positive communities and organisations. Here, support and information needs intra-act with the cultural position of illness. Hepatitis C was perceived as less socially acceptable than HIV and participants described reluctance to enfold people with it into gay and HIV positive communities and organisations, and thus acknowledge it as a health issue they should be concerned with. This has implications for participants' self-esteem and sense of identity, and exacerbates and re-enacts the sense of unacceptability that participants recounted (see research question three).

Testing and diagnosis

The majority of participants in this research did not necessarily identify themselves as requiring a test for hepatitis C, but were nevertheless experiencing illness and sought support from a GP. A key finding is that low levels of awareness and knowledge amongst GPs, intra-acted with age and gender related expectations, making visible the multiple and contingent nature of the virus with serious consequences for participants' feelings about

themselves, their relationships and even their employment. This lack of awareness functions as a structural barrier to diagnosis.

Here, issues identified in relation to research question one intra-act with, and enact, findings in relation to research question two. Descriptions of hepatitis C as a 'silent killer' or 'silent epidemic', frequently used in medical literature (see Bockhold, 2000; Cole, 2007), enact the virus itself (rather than the structures surrounding it) as silent (see Fraser and Seear, 2011) in order to emphasise the importance of testing and treatment. However, other participants suggested that hepatitis C is *silenced* through lack of impetus to take action, poor policy response and lack of funding (Edlin, 2011).

Participants described absorbing dominant views about 'responsibility' for their health and using the 'silent' nature of the epidemic to emphasise the importance of accessing a test and being treated - and the irresponsibility of those who had not done so - which obscures the lack of support and structural response, the challenges of treatment and the wider cultural associations of hepatitis C diagnosis.

Participants described occupying a liminal (Turner, 1966; Murphy *et al.,* 1988) zone prior to diagnosis, *'knowing something was wrong'* but not being given a clear diagnosis, or receiving numerous diagnoses. This protracted process not only meant that participants were not accessing support for their hepatitis C, but also that they absorbed wider beliefs that they were 'malingering'. Participants described invalidation (Wendell, 1996; 2001) from family, friends and professionals (and for two participants, discriminatory treatment) which undermined the confidence they had in their knowledge of their body (Mendelson, 2009), and placed strain on existing support networks - with implications for treatment and post-treatment.

The impact that living with undiagnosed (untreated) hepatitis C might have on a person's family, social and working life, and the subsequent need for support is not taken into

account when the diagnosis is eventually given, ignoring the cumulative impact (Reeve, 2008) of living with long term impairment and disablism.

A key finding here is that although some improvement in the experience of diagnosis was visible in participant accounts, over a decade after diagnosis experience began to be explored qualitatively (Crofts *et al.,* 1997; Glacken *et al.,* 2001) there is still a need for major investment and attention. Participants frequently described being poorly prepared – not being aware they were being tested or unsure of what hepatitis C actually was. Participants who felt their diagnosis had been handled well, described being given time, clear explanations of the virus, the implications and treatment, along with the offer of family testing, vaccination against hepatitis B, information and a sustained point of contact. Most participants diagnosed by their GP or in unexpected settings (i.e. when seeing a consultant for something else) described being provided with limited or no information.

These experiences enacted hepatitis C as of little importance, which directly contrasted with participants' own experiences and the information they accessed, leading to unnecessary stress and anxiety ultimately reinforcing the need for a medical response. This finding mirrors Harris's (2009b) observations that reactions and responses to diagnosis are contextual. The contingent and enacted nature of hepatitis C comes to the fore again. It is not inherently difficult or troublesome, but is co-constituted though social forces and support surrounding it.

Diagnosis simultaneously functioned as a form of validation and a source of oppression[156]. The initial relief participants described on diagnosis dissipated when they did not receive the support they had hoped for, and thus experienced further liminality (Murphy *et al.,* 1988). When nothing else is forthcoming, medical responses provide a kind of stability (Jutel, 2009) contributing to specific medical (and individualising) realities.

---

[156] As pharmakon (Derrida, 1981) both beneficial and detrimental.

Post diagnosis

The post diagnosis period required specific support and information, notably the opportunity to talk through the diagnosis and its implications with someone knowledgeable. A key finding in relation to information and support was the vital role of peers, including face to face support groups, online, telephone support and annual gatherings. This meant that support was available in a variety of mediums and allowed peers to compare experiences, read each other's stories, 'sound off' and compare bodies, though a lack of support groups outside of major cities and inadequate funding inhibited this. An important finding was that peer support was often located by participants in the course of their search for information, rather than being signposted by professionals.

Wider support

The input of specialist hepatitis C nurses (or specialist teams) was highly valued for the majority of the participants in the study, especially during treatment. Some participants emphasised the availability of their specialist nurse, and their flexibility and speed of response, when they had problems. Others described difficulties in getting in touch with their specialist nurse or in getting answers about difficulties they were having on treatment. Participants felt that this was in part connected with hepatitis C's status as 'under construction' (Duffin, 2004a), where information is constantly developing. Others felt that that this was due to caseload or because their support needs went beyond what a specialist medical team could (and should) provide. A key finding is that input is required from a much wider range of professionals and services (detailed below).

Despite a clear need for the development of services, the research found a postcode lottery continues to exist across all services (including medical ones). Participants were aware of the financial and other resource constraints, and that any improvement would require strong

relationships between professionals in multiple organisations (i.e. substance use services, social work services, health services, sexual health services and peers with varied experiences of hepatitis C).

If hepatitis C is not addressed locally, this could potentially lead to health inequalities and different materialisations of experience, including concentrations of hepatitis C (genotypes) in particular areas (Fraser and Seear, 2011). Ongoing reforms to housing benefit, including the introduction of the size criteria or 'bedroom tax' (DWP, 2013a) and the migration of families into different areas of the country, may mean that specific geographical areas find themselves with increased numbers requiring support and treatment, further reinforcing the need for consistent (minimum) local services. The lack of accessible services was explored in the thesis as a form of structural and indirect psycho-emotional disablism (see research question three).

Central to all of these findings is the rhetoric of 'increasing effectiveness' (Fraser and Seear, 2011), which is perpetuated in the development of new drugs. This potentially obscures the needs of those undergoing treatment *now,* and allows services and a wider range of professionals to elide the responsibility to provide support and information to those living with, and on treatment for, hepatitis C.

Treatment

Participants described long and arduous treatment experiences, a form of 'embodied labour' (Keane, 2011). Treatment impacted on the majority of participants' bodies and lives mentally, physically and emotionally, and their discussions of treatment were characterised by ambivalence. This ambivalence was explored using Derrida's (1981) concept of *pharmakon*, meaning simultaneously poison *and* remedy. The thesis explored how the remedy aspect of treatment was frequently privileged by participants, professionals and in

wider structural responses to hepatitis C, with the 'toxic'' aspects under supported and invalidated. Treatment is presented as a means of avoiding future ill health (such as liver damage, cancer or even death), whilst at the same time creating impairments (both short and long term) around which participants received limited support.

All participants were aware of the possibility of side effects, but these were displaced either as 'individual' (i.e. not likely to happen to everyone) or a small price to pay in pursuit of the wider goal of clearing. The thesis found that this displacement was enacted and materialised on a micro scale during interviews and on a macro scale with the lack of support services on treatment. This ambivalence needs to be materialised through structural service responses, which acknowledge the illness involved in becoming well, and that divisions between ill and well, disabled and non-disabled, are not fixed, but depend on enactments and contingent realities.

A key contribution to knowledge made by this thesis was the potential role for social work in supporting people with hepatitis C. These findings show that social work (both statutory and third sector) support for people with hepatitis C exists sparsely in the UK. There is an urgent need to build capacity here, as the thesis highlighted the intra-active nature of hepatitis C with life circumstances, ageing, additional impairments and disabling barriers. If these additional needs are not adequately taken account of and responded to, then the sole focus on treatment enacts hepatitis C as a public health problem which individuals need to take responsibility for (Fraser and Seear, 2011), rather than an experience which impacts on, and is affected by, wider social networks and structures.

The thesis highlighted a vital and unique role for social workers given their skill set and expertise. Social workers are ideally placed to deal with the ambiguity and complexity of supporting service users with the issues identified in this thesis, both as a specialist role and as part of an existing team where hepatitis C may not be the key focus.

The thesis highlighted specific areas where social workers could and should become involved, ranging from the provision of information and referral to testing, through treatment and post treatment. Social workers' daily contact with those who have the potential to be affected by hepatitis C and their engagement with 'messy' issues faced by people who use services, mean they are well placed to address hepatitis C whilst paying attention to the wider context of service users' lives.

The thesis highlighted that those with hepatitis C could benefit from social work involvement, from information provision and discussion, to facilitating access to treatment, advocacy and peer support. Most importantly, social workers could address needs which at present are the most under supported - those relating to housing, finances, childcare, family and relationship issues. There is also a unique role for social work in the post-treatment phase where medical support is limited.

However, current cuts also risk disinvestment in services as local authorities and health boards set their own priorities (Daddow and Broome, 2012; Hepatitis C Trust, 2013d). This may mean that services are reduced to such a degree that social work involvement becomes disabling, rather than enabling (Roulstone, 2012). Given that social workers are taught to critically reflect on current systems and to challenge oppression (Findlay, 2014) they could (and should) play a role in lobbying for improved responses to and services for hepatitis C and against cuts to services.

Participants acknowledged that there was no 'quick fix'. The danger in times of austerity is that the lack of a quick or easy solution in responding to hepatitis C means those living with it are marginalised altogether. By recognising and taking an active role in the lives of people with hepatitis C, social work can challenge the hidden and 'silenced' nature of hepatitis C (and indeed co-infection).

Finances: employment and welfare benefits

The financial aspects of living with hepatitis C formed a central finding within the thesis. Whilst money has been recognised as vital in maintaining stability (Hopwood and Treloar, 2007), and poverty can be intertwined with drug use (Seddon, 2006), there has been less of a focus on participants applying for welfare benefits or their experiences of employment.

Most participants described changes to their work patterns during the treatment and post treatment period, so this is a specific area where information and support are required. A few participants described obtaining a positive response from employers who made reasonable adjustments or allowed them to work flexibly. Others described a lack of knowledge and understanding (both themselves and from their employers) regarding entitlements under legislation, or the degree to which they were covered. This highlights that the process intended to enable working, is actually vague and difficult to apply in practice (Crooks *et al.,* 2013), particularly when combined with the hidden nature and the lack of awareness around hepatitis C.

As explored in chapter nine, the process of pursuing rights under legislation can result in greater disablement. Those who did report reasonable adjustments felt that this was due to the size and nature of their employer, as well as the requirements of their job. This may prove even more difficult for those who find themselves in low paid and insecure employment (Patrick, 2011). There is a notable lack of publicly available information regarding participants' entitlements to reasonable adjustments at work under the Disability Discrimination Act (now covered under the Equality Act, 2010), adding to the silent and marginalised nature of hepatitis C as a political (as opposed to medical) issue. It further enacts hepatitis C as a virus which does not affect those in employment and is of marginal concern in the workplace.

Limited perceptions around what constitutes work were also made visible, given that the majority of participants were working unpaid, providing support and information and raising awareness of hepatitis C - both within their social networks and in a wider arena – in a way which potentially saved vast sums of money for government and services.

Those who encountered disabling barriers in employment, or impairment/treatment effects too severe to continue working, described attempting to claim benefits. This was a particular area of difficulty for participants and the findings of this thesis mirror the experience of many (other) disabled people. Participants described occupying a liminal position, enacted in applications as fit for work, or ineligible for benefits, when in practice the opposite was the case.

The experience of claiming welfare benefits was not an area I initially set out to explore. This adds to the value of the research in terms of exploring and raising issues which are current and important to people with hepatitis C. Participants described specific costs associated with living with hepatitis C, including diet, support, fuel and travel. This placed a strain on resources, which is arguably detrimental to a positive (and potentially successful) treatment experience.

The findings related to two benefits in particular ESA and DLA. Almost half of the sample reported applying for benefits, with a significant number being found eligible on appeal (where this was pursued), although they reported a lack of professional information and support concerning their possible entitlement. Just two participants had accessed support and information from formal services or helplines. Others described gaining support and advice from peers, concerning entitlements and attending medicals, though they described this as adding to the sense that they were acting fraudulently (Reeve and Soldatic, 2012) or 'didn't deserve' support, see research question three.

A key finding related to the participants' sense of entitlement to claim welfare benefits participants felt (mirrored in other chronic illness literature) that the processes used to determine eligibility did not take account of the hidden or fluctuating experiences of living with hepatitis C. The liminal experiences of pre diagnosis and post treatment are not adequately accounted for, either in services or captured in processes such as DLA/ESA applications.

The application process was disabling on two counts. First it forced participants to detail their impairments in a way which enacts them as incapable; this is an example of direct psycho-emotional disablism (Reeve, 2002; 2008). Second, that not being found eligible enacts them as not 'ill enough' for financial support effectively ignoring their experiences of impairment and disablism (Bambra, 2012) and that providing financial support to some people now, ultimately saves money and resources in the longer term.

Participants felt that the descriptors and assessment did not take adequate account of the impact of the hepatitis C treatment, which is when they most needed support. The fixed nature of the forms effectively 'others' that which does not fit and makes it absent. Changes to benefit entitlement and increasingly restrictive criteria, will mean those who may have previously been eligible for a small amount of financial support [integral to their participation in society (Campbell *et al.,* 2012)] will no longer have this, placing greater pressure on local services, further reinforcing the need for knowledge among social workers.

Post treatment

A central finding of the thesis related to the post treatment experience. Many participants indicated that SVR did not necessarily equate with improved health and instead, enacted new impairments and challenges which have only recently begun to be recognised (Foster

2013). Participants described needing information concerning the possibility and duration of effects, as well as support and services, to address the post treatment period.

Those who reported post treatment effects described being unaware how long the treatment would take to clear from the body, or only being told towards the end of treatment. The remedy aspect of the treatment is privileged where the toxic aspect is silenced. Others acknowledged that they had been informed of the possibility of post treatment effects but had not expected it to happen to them, exacerbated by the focus on the 'individual' nature of treatment and the lack of formal support services. The thesis suggested that the marginalisation of the post treatment experience by services, makes a wider point about the dominance of medicine, given that there were clear differences in what medicine was prepared to provide support for and the embodied experiences of the participants (cf. Persson, 2004; 2006). Currently hepatitis C is treated using an acute model of care with very little acknowledgement of the long term or lasting impact (Paterson *et al.*, 2006).

These findings opened up discussion of the design of post treatment support service. It was suggested that important lessons could be learned by looking at support provided to cancer survivors, including: an end of treatment support pathway, contact between the GP and specialist team to deal with any on-going medical and social needs, the provision of multidisciplinary support and information, signposting to support with finances and returning to work, along with peer and emotional support.

This thesis explored the application of self-management programmes (National Cancer Survivorship Imitative, 2013; Expert Patient Programmes, 2013), given that these are a key component of cancer survivorship programmes and Expert Patient Programmes are being increasingly rolled out within hepatitis C services. The thesis argued that the focus on self-management potentially perpetuated the individualising responses which already dominate.

While these forms of support may be valuable in some respects, they are still rooted in the belief that *impairment causes disability* rather than the barriers faced by people with hepatitis C. Further to this, existing research found that many of the barriers faced by participation in EPPs were similar to the ones already faced by participants for example, related to transport and childcare (Paterson and Hopwood, 2010). The aim of EPPs is to reduce 'dependency' on services and manage costs - counter to the philosophical, ethical and political commitments of this thesis. I suggested that the concept of 'recovery in' (Davidson and Roe, 2007) might be more useful as a means of capturing the messy, nonlinear nature of post treatment. This potentially has added value given its increased currency in both drug use and mental health fields, which may contribute to more high profile enactments of hepatitis C and treatment.

The next research question focuses on how participant accounts contributed to, and drew from, current cultural understandings of hepatitis C.

Research question two

What do participant accounts reveal about the cultural and social position of hepatitis C in the UK at the moment, and how can this improve our understanding and response?

Whilst talking about their support and information requirements, it became clear that participants' needs (and perceptions of them) were shaped by understandings and expectations related to the cultural position of hepatitis C. With this in mind, the thesis foregrounded selected aspects of participant accounts and discussed how these elements co-constituted hepatitis C, its treatment and the participants. Insights were offered as to how these understandings might enable reflection on, and improvement of, service responses.

Chapter six, in particular, explored the dominant values and assumptions associated with specific metaphors and how they constitute groups in positive and negative ways (O'Brien, 2009). The participants' use of the metaphor 'hepatitis C as a silent killer' established that although it was originally intended to refer to the silent nature of individual symptoms, it actually served to highlight the structural silence (lack of political response, lack of funding, lack of awareness) surrounding hepatitis C. Participant accounts also made visible the intra-action between the 'silent killer' metaphor with cultural beliefs around 'self-inflicted' hepatitis C, drug use and personal responsibility for health, which serves to re-enact and reinforce the dominance of medical treatment.

The support and information needs of participants were related to the low profile of hepatitis C and the lack of support, and necessitated comparisons with other high profile illnesses, ultimately both resisting and reinforcing oppression and psycho-emotional disablism. A central and unique finding was participant's use of the comparison between hepatitis C, cancer and chemotherapy across a variety of topics. Though the comparison between hepatitis C treatment and chemotherapy appears in some literature (Hopwood *et al.*, 2006; Harris, 2009; Leavitt, 2010), this has not been extensively explored.

Cancer was perceived and re-enacted by participants as a serious, well-funded, publicly supported, high profile illness, involving an often lengthy and difficult treatment. This was used by participants to illuminate the cultural position of hepatitis C as trivial, blameworthy and vastly underfunded with a treatment which is inadequately understood and a poor service infrastructure.

Participants' comparisons with cancer were useful because they helped convey the seriousness of treatment and enabled participants to access support and information from friends and services though the comparison as *pharmakon* was also made clear. The chemotherapy comparison involved significant emotional work (Thomas *et al.*, 2002)

compounding participants' anxieties about being exposed and ultimately re-enacting the silence associated with hepatitis C, which makes concealment necessary. The perceived 'inferiority' of invisible impairments remains unchallenged. In making comparisons between hepatitis C (treatment) and cancer (chemotherapy), participants augmented and maintained a hierarchy of impairment whereby people with cancer were seen as 'deserving', whilst those with hepatitis C were 'less deserving' of support. There was evidence that participants had internalised this as they consistently added caveats in their discussion of the comparisons between cancer and hepatitis C.

However, positioning cancer as 'superior' also obscured the difficulties experienced by people with cancer that were similar to those experienced by participants, including limited support due to funding constraints in local areas, the fear and isolation associated with a diagnosis, the unmet needs (Thomas *et al.*, 2001), and difficulties in being found fit for work or not knowing about welfare benefit entitlements. The implications of this on their sense of self are discussed in greater depth under research question three.

Comparisons were also made between HIV and hepatitis C. This is perhaps less surprising than the comparison made with cancer, given that HIV and hepatitis C are both blood borne viruses frequently compared within existing literature (Treloar *et al.*, 2002; Copeland, 2004; Davis and Rhodes, 2004; Korner and Treloar, 2006; Harris, 2009b; Treloar and Rhodes, 2009; Swan *et al.*, 2010; Farrell and Comisky, 2012). The comparisons made by participants in this study reveal important insights into the current cultural position of HIV, offering insights for HIV services as well as those associated with hepatitis C.

Unlike cancer (which maintained a position of superiority in the hierarchy of impairment), HIV's position shifted between being 'better than' having hepatitis C and being 'worse than' having hepatitis C, further exhibiting how stigma, oppression and disease are temporally, discursively and intra-actively constructed depending on social, cultural and political forces

(Fraser and Seear, 2011) and social group (Harris, 2009a). Furthermore, these phenomena can be enacted, re-produced and remade, via intra-actions between policy, public responses and people affected. This shows that oppressive treatment is not inevitable but, rather, is dependent on context and thus open to change (Reeve, 2008). The shifting nature of the comparison also means that hepatitis C may need to be addressed differently among different groups (see also Lekas *et al.*, 2011)

Most of the gay men I interviewed who were co-infected described HIV as *'more socially acceptable'* and better understood than hepatitis C. HIV was perceived as easier to manage than hepatitis C and treatment was perceived as less arduous - helpful for those who go onto HIV treatment after treatment for hepatitis C. The amount of information available around HIV treatment threw into sharp relief the lack of hepatitis C information. Here the comparison with HIV highlights important lessons that can, and should, be taken from strategies to support those with HIV.

The thesis found that the pride some of the men with HIV felt regarding their status, did not exist in the same way for hepatitis C. Participants felt that there was a silence around hepatitis C within communities and organisations (both in terms of health messages and visibility in the community), further contributing to its unacceptability and creating a cycle of stigma, shame and silence (Owen, 2008). Participants pointed to the need for an increased profile, and ownership (Owen, 2008), of hepatitis C within the gay and HIV communities, but described concerns over the relevance and effectiveness of a campaign like the one which existed for HIV in the 1980s.

For participants who did not live with HIV but had been exposed to the hard hitting UK campaigns of the 1980s[157], the shifting and contingent nature of understandings of HIV was made clear. HIV/AIDS (frequently referred to as AIDS – a legacy of the campaigns and media

---

[157] Notably the TV and leaflet campaign by the British Government 'AIDS Don't die of Ignorance' (Central Office of Information for the Department of Health, 1987).

messages and indeed the lack of contemporary presence) was simultaneously used as an example of an blood borne virus which is serious and stigmatised *and* perceived to be well understood and supported (cf. Munoz-Plaza *et al.,* 2010). HIV was seen as culturally more significant than hepatitis C, both in terms of actions that have been taken to raise awareness and the visibility of illness and death from HIV globally. As with cancer, the comparisons with HIV obscure as well as highlight issues or difficulties for those with hepatitis C and with HIV, including: cuts in funding to local and national HIV support services, waning public awareness, the differences in global responses to HIV and the need for a holistic response.

Hepatitis C as a disability issue.

This thesis made an important contribution in initiating discussion in academic and practice arenas around hepatitis C as a disability issue. This thesis acknowledged hepatitis C as a chronic illness and raised the possibility of including people with hepatitis C within the disabled people's movement in order to build on areas of common experience, and challenge the individualist focus that currently predominates.

Participants held mixed views on identifying as disabled with hepatitis C. The hinterland of messages around impairment and disability as 'personal tragedy' (Oliver, 1990; Thomas, 2007), and largely static and physical (Grewal *et al.*, 2002), meant that a disabled identity was enacted as simultaneously undesirable and not applicable to people with hepatitis C, given it is a fluctuating and hidden impairment. Additionally, the current enactments of disabled people who claim benefits as 'shirkers and scroungers' (Garthwaite, 2011) means that adopting a disabled identity, might further enact people with hepatitis C in negative ways.

This thesis has made a unique contribution in initiating a discussion around the inclusion of people with hepatitis C within disability studies and argued that there should be greater

recognition of the disabling processes and barriers they face in accessing information, support, recognition and treatment. At present, the institutional processes used to define the ability to work (for ESA) and determine eligibility for Disability Living Allowance (soon PIP) frequently exclude and marginalise the experience of people with hepatitis C. There is little (if any) guidance around the application of legislation (e.g. protection under The Equality Act, 2010) to people with hepatitis C, or people undergoing treatment. The lack of acknowledgement of their needs and the absence of publicly available information and support concerning how the legislation could apply, further enacts hepatitis C as something which must be addressed and managed individually. A consequence of this individualism is that hepatitis C becomes depoliticised (Persson, 2003) and an exercise in self-management (Race, 2001), which is further reinforced through the proliferation of EPPs.

There were a small number of participants who described themselves as disabled people or referred to incidences where disability legislation and entitlements might apply to themselves and others. This is explored in greater depth under research question three.

In exploring the cultural position of hepatitis C, the role and position of treatment is key. Treatment was recognised as cultural, medical phenomena (Persson, 2003) used to address participants' liver damage and impairment effects, but also to enact and re-enact discourse around (moral) responsibility for health and wellbeing. There was evidence that participants undertook treatment for ontological, as well as health reasons, particularly where treatment was one way of addressing the oppression, stigma and blame associated with hepatitis C. Paradoxically, this reinforced its unacceptability and reinforced normative ideas about the clean, closed body (Fraser and Treloar, 2006), as well as binary understandings of health/illness, disabled/non-disabled, good drugs/bad drugs.

Pharmakon and pharmakos

The concept of *pharmakon* was used to challenge these binaries and unfold the ambiguities participants expressed around treatment, and those which were present in the structure of services. *Pharmakon* acknowledges the contingent enactments of hepatitis C (and treatment) and how these enactments shape those who are living with, and being treated for it.

Participants' accounts of treatment as being simultaneously damaging to health and necessary for attaining it were explored. Discussion took place around the marginalisation of the inseparable 'toxic' aspects of treatment which are ignored by current services. A key finding is that the current focus on increasing effectiveness and medical progress, with regards to treatment (see Fraser and Seear, 2011), obscures the impact of treatment and the need to pay attention to the wider implications and barriers when living with hepatitis C. The singular nature of the treatment response makes living with hepatitis C an increasingly invalid ontological status (Hughes, 2012).

The privileging of the remedy (and the silencing of the poison) became particularly clear in participant discussions of the post treatment experience and the way in which this phase of living with the virus is poorly addressed and acknowledged. This is a materialisation of the politics and authority of medicine - effects of treatment which cannot be managed with medication are marginalised. Acknowledging treatment as pharmakon forces us to think through ambivalence, the need to accommodate illness in becoming well, and develop this within services for hepatitis C.

The related concept of *pharmakos*, meaning scapegoat, was also used to explore the intra-action between hepatitis C, injecting drug use, treatment and treatment effects. *Pharmakos* - a concept I discovered fortuitously in reading both disability studies literature and literature from the drugs field - was used to highlight commonality between those with hepatitis C and

(other) disabled people. The crossover in these two bodies of literature lends weight to my argument that hepatitis C should be considered as a disability issue.

The concept of *pharmakos* is both timely and relevant given that scapegoats are most commonly utilised in times of difficulty and unsettlement to rid the community of that which does not conform to moral order. At the time of writing, the coalition government has planned, or implemented, deep and enduring cuts to services which provide support to those who most require them (Soldatic *et al.,* 2012; Patrick, 2012), together with increasing pressure on resources and services. The focus on depleted and stretched resources (within the NHS, local authorities and government spending) enacts and materialises hepatitis C participants and treatment as *pharmakoi* at various points. Treatment as *pharmakos* is visible in that it acts as a remedy for overstretched services. Those with hepatitis C are enacted, and re-enacted, as *pharmakos* for the needs of the wider community, by reducing pressure on NHS resources, available livers for transplant and the potential spread of the virus in the wider community. The limited attention paid to post treatment effects in service responses also enacts participants as *pharmakos* for the 'failures' of medicine.

The concept was also used to highlight parallels between people with hepatitis C and the historic treatment of disabled people. As those with hepatitis C exist on the margins, so too do (other) disabled people. The increased scapegoating of disabled people who attempt to claim benefits - which extended to participants with hepatitis C - directly influenced their willingness to claim and identify as disabled, and re-enacted a disabled identity as undesirable (Garthwaite, 2011). Scapegoating was also particularly visible in the pressure participants felt to do treatment (via discourses of uncertainty, infectiousness and responsibility for health), particularly in light of participants' internalised perceptions of hepatitis C as 'self-inflicted'.

The thesis highlighted how those who take treatment existed 'inside' and 'outside' of communities and institutions; for example, the current emphasis on treatment (and the experiences of both structural and psycho-emotional disablism) enacts hepatitis C as something which must be eradicated. Yet, people with hepatitis C remain integral to clinical trials, professional development and employment of a diverse range of professionals.

Furthermore, treatment was described by participants and professionals as a 'turning point' when this actually occludes the power relations which only make treatment available to those who have stopped using drugs. For those who had previously used drugs, a clear division was not maintainable given the crossover with the drug use ritual evoked in treatment preparation, and the blurring of boundaries between good and bad drug use. Treatment for hepatitis C was frequently prioritised over other medical investigations or surgery. Whilst this may be connected to contra indications associated with anaesthetic or viral load, others described being told that doctors did not want to put themselves at risk, potentially pushing them further onto the margins and ultimately further into treatment.

It is important to say here that research questions two and three are co-constitutive and have mutually informed each other, hence the focus on psycho-emotional disablism explored below.

Research question three

To what extent do participants experience stigma and discrimination?

Stigma has been recognised as a key component of the experience of living with hepatitis C (Crofts *et al.*, 1997; Treloar and Hopwood, 2003; Richmond, 2008) and I initially set out to explore experiences of stigma and incidences of discrimination among people living with hepatitis C in the UK.

I have been informed by Harris' (2009a) recent work which explored how stigma is constituted for people with hepatitis C and that of Fraser (2011) which highlights that stigma does not exist prior, but is enacted and materialised through specific practices. The thesis has built on this work, recognising the power relations and forces which constitute hepatitis C as stigmatised and undeserving. For example, the hidden and fluctuating nature of impairment and treatment effects, the 'individual' and variable nature of treatment, and the association between drug use and hepatitis C, all of which impact on participants' wellbeing and shape wider (perceptions of) entitlement to support.

A key finding is that although participants made frequent reference to stigma and did describe serious incidents of directly stigmatising treatment (for example, having their blood labelled as infectious, being avoided by professionals, being deterred from surgery), these incidences were less common than participants accounts of *knowing and feeling* that hepatitis C was stigmatised irrespective of whether they had experienced it. Many participants described feeling shocked, embarrassed or inferior in interactions with friends or professionals, which was enacted on a macro level in the structure and funding of responses. This, coupled with the frequent referral to the 'individual' experience of living with hepatitis C, limited infrastructure and the lack of awareness or profile of participant rights and entitlements under legislation and guidance, opened up an opportunity to recognise and discuss participants' experiences in terms of oppression and disablism, rather than stigma - specifically the experience of psycho-emotional disablism.

The decision to theorise the experience of hepatitis C using disability studies is commensurate with the political and ethical commitments outlined throughout the thesis concerning the kinds of realities I want to enact. The move away from stigma, (which can be individual and has pervaded the hepatitis C literature) was an important aspect of this thesis.

Talking about hepatitis C as disablism breathes new life into participant experiences and the action to be taken.

Recent work by Harris *et al.,* (2012), Paterson *et al.,* (2013) and Butt *et al.,* (2008), has made the links between stigma and wider social and institutional structures, which meant that the time is particularly ripe to initiate a discussion around disablism and hepatitis C. The concept of psycho-emotional disablism, which recognises that oppression operates at an inner level affecting not only what people can do but what they can be (Thomas, 1999; 2007; Reeve, 2008; 2012a), was highly relevant to the experience of living with hepatitis C.

Participants described experiencing structural disablism in the services they visited. They referred to inaccessible and remote services, cramped and run-down clinics, segregation from others, difficulties with transport to and from appointments, lack of information and support, and lack of reasonable adjustments in employment. These barriers were rooted in poor understanding and inadequate recognition of the needs and experiences of people with hepatitis C. These structural barriers and challenges functioned as a message that people with hepatitis C were unworthy of support and needed to be hidden from view, thus re-enacting hepatitis C as trivial and unwelcome in wider society; what Reeve (2012a) terms as indirect psycho-emotional disablism. Given the current constraints to services and lack of available funds, it is possible these experiences will increase rather than decrease.

The thesis has explored how frequently in attempting to address or circumvent stigma, participants both resisted and became complicit in their own oppression. The hierarchy of impairment, a manifestation of internalised oppression and a central component in psycho-emotional disablism, has been explored at length under research question two, but is clearly a central component in addressing research question three, as the comparisons with cancer can be interpreted as a manifestation of absorbed negative perceptions and a form of resistance.

Participants also described 'passing' (explored above) or using disclosure strategies which concentrated on more 'acceptable' (i.e. household) transmission routes - thus marginalising drug use. This may have implications for some participants' sense of self by denying, or maintaining, the unacceptable nature of their former drug use in the wider goal of telling people about it. Further to this, the focus on transmission route means that participants are fulfilling a wider education role rather than garnering support for themselves.

Here participants' information and support needs, intra-act with cultural position and psycho-emotional disablism. Participants described information (what little there was) enacting hepatitis C, and therefore themselves, in particular ways (Fraser and Seear, 2011). For example including a focus on transmission at the treatment stage, maintains hepatitis C as transmissible and negative and carried only by people using drugs. Further, media images related to 'scrounger rhetoric' inhibit participant sense of entitlement to benefits enacting them as scapegoats for poor government spending plans and priorities. Information on the DWP/Hepatitis C Trust website which enacts benefits as a form of dependency reinforces the dominant position that they should not be claiming. This overlooks that benefits can be a form of maintaining work and marginalises the daily challenges which those with hepatitis C face.

There was evidence that although many participants were concerned for their health (connected to the 'uncertain' nature of hepatitis C and its impact) other participants sought treatment for moral and ontological reasons; this suggests that living with hepatitis C was not acceptable[158], that taking treatment was part of taking responsibility, or was a way of

---

[158]This sense of ontological invalidation is unlikely to be assuaged by messages from the national hepatitis organisation, The Hepatitis C Trust, which state: 'knowing you are no longer carrying an infectious and harmful virus may help you to feel better about yourself'. Whilst it is not my intention to dismiss that this may be the case for some people (indeed, was the case for my participants) here contagiousness is prioritised over harm and there is an increased sense of responsibility to do treatment.

addressing feelings of shame and dirt, and the concern that it might be passed on to others, rather than explicitly having concern for their own health.

Furthermore, the marginalisation of the post treatment experience discussed above, enacts those who can no longer be treated with available drugs or whose impairments cannot be quantified through testing, as of limited concern and 'worth' to medicine (see Reeve, 2004). In practice, the lack of support enacts those for whom treatment failed as of little interest unless they can participate in newer clinical trials.

Disclosure (or not) of hepatitis C status proved to be a key element and event in the experience of stigma, discrimination, and what I subsequently theorised as incidences of psycho-emotional disablism. Participants described protecting others from what they felt was an unacceptable diagnosis or a diagnosis acquired via unacceptable behaviour. Some described feeling compelled to disclose for the safety and wellbeing of others (see above); others described taking a more balanced approach and were better informed of the requirements to disclose.

Naming the experiences of people with hepatitis C and the subsequent impact on them as disablism, enacts and materialises it as recognisable and unacceptable, and connects individual feelings and experiences to wider societal, cultural and political structures. It also opens up the possibility for collective action with other disabled people and organisations lobbying for the rights and possible ways to address it (i.e. improved relationships with workers and lessons from existing services). It also highlights the cross cutting nature of experience, such as those described by co-infected gay men and offers the opportunity to explore the intersection between disablism related to hepatitis C and that faced by those who use drugs, where little research exists.

Participants described resisting negative views, although this often depended on how the initial diagnosis was handled, their previous experiences and messages from peers. This

reinforces Milton's (2012) findings that positive relationships with others can combat psycho-emotional disablism. Reeve (2012b) points to the importance of teaching student professionals (specifically social work students) about the impact of psycho-emotional disablism and how to combat it in the course of their work. Opening up this discussion to a wider number of students and professionals, not only addresses disablism on a micro level, for the individual service user, but helps move hepatitis C into an arena where it can be discussed as a disability issue.

This chapter has brought together the key findings from the research and addressed each of the three research questions in turn. Research findings are intertwined and overlap, testament to the messy and complex enactments of hepatitis C as experienced by those living with it. Drawing on these conclusions, and acknowledging the intertwining of hepatitis C services, appendix one makes important recommendations for practice.

Appendix one: Recommendations and areas for further research.

The findings presented in this thesis support a number of recommendations at an academic, practice and policy level, to improve responses to living with, and being treated for, hepatitis C. Before discussing these in greater depth, an important point must be made:

This thesis has explored the multiple, messy nature of living with hepatitis C: how the virus and people with it are co-constituted and enacted via social, cultural and political forces (Fraser and Seear, 2011). It has emphasised that understandings presented here are necessarily partial, thus raising issues and questions regarding the development of recommendations, which imply stability.

The theoretical commitment to contingency is balanced with the commitment to positive changes for people with hepatitis C - something which inspired and sustained this research from the outset - and the need for actionable points which can be absorbed, and implemented, by services and policy makers in these 'messy' times.

Thus, recommendations are based on the enactments of hepatitis C made visible within this thesis, with the aim of contributing to realities and enactments with new social and material consequences[159] although is important to acknowledge that these recommendations have their own agentic qualities (Moore and Measham, 2012). In managing this, I have paid attention to, and reflected on, the kinds of realities I want to contribute to, with a mindfulness (Warin, 2011) about my choices.

The chapter is organised into areas of recommendation. This is then subdivided into sections for relevant groups, though clearly recommendations in one area intra-act with others.

---

[159] For example, challenging the dominance of a medical response and bringing into being realities which acknowledge the role of social support and social work alongside this.

Although co-infection is covered in a specific section below, all recommendations should be considered in the context of addressing co-infection.

Key recommendation: Development of local and national services and infrastructures of support across the UK.

This thesis has shown that there is a vital need for the development and improvement of an infra-structure of support, both locally and nationally, without which the silent nature of hepatitis C is further reinforced. Given the current changes to public services, the NHS and welfare, these recommendations are particularly important and timely.

All stakeholders

1. Adequate funding and investment in hepatitis C awareness, education, testing, support and treatment should be addressed as a matter of urgency. This is the cornerstone of the recommendations which follow, without which the recommendations will be difficult and even impossible to implement, ultimately leading to longer term costs both at a micro and macro level.

2. Addressing hepatitis C and co-infection needs to be recognised as a priority by service commissioners, including new NHS Health and Wellbeing Boards, Clinical Commissioning Groups and Local Authorities.

3. Local hepatitis C and/or blood borne virus strategies need to be developed in all local areas as a matter of urgency, with clear delegation of responsibility for development, implementation and review. Links to existing cross cutting strategies, teams and actions should be made. As this thesis has shown, participant needs went beyond drug services, so inclusion *only* in drug strategies is inadequate.

4. Local multidisciplinary networks of services, including sexual health services, social work/care services, HIV services, housing services, drug services, financial support services, and health (including mental health) services, should be brought together

to explore the issues in their local areas and to plan and develop services which acknowledge social, as well as medical, consequences of hepatitis C.

5. There is a need for adequate recognition and funding for support around the issues raised by hepatitis C (and its treatment) more widely. This includes funding for treatment, but also extends to support around housing, benefit changes, employment and co-infection with hepatitis C.

6. Social workers, as professionals who are trained to challenge oppressive systems and to enable service users to empower themselves, should be lobbying for improved and expanded hepatitis C services, included integrated services and specialist social work teams.

7. Social workers should also be emphasising their unique role in supporting people with hepatitis C across user group,. This has the potential to be mutually beneficial in terms of addressing negative perceptions given that hepatitis C and social work and social workers are potentially poorly understood in the media and in wider society.

8. Specific, tailored information should be developed for various professional groups (e.g. housing service and social workers) and made easily accessible, to highlight where and how hepatitis C is relevant to them and junctures where they might become involved.

9. Consideration should be given to expanding the remit of HIV services to incorporate hepatitis C. This enfolds the needs of people with hepatitis C into an established and high profile service. This is not to obscure the differences in need or services for the different viruses, but to improve the availability of support and to promote the recognition of hepatitis C among HIV services. Clearly this requires adequate funding.

Key recommendation: Increased awareness, information and knowledge

Based on the findings of this thesis, specific recommendations here relate to the development and enhancement of awareness of hepatitis C, the distribution of information and the development of knowledge.

General public

In addition to current campaigns, there is a need to:

1. Expand campaigns to highlight the nuanced and complex experience of hepatitis C with a range of representations. Those that identify the need for testing should sit alongside representations of what it is like to live with hepatitis C on a daily basis, as personal and embodied experience[160], which includes representations of how a body with hepatitis C (and on treatment) might feel. This is intended to encourage testing, highlight the need for support and garner greater attention from a wider range of organisations.

2. Greater attention to the context of living with and being treated for hepatitis C, and the structural and psycho-emotional barriers, should also be addressed in information and awareness campaigns, including the subsequent impact on employment, social relationships, and finances.

3. Specific attention should be paid to the assumptions inherent in information provision and information should be developed in ways which do not perpetuate negative views around hepatitis C.

4. There is a need for a greater cultural presence of hepatitis C. This clearly requires further research but might include sensitive and accurate media portrayals, including characters in radio plays, soap storylines, medical dramas, as well as a greater number of billboard campaigns and 'real life' stories.

---

[160] Lesley Jenkins Radio 4 appeal is an example of this (see BBC Radio 4 appeal for the Hepatitis C Trust, 2012).

5. The presence of hepatitis C in a greater number of public places, emphasising that hepatitis C is a part of life, not just part of a health campaign which people perceive as relevant or not. This might include partnerships with chains or brands which display messages and information about hepatitis C on products, or leaflets which can be picked up. This could build on recent progress made by the World Hepatitis Days[161] over the last three years, with targeted campaigns to tie in with this.

Co-infected gay men

Further research is needed here, but as a starting point the following recommendations are made around increased awareness among the gay population, specifically those who are HIV positive:

1. Press and poster campaigns highlighting hepatitis C and HIV co-infection, both online and offline in public places.

2. Harnessing social networking to raise awareness and provide signposting to support.

3. Combatting the structural silence around hepatitis C via inclusion of it in gay men's health surveys, local awareness campaigns and academic social research literature.

4. The development of specific drug use and harm reduction messages, and information messages available locally.

5. Development of local and national strategies around co-infection.

6. Specific training and awareness around co-infection for professionals such as drug workers, HIV support workers and social workers.

7. Personal stories in the gay press, hepatitis C specialist organisation websites and HIV specialist organisation websites.

---

[161] For WHD 2013, Scotland's 'big red C' campaign which ran alongside the Hepatitis C Trust's big purple C campaign in England displayed giant (two metre high) 'C's' in public places across Scotland, in areas where local NHS boards were involved in the campaign. These were accompanied by volunteers who answered questions and provided information. In England these were accompanied by members of staff from the Hepatitis C Trust and the testing van (Hepatitis Scotland, 2013; The Hepatitis C Trust, 2013e).

Family and friends

1. Specific information and guidance should also be developed across a number of areas for family, friends and carers; including clear and realistic information regarding transmission and the implications of a diagnosis, on treatment and post treatment, highlighting the fluctuating and hidden nature of hepatitis C impairment effects, as well as managing the impact on relationships and emotions.

2. This should be developed in partnership with current and previous families who support people with hepatitis C, and be made available both in written formats and online.

3. Adequate support should also be available for those caring for people with hepatitis C.

Professionals

This research found that living with hepatitis C impacts in multiple ways and that specific guidance and training should be developed and delivered specifically for the professionals outlined below:

Department for Work and Pensions and ATOS staff

1. There is a need for greater training and specific guidance for DWP and ATOS staff around hepatitis C (and co-infection) impairment and treatment effects.

2. Ideally this would take the form of dedicated organisational training, but as a minimum should extend to accurate updated information on the DWP website.

3. This should address the cumulative impact of illness experienced before diagnosis and before treatment (which may affect eligibility for benefits), the effects of treatment and post treatment, and the impact this can have on a person's life.

4. This should be regularly updated in line with welfare reforms and treatment developments.

Welfare Benefits Advice Organisations

1. These services should also be provided with easily accessible training and guidance on hepatitis C in order to inform people about possible forms of support and welfare benefits applications, and to assist with completing and appealing these where necessary.

2. Cuts to legal aid and funding for welfare benefits organisations should be reconsidered urgently, given the disproportionate impact of the cuts upon those hepatitis C is likely to affect.

Social work teams

1. There is a need for UK specific guidance and information for social workers (team specific), explaining where and how hepatitis C (and co-infection) might be an issue. This might include providing support to parents on treatment within children and families teams, acknowledging the additional needs materialised on treatment which may interact or exacerbate existing impairments. It might also include supporting older people to access testing and treatment, as well as those working on specific substance use teams. Guidance should be developed in partnership with specific service user groups.

2. There should be a greater presence of hepatitis C on professional social work education courses - at undergraduate, postgraduate and continuing professional development levels. This might be included on courses that deal with substance use, immigration and asylum seeking, child protection as well as disability and ageing.

3. This might eventually be extended to broader health and social care courses, such as National Vocational Qualifications, for those who may work in support worker/personal assistance roles.

GPs

There is still an urgent need to raise and augment awareness among GPs across the UK.

1. There should be a greater presence of hepatitis C within GP surgeries - posters, support groups, televised messages on electronic noticeboards, and availability of oral and dried blood spot tests.

2. 'Conversation starters' should be developed to enable patients and GPs to discuss a test, treatment or diagnosis.

3. Greater awareness of the availability of training for GPs. Ideally all, but at least one GP in each practice should have the Royal College of GPs hepatitis B and C certificate.

4. Contact details (e.g. to a local liver specialist, or specialist support service) should be easily available for GPs delivering test results or who have questions.

5. Training and education around awareness of extra-hepatic manifestations of hepatitis C should be rolled out and testing offered to those with common extra-hepatic manifestations.

Key recommendation: Access to swift testing

Stakeholders with responsibility for testing

1. Consideration should be given to the expansion of innovative testing practices, such as mobile testing, dried blood spot testing and testing by peers as part of local

strategies. Clearly this would need to be accompanied by seamless and easily accessible aftercare and adequate training.

2. Consideration should also be given to incidences where routine testing should be offered, including routine annual testing to those over 40 years old, pregnant women and those presenting with common extra-hepatic manifestations[162].

3. In addition, GPs should check annually whether a person has ever been tested for hepatitis C and whether they are aware of the results. This could also provide an important juncture to discuss treatment and support for those who may not have felt ready to address it.

4. Local services (including social work services and substance use services) should be aware of local referral procedures for testing and support.

Key recommendation: Support around diagnosis

Greater attention should be paid to the post diagnosis period.

All stakeholders

1. There needs to be clear preparation for a diagnosis every time someone is tested. Participants should be aware when they are being tested, why and what the implications of a test (both positive and negative) are.

2. Post diagnosis support should include provision of clear, printed information and signposting to relevant websites.

3. Participants should be clearly directed to relevant sources of peer support, including support groups and forums.

---

[162] Clearly this is highly dependent on the existence of a solid infrastructure of support to deal with increased diagnoses, one which is not focused only on clearing the virus, but supports people to live with it.

4. A point of contact should be provided to address questions and issues between diagnosis and referral to treatment.

5. Social workers could play a key role here in acting as that point of contact and consideration should be given to how they could become integrated into services providing diagnoses. A key observation here is that social workers are uniquely placed to understand hepatitis C in the context of participants lives, as something that (with the correct support) it is possible to live well with, rather than something which needs to be cured or fixed.

6. Counselling following diagnosis should be offered routinely as an available option for those who feel they need it, irrespective of transmission route.

7. A number of participants suggested that 'buddying' (the pairing of someone living with hepatitis C with someone recently diagnosed) could function as a valuable source of support here. Consideration should be given to developing these services in local areas.

Key recommendation: Providing holistic support

There is a need for multidisciplinary involvement and support of people with hepatitis C within the specific context of their lives, particularly the cumulative impact of treatment.

1. Multidisciplinary teams and networks of support need to be developed and piloted in order to contribute to a more even coverage of support across the UK. These should include medical and social work staff as well as trained peers. Examples of integrated services already exist in the literature and these should be trialled at the earliest possible opportunity.

2. Specific attention and support should be provided with regard to childcare, maintenance of tenancy, employment and financial stability. Support services in the local area should be developed across the UK, including the expansion of the role of

specialist hepatitis C (or blood borne virus) social workers and the integration of this support within wider social work teams. Specific areas of support are addressed below.

Mental health services

1. Psychological/counselling support should form a component of a consistent multidisciplinary service, available for those who need it.

2. Funding should be provided for out of hours support, specifically a telephone helpline which provides social and emotional support for people on treatment. This could incorporate HIV and other BBV support to be cost effective. Further research is required into how and where this should operate, though it was felt to be important that this was staffed by people who have had experience of hepatitis C and its treatment.

The role of social work

As well as the recommendations that have gone before:

1. Funding, training and development of specialist social work roles (both for hepatitis C and for blood borne viruses), as part of a multi-disciplinary response to hepatitis C, should be developed across the UK to facilitate access, to support through treatment and to recognise the messy and contingent nature of the experience.

2. Consideration should be given to how social work (both statutory and third sector) can take a greater role in supporting people with hepatitis C, including the provision of self-directed support and alliances between local authorities and new NHS and wellbeing boards.

3. The valuable and unique role that social work can play in the lives of those with hepatitis C needs to be urgently recognised both by those within and outside the

profession. Social work involvement needs to go beyond basic information and signposting towards a more active role in discussing hepatitis C in the context of service users lives.

4. Social workers have a clear potential role at every stage of the hepatitis C experience, from supporting with undiagnosed chronic illness, to supporting through a test and post diagnosis, referring to treatment, advocacy and peer support and supporting through treatment. Specifically social work could provide support with issues that participants in this research maintained were overlooked; issues related to co-infection, housing, finances, childcare, family and relationship issues and the emotional impact. There is also a unique role for social work in the post treatment phase where medical support is limited.

5. Brief training and information on hepatitis C and its treatment should be distributed to those who take social work referrals, emphasising the potential role for social work support.

Housing services

1. The impact of hepatitis C (treatment) needs to be made clear to housing support services so that people can be assisted to find suitable housing and maintain their tenancy to avoid extra stress.

Welfare benefits

1. Specific, easily accessible guidance should be developed around available benefits for people with hepatitis C (including PIP and ESA).

2. Attention should be paid to the assumptions and enactments contained in information. Guidance should not perpetuate the idea of welfare benefits as a form

of 'dependency' and recognise that it can in fact facilitate a return to work and address disabling barriers.

3. Those undergoing treatment should automatically be placed in the Support Group when claiming Employment Support Allowance.

4. Those with compromised immune systems should be provided with home visits.

5. Applications for Disability Living Allowance (and later Personal Independence Payment) should take account of the amount of time a person may have been living with illness and the cumulative impact this will have on their wellbeing.

6. The possibility of post treatment effects should also be included and this should be made clear in guidance and information.

7. Wider recommendations commensurate with the findings of other disabled people's organisations are relevant here, including the implementation of recommendations regarding taking more adequate account of fluctuating and variable impairments.

8. Links between hepatitis C services and other disability groups (i.e. Disability Benefits Consortium) should be forged to provide a unified voice addressing issues of concern, including cuts to services and difficulties around welfare benefits. This would also raise the profile of hepatitis C as an issue which should not be addressed solely by increases in medical treatment.

Peer support

1. There is a need for greater formalised and funded roles for peers in supporting people with hepatitis C at every stage, and in a variety of innovative ways alongside professionals.

2. This includes the development and maintenance of local support groups, social events and 'buddying', as well as online support, telephone support, and links to wider multidisciplinary networks.

3. Peers should be adequately funded, trained and supervised with a clear professional job description and boundary.

Transport

1. Patient transport to appointments, or funding to cover the costs of taxis, should be provided to enable participants who may be experiencing impairment, treatment or post treatment effects to travel as comfortably and easily as possible.

2. Consideration should be given to providing services more locally to reduce travelling.

Key recommendation: Support around employment

All stakeholders

Those who wish to continue to work should be supported to do so through provisions such as:

1. Reasonable adjustments under the Disability Discrimination Act 1995, 2005 (now covered under the Equality Act, 2010) including flexible working arrangements, working from home where possible and provision of equipment to facilitate this.

2. The work that participants are already doing unpaid (i.e. awareness raising and support via online forums) should be recognised, not least by DWP staff and local hepatitis C services.

3. Information regarding benefit entitlement for those who continue to work should be developed and easily accessible.

4. Specific guidance, information and training should be developed for employers around employing someone with hepatitis C and supporting someone on treatment – similar to the recently developed Macmillan Toolkit for employers. This would

enable those with hepatitis C to stay in work and to increase the visibility of hepatitis C treatment in the workplace, without necessarily requiring disclosure.

5. Paying attention to the education, training and responses of employers and staff would take the sole focus from the person disclosing.

6. Specific guidance and support around employment rights should be developed and easily accessible.

Key recommendation: Attention to post treatment effects

The post treatment phase needs to be explicitly acknowledged through provision of both formal and informal support.

All stakeholders

1. Information on possible post treatment effects should be provided before the end of treatment by the professionals involved in their care, so that appropriate post treatment arrangements can be made (i.e. continuation of agreements with employers, childcare arrangements).

2. Digestible information which can be referred back to should be available. This might take the form of a post treatment guide written by service users and professionals.

3. Models of support may be derived from existing services where post treatment is acknowledged as a specific phase requiring information and support (i.e. cancer survivorship services/application of the concept of 'recovery in').

4. Post treatment support protocol should be developed, such as: 'buddying' for 12 months post treatment, contact details for a specialist nurse, routine follow up appointments or telephone conversations beyond attainment of 6 month SVR to establish post treatment requirements. . This could also include referral to and

support from a social worker working alongside medical professionals in addressing post treatment related issues.

5. Awareness of post treatment effects needs to be raised among professionals who may come into contact with people in the post treatment phase, including: GPs, social work staff, DWP (and ATOS) and welfare benefits advice staff. Clear guidance and information regarding post treatment effects should be provided, including how these may impact on a person's life. Information on post treatment effects should be updated as new information is gathered.

6. Post treatment effects should be adequately taken account of in applications for welfare benefits. Participants should be informed that they should continue applications and appeals of welfare benefits because of the possibility of on-going treatment effects.

7. Support networks of family and friends may be expecting those who have finished treatment to feel better immediately. Clear information and guidance about post treatment effects should be provided to them in advance of the end of treatment.

8. Adequate support should be available for those providing care and support post treatment, via telephone, online and in person. This could also take the form of support from social work staff.

Key recommendation: Discussion as a disability issue

Hepatitis C could benefit from being discussed in both academic and practice arenas as a disability issue - insights gained here could help to improve the experience of living with hepatitis C.

Academics and researchers

1. There is a need for greater academic attention to the qualitative experience of living with hepatitis C, which goes beyond current medical focus, particularly in light of the development of new treatments.

2. Attention should be paid to exploring how greater numbers of (disabled) people with hepatitis C can participate in the research process, including the development of peer researcher training programmes and steering groups, so that pertinent areas of research can be identified.

Activist groups and movements

1. In order to promote solidarity and action over issues that cut across groups who face similar barriers to participation, consideration should be given to how to develop links between people with hepatitis C and other chronic illnesses (i.e. Fibromyalgia, Cancer, Lupus), and other disability organisations (i.e. DPAC, We Are Spartacus) and blood borne virus organisations.

Key recommendation: Addressing disablism

1. Explicit acknowledgement and publicising of hepatitis C as impairment covered under the Equality Act (2010) may provide validation and support to people living with hepatitis C.

2. Specific guidance should be produced which details and explores where, and how, people with hepatitis C would be covered; this should be easily accessible and widely distributed.

3. Poor treatment experienced by people with hepatitis C should be recognised as disablism, elevating it to a similar status as racism and sexism. Acknowledging the impact of disablism, specifically psycho-emotional disablism, means that participants gain recognition of the experience and validation.

4. This should comprise a specific area of training for organisations involved with people who have hepatitis C. As Reeve (2008; 2012b) has noted, this could begin with education of undergraduates and master's students, trainee social workers, nursing and medical students.

5. Comparisons that participants made with cancer and HIV should be used as points of reflection and discussion among professionals concerning the current cultural position of hepatitis C. This should be used as a starting point for developing services and raising awareness.

6. The focus on newer treatments should not be used as a reason to elide responsibilities for developing support (not least because of new treatment costs). Even in the event that hepatitis C becomes a curable virus with a very short treatment, with no side effects, those living with hepatitis C will likely still require support (including treatment advocacy) by virtue of the cumulative and intra-active nature of living with hepatitis C, their life circumstances and existing impairments.

7. Information which focuses less on transmission and more on how people with hepatitis C can be supported combats the internalisation of negative beliefs.

Areas for further research

There is a limited body of qualitative research exploring the experience of living with hepatitis C in the UK. This needs to be expanded as political and service reforms and drug developments continue, and services change.

In particular this exploratory study could be expanded to incorporate those whose views have not been made present in this thesis, including those who have immigrated to the UK and encounter both cultural and language barriers, as well as structural ones. There is also an urgent need for an expansion of research into the experience of living with HIV and hepatitis C co-infection, including awareness raising, support needs and treatment

experiences. The support and information needs of family, friends and carers for people with hepatitis C also need to be researched.

There is a need for research with professionals, including social workers, DWP staff, GPs and hepatitis C specialist staff, specifically within the UK, to explore their understandings of their roles and responsibility around hepatitis C; this is especially important in light of the major changes and cuts to services.

The support needs of those currently using drugs could be further researched, specifically in the context of life history interviews exploring the incorporation of hepatitis C and its long term impact on their lives as a whole - both for those who have done treatment and those who have not. The intersection between hepatitis C, impairment, disability, drug use and recovery should also be explored. Vitally, models of multi-disciplinary support for those living with hepatitis C should be further researched and developed.

Appendix Two: Request for participants

LANCASTER
UNIVERSITY

REQUEST FOR RESEARCH PARTICIPANTS

Do you have hepatitis C?

Have you cleared hepatitis C?

Do you work with people who have hepatitis C?

Where do you access support if you need it?

What do you think about hepatitis C services?

I am a postgraduate research student from Lancaster University. I am researching how health and social care services are responding to people with hepatitis C.

I am looking for volunteers to take part in my research. I would like to talk to people who live with or who have cleared hepatitis C about their experiences of living with the virus and the support and services they have received. I would also like to speak to people who work with people with hepatitis C about the support and services they provide.

The research will involve one, possibly two interviews. The research is an opportunity for you to give your views on the experience of hepatitis C. Interviews will take place between September 2009 and December 2010. All information you provide will be treated confidentially and will be anonymised.

If you are interested or would like to know more, please feel free to contact me:

Heather Mack, Department of Applied Social Science, Bowland North, Lancaster University,

LA1 4YTEmail: h.mack2@lancaster.ac.uk

Telephone: 01524 594118 (answer phone available)

Appendix Three: Participant Information Sheet

Project: Exploring personal and professional responses to Hepatitis C (HCV)

Researcher: Heather Mack

PARTICIPANT INFORMATION SHEET (V2. September 2009).

About the researcher:

My name is Heather Mack and I am studying for a PhD in the department of Applied Social Science at Lancaster University. I would like to invite you to take part in my research.

Aims of the research:

The overall aim of the research is to explore the experience of health and social care services, from the perspective of people who are living with (or have cleared) Hepatitis C and from the perspective of health and social care professionals in the field, in order to develop an understanding of how the two perspectives can contribute to improved responses to HCV.

The participant's role

I would like to invite you to take part in an interview (either in a group or by yourself, whatever you prefer). The interview will take approximately 1 – 1.5 hours. I would like to conduct all interviews face to face, but I am happy to conduct individual interviews over the phone or the internet (via email, MSN, or webcam) if that is easiest for you. We can negotiate a suitable time date and place for the interview. I have access to rooms at

Lancaster University but would be happy to travel to a location which is most convenient for you.

I intend for the research to have two stages;

Stage 1: Focus groups/interviews with people like yourself, who have experience of living with Hepatitis C and receiving Health and Social care services.

Stage 2: After I have conducted Focus Groups/Interviews I would like to use the general findings to help me develop questions to ask a range of Health and Social Care professionals in interviews. All information you provide will be used anonymously and confidentially.

After these interviews have been carried out I may ask you if you would like to participate in a second focus group/interview to discuss the (anonymous and confidential) findings and how they will be used in the final piece of work and beyond.

Please remember that your participation in this research is entirely voluntary, you have the right to withdraw at any time during the interview process and do not have to give a reason for doing this.

All interviews will take place between September 2009 and August 2010. Before we meet I will send you a copy of the interview questions, so that we can discuss any topics/areas which you might be unsure about.

All interviews will be tape recorded and written out in full (transcribed). During the interview you have the right to stop, start or rewind the tape at any point. The recording will be confidential and I will be the only person who has access to it.

After I have transcribed the interview, you will be sent a copy so you have the opportunity to review the transcript and amend your comments.

Before we conduct the interview I will ask you to sign a consent form to show you have received this information sheet and are willing to take part in my research. I will provide you with a copy of the signed form. On this form you will also have the opportunity to choose a different name (pseudonym) which I will then use when quoting you in the final piece of work (thesis) and any publications or reports.

How the interview data will be used:

The information collected during the focus group/interviews will be used as part of my PhD thesis. It might also be used in some future presentations, publications or reports. All information will be used anonymously.

After the first focus group or individual interview I will produce a summary of the main findings and how these have informed the questions for the interviews with health and social care professionals. Please make sure that you have provided the correct email or home address if you would like to receive this. Your comments on this will be welcome.

Confidentiality and anonymity

I will treat all the information you provide as confidential (in accordance with the Data Protection Act 1998). The data you provide will be stored securely in a locked filing cabinet in a locked office on Lancaster University premises. I will be the only person who has access to it. When the research has finished all confidential information will be destroyed.

If you disclose that you intend to cause harm to others or to yourself this will result in a discussion of further action.

The final PhD Thesis and any resulting publications will not contain any information which will identify you as a participant, when you complete the consent form you can choose your own pseudonym, this will be used in the final thesis and any additional publications. This

means that you will be able to identify your own contribution to the research but will your identity will still remain anonymous. If you prefer not to pick your own pseudonym, I will choose one on your behalf. Place names will also be provided with pseudonyms in order to preserve participant confidentiality.

Time commitment

The focus group will take approximately 1hour (excluding breaks). You may also wish to discuss potential questions with me prior to taking part and/or check through your own transcript and take part in a second interview. Therefore I anticipate that the total amount of time required of you, will be approximately 1- 3 hours.

Conduct of the researcher

If you are unhappy with my conduct during the interview process you can contact a person independent of the study; Karenza Moore, Department of Applied Social Science, Bowland North, Lancaster University, Lancaster LA1 4YW. Email: Karenza.moore@lancaster.ac.uk

Sources of support and information

The Hepatitis C Trust helpline: 0845 223 4424

Staffed solely by people with Hepatitis C. This confidential service provides both listening support and information on any aspect of Hepatitis C.

Open 10.30am to 4.30pm Monday to Friday (except Bank Holidays)

Calls cost 3.5p per minute (more if you are calling from a mobile)

If you have access to the internet you can also visit: http://www.hepctrust.org.uk/ for a wide range of information relating to Hepatitis C and details of support.

The HepCnomads www.hepcnomads.co.uk

Online support forum for people who have experienced or are living with Hepatitis C. It can only be viewed by registering and all membership is free. It does focus on the social side of support. Carers and health professionals are also members and all are welcome.

The British Liver Trust Medical Helpline

For worries or concerns about liver disease. The free medical Helpline number is 0800 652 7330 and is open Monday to Friday from 9am until 5pm.

You can also email your enquiry at: info@britishlivertrust.org.uk

Samaritans

For general confidential non-judgmental emotional support, 24 hours a day

Tel: 08457 909090

Email: jo@samaritans.org

Write to: Chris, PO Box 9090 Stirling, FK8 2SA

Contact Details

If you would like to ask further questions or would like to take part in the research I can be contacted:

Heather Mack, Department of Applied Social Science, Bowland North, Lancaster University, Lancaster, LA1 4YW.

Office telephone: 01524 594118,

Email: h.mack2@lancaster.ac.uk

Appendix Four: Topic guide for interviews

Project Title: Exploring personal and professional responses to Hepatitis C

Researcher: Heather Mack

Interview Schedule

This document outlines some of the topics I would like to cover in an interview with you.

I am sending it to you now so that you have an opportunity to think about how these questions relate to your own experiences. If you do not wish to answer a specific question or wish to avoid specific topics, please let me know and I will remove them from your interview guide.

The areas below are to be used as a guide. I am most interested in your own experiences and as such would encourage you to expand on your responses and areas of specific interest or experience.

Opening Questions:

- Researcher to introduce herself, talk about the research and reiterate the purpose of the Interview. Go through consent form and information sheet.

- Can you tell me a little bit about yourself? (this can be anything you like)

Introductory Questions:

- Can you tell me about the first time you heard of Hepatitis C?

- When did you first realise you might have it?

- At the time, did you know anyone else with Hep C?

- What did you think when you found out you had it?

- What was your experience of diagnosis like?

Questions about knowledge

- What kind of information were you given?

- Was this useful or not?

- Did you need to seek further information?

- Have you always received accurate information?

- Where do you get your information from now?

- Do you keep up to date with the latest information?

- Do you pass this information on to others?

Questions about identity/self-perception

- How do you see yourself?

- Does Hepatitis C impact on the way you feel about yourself?

- Has this changed over time? If so, why?

- Do you feel Hepatitis C is a part of who you are?

- Is it an important part?

- Do you think Hep C affects the way you feel about your body?

- Have you told anyone about your Hep C?

- What was this experience like?

- How do you decide who to tell?

- Is this something you had to think about?

- Is this something you still think about?

Questions about professional interaction

- Thinking about the services you have received...Have you had a lot of input from health and social care services?

- Which professionals have you had contact with since you found out you had Hepatitis C and why?

- What were they like?

- Were there any that were more/less supportive?

- What did you think about this?

- Is professional support important to you?

- If so, what is important in a professional? If not, what kind of support is important?

- What is important in services for people with Hepatitis C?

- What issues do you think need addressing for people living with Hep C?

Summary Questions

- What might you say to someone who has just found out they have Hep C?

- Can you tell me about any positive aspects of living with Hep C that you don't think have been discussed?

- Can you tell me about any negative aspects that you think need addressing that have not been discussed?

- Is there anything else that you feel has not been covered that you would like to add?

END

References

Aaron, S., McMahon, J. M., Milano, D., Torres, L., Clatts, M., Tortu, S., Mildivan, D. and Simm, M. (2008) 'Intranasal transmission of Hepatitis C: virological and clinical evidence'. *Clinical Infectious Diseases,* **47**, pp. 931-934.

Abel, E.K. and Subramanian, S. K. (2008) *After the Cure: The Untold Stories of Breast Cancer Survivors,* London, New York University Press.

Abberley, P. (1987) 'The Concept of Oppression and the Development of a Social Theory of Disability', *Disability, Handicap and Society,* **2** (1) pp. 5-19.

Aceijas, C. and Rhodes, T. (2007) 'Global estimates of prevalence of HCV infection among injecting drug users', *International Journal of Drug Policy,* **18** (5) pp.352-358.

Acevedo, B., Warren, S., and Wray-Bliss, E. (2009) 'The devil in high heels: drugs symbolism and Kate Moss', *Culture and Organisation,* **15** (3-4) 331-345.

Advisory Council on the Misuse of Drugs (2009) *The Primary Prevention of Hepatitis C Among Injecting Drug Users,* London, Home Office.

Agarwal, K., Cross, T. J. Gore, C. (2007) 'Chronic Hepatitis C', *British Medical Journal,* **334** (7584) pp. 54–55.

Aitken, C.K., Kerger, M., and Crofts, N. (2002) 'Peer-delivered hepatitis C testing and counselling: a means of improving the health of injecting drug users', *Drug and Alcohol Review,* **21,** pp. 33 -37.

Album, D. and Westin, S. (2008) 'Do diseases have a prestige hierarchy? A survey among physicians and medical students', *Social Science & Medicine,* **66** pp.182–188.

Alderson, P. and Morrow, V. (2011*) The Ethics of Research with Children and Young People: A practical handbook,* London, Sage.

All Party Parliamentary Group on Hepatology (2006) *A Matter of Chance: An Audit of Hepatitis C Healthcare in England,* available at: http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Resources/Reports/A%20matter%20of%20chance.pdf [accessed 14th September 2011].

All Party Parliamentary Group on Hepatology, (2007) *Improving public awareness of viral hepatitis and other key health care concerns,* available at: http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Resources/Reports/Improving%20Public%20Awareness%20Report2007.pdf [accessed 2nd January 2013].

All Party Parliamentary Group on Hepatology (2008). *Location, Location, Location: An audit of Hepatitis C healthcare in England,* available at: http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Resources/Reports/Locationlocationlocation.pdf [accessed 14th September 2011].

All Party Parliamentary Group on Hepatology (2009) *Divided Nations: Tackling the Hepatitis C challenge across the UK*, available at:
http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Resources/Reports/Divided%20Nations%20Tackling%20the%20hepatitis%20C%20challenge%202009.pdf [accessed 16th September 2011].

All Party Parliamentary Group on Hepatology (2011) *Commissioning for better outcomes in hepatitis C,* available at:
http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Resources/Reports/APPHG%20Commissioning%20for%20better%20outcomes%20in%20hepatitis%20C.1%20pdf. [accessed 11th December 2011].

Allman D, Myers T, Schellenberg J, Strike C, Cockerill R, Cavalieri W. (2007) 'Improving health and social care relationships for harm reduction', *International Journal of Drug Policy*, **18** (3) pp.194-203.

Alter, M.J. (2006) 'Epidemiology of viral hepatitis and HIV co-infection', *Journal of Hepatology*, **44**, s6-s9.

Altman, M. (1990) 'How not to do things with metaphors we live by' *College English*, **52**, (5) pp. 495-506.

Anderson, N. (2008) 'Shoppers of the World Unite: (RED)'s Messaging and Morality in the Fight Against African AIDS' *The Journal of Pan African Studies*, **2 (**6) pp. 32-54.

Anti-Discrimination Board of New South Wales. (2001) *C Change: Report of the enquiry into hepatitis C related discrimination*, available at:
http://www.lawlink.nsw.gov.au/lawlink/adb/ll_adb.nsf/pages/adb_hepatitis_c_enquiry. [accessed 30th September 2011].

Aphramor, L. (2009) 'Disability and the ant- obesity offensive, *Disability and Society*, **24**, (7) pp. 897-909.

Archer, L., Jones, N. and Willets, J. (2009) *The Archer Inquiry: Independent Public inquiry Report on NHS Supplied Contaminated Blood and Blood Products,* available at: http://www.archercbbp.com/ [accessed 5th August 2009].

Asbring, P. and Narvaren, A. (2002) 'Women's Experiences of Stigma in Relation to Chronic Fatigue Syndrome and Fibromyalgia', *Qualitative Health Research*, **12** (2) pp. 148-160.

Ashby, C. (2011) 'Who's "Voice" Is It Anyway? Giving Voice And Qualitative Research Involving Individuals That Type To Communicate', *Disability Studies Quarterly*, **31** (4).

Astell-Burt, T. Flowerdew, R. Boyle, P. and Dillon, J. (2012) 'Is travel time to a specialist centre a risk factor for non-referral nonattendance and loss to follow up among patients with hepatitis C (HCV) infection?' *Social Science and Medicine*, **75**, pp. 240-247.

ATOS Healthcare (2011) *Disability Assessment*, available at:
http://www.atoshealthcare.com/services/disability_assessment [accessed 3rd October 2011].

Balfour, L., Tasca, C., Kane, G., Kowel, J., Garber, G. (2004) 'Evaluation of Health Care Needs and Patient Satisfaction among Hepatitis C Patients Treated at a Hospital-based, Viral Hepatitis Clinic', *Canadian Journal of Public Health*, **19** (4) pp. 272-277.

Bahn, S. (2012) 'Keeping Academic Fieldwork Researchers Safe; Ethical Safeguards', *Journal of Academic Ethics*, **10**, pp.93-91.

Bambra, C. (2008) 'Incapacity Benefit reform and the politics of ill health', *British Medical Journal*, **337,** 30 August, p.518.

Bambra, C. (2010) 'Doctors are key to welfare reform', *British Medical Journal*, **341**, 30 October, p.941.

Bambra, C. and Smith K. E. (2010) 'No longer deserving? Sickness benefit reform and the politics of (ill) health', *Critical Public Health*, **20** (1) pp. 71-84.

Banwell, C., Bammer, G., Gifford, S. M., & O'Brien, M. L. (2005). 'Australian lesbian and bisexual women's health and social experiences of living with hepatitis C' *Health Care for Women International*, **26** (4) pp.340-354.

Banks, P. and M. Lawrence (2005) 'Transparent or Opaque? Disabled People Living in Scotland Describe Their Experience of Applying for Disability Living Allowance' Journal *of Social Work* **5** (3) pp. 299-317.

Barad, K. (1998) 'Agential Realism. Feminist Interventions in understanding scientific practices' in Baglioli, M. (1999) *The Science Studies Reader*, London, Routledge, pp. 1-12.

Barad, K. (2003) 'Post humanist Performativity: Towards an Understanding of how matter comes to matter', *Signs: Journal of Women in Culture and Society*, **28,** (3) pp. 801-831.

Barker, K. (2005) *The Fibromyalgia Story; medical authority and women's worlds of pain*, Philadelphia, Temple University Press.

Barker, K. (2011) 'Listening to Lyrica: contested illnesses and pharmaceutical determinism', *Social Science and Medicine*, **73**, pp.833-842.

Barnes, C. (1997) 'A Legacy of Oppression: A History of Disability in Western Culture' in Barton, L. and Oliver, M. (eds) *Disability Studies: Past Present and Future*, Leeds, The Disability Press, pp. 3-24.

Barnes, C. (2003a) 'Work is a four letter word? Disability Work and Welfare, Working Futures: Policy, Practice and Disabled People's Employment', University of Sunderland, Marriott Hotel Seaburn, 3rd December 2003.

Barnes, C. (2003b) *Disability: The Organisation of Work and the need for Change*, available at: http://disability-studies.leeds.ac.uk/files/library/Barnes-OECD-Statement.pdf [accessed 1st June 2013].

Barnes, C. (2012) 'Understanding the Social Model of Disability: Past, present and future', in Watson, N. Roulstone, A. And Thomas, C. (Eds) *Routledge Companion to Disability Studies*, London, Routledge, pp.12-29.

442

Barnes, T. (2008) 'Product (RED): the Marketing of African Misery', *The Journal of Pan African Studies,* **2**, (6) pp. 71-76.

Barnes, C. and Mercer, G. (1996) 'Introduction; exploring the divide', in Barnes and Mercer, G. (eds) *Exploring the Divide*, Leeds: The Disability Press, pp. 1-16.

Bartels, E.C. (2009) 'Outside the Box: Surviving Survival', *Literature and Medicine,* **28** (2) pp. 237-252.

Bauld, L. McKell, J., Carroll, C., Hay, G,. and Smith, K., (2012) 'Benefits and Employment: How Problem Drug Users Experience Welfare and Routes into Work', *Journal of Social Policy*, **41** (4) pp.751-768.

BBC Radio 4 Appeal for the Hepatitis C Trust (2012) Radio Programme, BBC Radio 4, London, 23rd September 2012, available at: http://www.bbc.co.uk/programmes/b01mtshj [accessed 1st June 2013].

Beauchamp-Pryor, K. (2011) 'Impairment, cure and identity: where do I fit in?' *Disability and Society*, **26** (1) pp.5-17.

Beat (2013) *Amy Winehouse Foundation to support Beat*, available at: http://www.b-eat.co.uk/about-beat/media-centre/press-releases/amy-winehouse-foundation-supports-beat/ [accessed 19th July 2013].

Beatty, C. (2010). 'Bringing Incapacity Benefit numbers down: to what extent do women need a different approach?' *Policy Studies* **31** pp.143-162.

Becker, H. (1966/7) 'Whose Side Are You On?' *Social Problems*, **14,** pp. 239-247.

Bell , K. (2009) 'If it almost kills you that means it's working' Cultural Models of chemotherapy expressed in a cancer support group, *Social Science and Medicine*, **68** (1) pp.169-176.

Berthoud, R. (1998). *Disability Benefits: A Review of Issues and Options for Reform*, York, Joseph Rowntree Foundation.

Beresford, P. Harrison, C. and Wilson, A. (2002) ' Mental health service users and disability; implications for future strategies', *Policy and Politics*, **30** (3) pp. 387-396.

Bird, C. (2005) 'How I stopped Dreading and Learned to Love Transcription', *Qualitative Inquiry*, **11,** (2) pp.226-248.

Birmingham Local Medical Committee (2013) *Benefits Reform – Request for GP Letters*, available at: http://www.blmc.co.uk/docs/docs/Benefits%20Poster%20A4%20Mar%2013.pdf [accessed 31st July 2013].

Birrell, P.J., Gill, O.N., Delpech, V.C., Brown, A.E., Desai, S,. Chadborn, T.R,. De Agnelis, D. (2013) 'HIV incidence in men who have sex with men in England and Wales 2001-2010: a nationwide population study', *The Lancet*, published online 1st February 2013.

Blacklaws, H., Gardner, A. and Usher, K. (2011) 'Irritability: an underappreciated side effect of interferon treatment for hepatitis C', *Journal of Clinical Nursing*, **20,** pp. 1215 – 1224.

Blaikie, N. (2007) *Approaches to Social Enquiry*; Second edition, Cambridge, Polity Press.

Blaikie, N. (2009) *Designing Social Research*, Second edition, Cambridge, Polity Press.

Blasiole, J.A., Shinkunas, L., LaBreque, D.R., Arnold, R.M., Zickmund, S.L. (2006) 'Mental and physical symptoms associated with lower social support for patients with hepatitis C', *World Journal of Gastroenterology*, **12** (29) pp. 4665-4672.

Bloor, M., Fincham, B., & Sampson, H. (2010). 'Unprepared for the worst: risks of harm for qualitative researchers' *Methodological Innovations Online*, **5** (1), pp.45–55.

Blumenreich, M. (2004) 'Avoiding the pitfalls of 'conventional' narrative research; using post structural theory to guide the creation of narratives of children with HIV', *Qualitative Research*, **4** (1) pp. 77-90.

Bockhold, K.M (2000) 'Who's Afraid of Hepatitis C?' *The American Journal of Nursing*, **100**, (5) pp. 26-32.

Bogdan,R. and Taylor, S.J. (1989) 'Relationships with severely disabled people; the social construction of humanness', *Social Problems*, **36** (2) pp. 135-148.

Borsay, A. (2005). *Disability and Social Policy in Britain since 1750*. Basingstoke, Palgrave, Macmillan.

Borsay, A. (2012) 'History and Disability Studies: Evolving Perspectives', in in Watson, N. Roulstone, A. And Thomas, C. (Eds) *Routledge Companion to Disability Studies*, London, Routledge pp. 324-333.

Bourgois, P., Prince, B. and Moss, A. (2004) 'The Everyday Violence of Hepatitis C among Young Women Who Inject Drugs in San Francisco, *Human Organisation*, **63** (3) pp.253-264.

Bowker, N., & Tuffin, K. (2004). 'Using the online medium for discursive research about people with disabilities', *Social Science Computer Review*, **22**, pp. 228–241.

Boyd, V. (2012) 'Are some disabilities more equal than others? Conceptualising fluctuating or recurring impairments within contemporary legislation and practice', *Disability and Society*, **27** (4) pp.459-469.

Bracarda, S., Eggermont, A.M.M. and Samuelsson, J. (2010) 'Redefining the role of interferon in the treatment of malignant diseases', *European Journal of Cancer*, **46**, pp. 284-297.

Branfield, F. (1998) ' "What are you doing here?" Non-disabled people and the Disability Movement: a reply to Robert F. Drake', *Disability and Society*, **13** (1) pp.143-144.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology' *Qualitative Research in Psychology,* **3,** pp. 77 – 101.

Briant, E. Watson, N. and Philo, G. (2011) *Bad News for Disabled People: how the newspapers are reporting disability,* Strathclyde Centre for Disability Research in association with Inclusion London, available at:
http://www.inclusionlondon.co.uk/domains/inclusionlondon.co.uk/local/media/downloads/bad_new s_for_disabled_people_pdf [accessed 4th November 2011].

Brener, L. Wilson, H. Grenville, R. Mackenzie, A. De Wit, J. (2013a) 'Challenging stereotypes and changing attitudes: Improving quality of care for people with hepatitis C through Positive Speakers programs', *Psychology, Health & Medicine,* **18** (2), pp.242-249.

Brener, L. and Treloar, C. (2009) 'Alcohol and other drug treatment experiences of hepatitis C positive and negative clients: Implications for hepatitis C treatment', *Australian Health Review,* **33** (1), pp. 100–7.

Brener L., Gray R., Cama E.J, Treloar C (2013b) 'Makes you wanna do treatment': benefits of a hepatitis C specialist clinic to clients in Christchurch, New Zealand, Health and Social Care in the Community., **21** (2) pp. 216-223.

Brener, L., von Hippel, W., & Kippax, S. (2007). 'Prejudice among health care workers toward injecting drug users with hepatitis C: Does greater contact lead to less prejudice?' *International Journal of Drug Policy,* **18,** pp.381-387.

British Sociological Association (2002) *Statement of Ethical Practice for the British Sociological Association,* British Sociological Association, available at: http://www.britsoc.co.uk/media/27107/StatementofEthicalPractice.pdf [accessed 1st June 2013].

The Broken of Britain (2011). *Response to Personal Independence Payment Draft Assessment Criteria* available at: http://thebrokenofbritain.blogspot.com/2011/05/response-to-personal-independence.html, [accessed 15th September, 2011].

Bro Taf Local Medical Committee (2013) *Bro Taf LMC Newsletter No. 3. 2013,* available at:http://www.brotaflmc.org.uk/ESW/Files/Bro_Taf_LMC_Newsletter_No_3,_2013.doc [accessed 18th July 2013].

Brown, L. and Boardman, F.K. (2011) 'Accessing the Field; Disability and the Research Process', *Social Science and Medicine,* **72,** pp.23-30.

Brownlow, C. and O'Dell, L. (2002). 'Ethical Issues for Qualitative Research in Online Communities', *Disability and Society,* **17** (6) pp. 685-694.

Bruyere, S.M., Erickson, W.A. and VanLooy, S. (2004) 'Comparative Study of Workplace Policy and Practices Contributing to Disability Non-discrimination', *Rehabilitation Psychology,* **29** (1) pp. 28-38.

Buchanan, D., Boddy. D and McCalman, J. (1988). 'Getting in, getting on, getting out and getting back' in Bryman, A. (ed) *Doing Research in Organisations,* London, Routledge: 53-67.

Buckle, J.L., Corbin--Dwyer, S. and Jackson, M. (2010) 'Qualitative bereavement research: incongruity between the perspectives of participants and research ethics boards', *International Journal of Social Research Methodology,* **13,** (2) pp. 111-125.

Burchhardt, T. (1999) 'The Evolution of Disability Benefits in the UK; Reweighting the Basket, available at: http://eprints.lse.ac.uk/6490/1/The_Evolution_of_Disability_Benefits_in_the_UK_Re-weighting_the_basket.pdf [accessed 1st June 2014].

Burgess, R. G (1984) *In the Field; an Introduction to Field Research,* London, George Allen and Unwin.

Bury, M. (2010) 'Chronic Illness, Self- management and the Rhetoric of Empowerment' in Scambler, G and Scambler, S. (eds) *New Directions in the Sociology of Chronic and Disabling Conditions: Assaults on the Lifeworld*, Basingstoke, Palgrave Macmillan pp.. 161-179.

Butt, G. (2008a) 'Stigma in the context of hepatitis C: concept analysis', *Journal of Advanced Nursing*, **62** (6), pp.712–724.

Butt, G. Paterson, B.L. and McGuiness, L.K (2008b) 'Living with the Stigma of Hepatitis C', *Western Journal of Nursing Research*, **30** (2) pp. 204-221.

Cameron, M. (2007) 'When Research Goes Pear-Shaped: Report and Reflections on a Failed Study of Exercise and Manual Therapies for Rheumatoid Arthritis', *Journal of Complementary and Alternative Medicine*, **12,** (1) pp. 63-77.

Campbell, J (1997) 'Growing Pains. Disability Politics; the journey explained and described' in Barton, L. and Oliver M. (eds) Disability Studies: past present and future, Leeds, The Disability Press pp. 78-90.

Campbell, S.J., Anon., Marsh, S., Franklin, K., Gaffney, D., Anon, Dixon, M., James, L., Barnett-McCormack, S., Fon-James, R., Willis, D., Anon., (2012) *Responsible Reform : A report on the proposed changes to Disability Living Allowance*, available at http://wearespartacus.org.uk/spartacus-report/ [accessed 13th August 2013].

Carrick, R., Mitchell, A., Lloyd, K. (2001) 'User Involvement in Research; Power and Compromise', *Journal of Community and Applied Psychology*, **11**, pp. 217-225.

Carrie, D.M., and Chan, N.K.C. (2008) 'Celiac disease in North America: The disabling experience', *Disability and Society*, **23**, (1) pp. 89-96.

The Caxton Foundation (2011). *Counselling and Support Service* available at: http://www.hepctrust.org.uk/Support/The+Caxton+Foundation/Counselling+and+support+service [accessed 31st October, 2011].

Central Office of Information for the Department of Health (1987) Public Information: Don't Die of Ignorance' available at: http://www.nationalarchives.gov.uk/films/1979to2006/filmpage_aids.htm [accessed 9th March 2009].

Chapple, A., Ziebland, S. and McPherson, A. (2004) 'Stigma, shame and blame experienced by patients with lung cancer: qualitative study' *British Medical Journal*, **328**, 1470 – 1475.

Charmaz, K (2002) 'Stories and Silences; Disclosure and the Self in chronic illness', *Qualitative Health Research*, **8**, (3), pp. 302-328.

Charmaz, K. (2004). 'Premises, Principles and Practices in Qualitative Research: Revisiting the Foundations.' *Qualitative Health Research*, **14** (7) pp. 976-993.

Chisholm, J. (2012) *The importance of self-care in the new commissioning world: Changing the way we work,* available at: http://www.expertpatients.co.uk/sites/default/files/publications/13111203-epp-cic-celebratory-event-15-11-12-importance-self-care-new-commissioning-world-v2.pdf [accessed 1st June 2013].

Chung, R.T. (2012) 'A Watershed Moment in the Treatment for Hepatitis C', *New England Journal of Medicine*, **366**, (3) pp. 273-274.

Citizens Advice Bureau (2010) *Not Working: CAB Evidence on the ESA work capability assessment*, available at: http://www.citizensadvice.org.uk/index/policy/policy_publications/er_benefitsandtaxcredits/not_working.htm [accessed 11th October 2011].

Citizens Advice Bureau (2013) 'Universal Credit – the claimant commitment' available at: http://www.adviceguide.org.uk/wales/benefits_w/benefits_welfare_benefits_reform_e/benefits_uc_universal_credit_new/benefits_uc_claiming_universal_credit/uc95_uc_the_claimant_commitment.htm [accessed 20th October 2013].

Clark, R. A. (1999). 'Reel oncology: how Hollywood films portray cancer', *Cancer Control Journal*, **6** (5) pp.

Clark, A. (2006) *Working Paper: Anonymising Research Data, Real Life Methods*, University of Manchester, available: http://www.socialsciences.manchester.ac.uk/morgancentre/realities/wps/5-2006-12-rlm-clark.pdf (accessed December 14th 2012).

Clark, T. (2010) 'On "being researched": why do people engage with qualitative research?' *Qualitative Research*, **10** (4) pp. 399-419.

Clarke, J.M., and Everest, M.M., (2006)' Cancer in the mass print media: Fear, Uncertainty and the Medical Model, *Social Science and Medicine,* **62,** (10) pp.2591-2600.

Clarke, J. (2012) 'Teaching a Module on HIV and AIDS for Social Work Students-Strategies, Content and Outcome', *Social Work Education: The International Journal*, DOI: 10.1080/02615479.2012.702207.

Clow, B. (2001) 'Who's afraid of Susan Sontag or the Myths and Metaphors of Cancer reconsidered' *Social History of Medicine*, **14**, (2) pp.293-312.

Cohen, D., McCubbin, M., Collin, J., Perodeau, G. (2001) 'Medication as social phenomena', *Health*, **5** (4) pp. 441-469.

Cole, A. (2007) 'Hepatitis C Morbidity to Double in the Next Decade' *British Medical Journal*, **334,** (7583) p.10.

Conrad, S., Garrett, L.E., Cooksley, G.E., Dunne, M., and Macdonald, G., (2006) 'Living with chronic hepatitis C "means you just haven't got a normal life any more"' *Chronic Illness*, **2** (2) pp.121-31.

Copeland, L. (2004) 'The Drug User's Identity and How It Relates to Being Hepatitis C Anti-body Positive: A qualitative study', *Drugs, education prevention and policy,* **11** (2) pp. 129-147.

Cook, T. (2009). 'The Purpose of Mess in Action Research: building rigour through a messy turn.' *Educational Action Research*, **17** (2) pp. 277-291.

Cook, T. (1998) 'The Importance of Mess in Action Research', *Educational Action Research*, **6**, (1), pp. 93- 108.

Corbin, J. and Morse J.M. (2003) 'The Unstructured Interactive Interview; Issues of Reciprocity and Risk when Dealing with Sensitive Topics', *Qualitative Inquiry,* **9**, (3) pp. 335-354.

Corden, A. Sainsbury, R. Irvine, A. and Clarke, S. (2010). *The impact of Disability Living Allowance and Attendance Allowance; Findings from exploratory qualitative research,* available at: http://research.dwp.gov.uk/asd/asd5/report_abstracts/rr_abstracts/rra_649.asp. [accessed 15th September 2011].

Coreil, J. Wilke, J. and Pintado, I. (2004) 'Cultural Models of Illness and Recovery in Breast Cancer Support Groups', *Qualitative Health Research,* **14**, (7), pp. 905-923.

Corrigan, P. N., Slopen,N., Gracia, G.., Phelan, S., Keogh, C. and Keck, L. (2005) 'Some recovery processes in mutual-help groups for persons with mental illness: Qualitative analysis of participant interviews'. *Community Mental Health Journal,* **6,** pp.721-735.

Coughlan, B., Sheehan, J., Hickey, A., & Crowe, J. (2002). 'Psychological well-being and quality of life in women with an iatrogenic hepatitis C virus infection'. *British Journal of Health Psychology,* **7** (1), pp. 105- 116.

Coupland, H. and Maher, L. (2010) 'Notions of injecting drug users candidacy for hepatitis C treatment: Conflicting provider, patient and public health perspectives', *Contemporary Drug Problems,*(37) Winter 2010, pp.549-573.

C-Plus (2012) 'C-Plus - Helping you live positively with hepatitis C' available at: http://www.addaction.org.uk/page.asp?section=363&sectionTitle=C+Plus++Helping+you+live+positiv ely+with+hep+C [accessed 3rd July 2013].

Craine N., Walker M., Carnwath T., Klee H. (2004) 'Hepatitis C and injecting risk behaviour: the results of a UK based pilot study', *International Journal of Drug Policy;* **15** pp. 115–22.

Crandall, C.S. (1991) 'Multiple Stigma and AIDS; Illness stigma and attitudes towards homosexuals and IV drug users in HIV related stigmatisation', *Journal of Community and Applied Social Psychology,* **1**, pp.165-172.

Crawford, R. (1994) 'The Boundaries of the Self and the Unhealthy Other: Reflections on Heath, Culture and AIDS', *Social Science and Medicine,* **38** (10) pp.1347-1365.

Crockett, B., & Gifford, S. (2004) ' "Eyes wide shut": Narratives of women living with hepatitis C in Australia' *Women & Health,* **39** (4), pp. 117-137.

Crofts, N., Louie, R. and Loff, B. (1997) 'The Next Plague: Stigmatisation and Discrimination related to the Hepatitis C virus infection in Australia' *Health and Human Rights,* **2,** pp. 87-97.

Crotty, M (1998*) The Foundations of Social Research; meaning and perspective in the research process,* London, Sage.

Crow, L. (1996) 'Including all of our lives; Renewing the social model of disability' in Barnes and Mercer, G. (eds) *Exploring the Divide* Leeds: The Disability Press, pp. 55 – 72.

Crooks, V.A. (2007) 'Women's experiences of developing musculoskeletal diseases: employment challenges and policy recommendations' *Disability & Rehabilitation* **29** (14) pp.1107-1116

Crooks, V.A., Stone, S. and Owen, M. (2009) 'Multiple sclerosis and academic work: Socio-spatial strategies adopted to maintain employment', *Journal of Occupational Science*, **16** (1) pp.25-31.

Crooks, V.A., Stone, S. and Owen, M. (2011) 'Enabling University teaching for Canadian academics with multiple sclerosis through problem focused coping', *Canadian Journal of Occupational Therapy*, pp. 45-49.

Crooks, V. A., Owen, M. and Stone, S. (2012) 'Creating a (More) Reflexive Canadian Disability Studies: Our Team's account', *Canadian Journal of Disability Studies*, **1** (3) pp.45-65.

Crutzen, R. and Goritz, A.S. (2012) 'Public awareness and practical knowledge regarding Hepatitis A, B, and C: A two-country survey', *Journal of Infection and Public Health,* **5**, pp.195—198.

Daddow, R. and Broome, S. (2012) *Whole Person Recovery; a user centred systems approach to problem drug use,* RSA, available at: http://www.thersa.org/action-research-centre/community-and-public-services/connected-communities/reports/whole-person-recovery [accessed 1st June 2013].

Damianakis, T. and Redford, M.R. (2012) 'Qualitative Research with Small Connected Communities; Generating New Knowledge While Upholding Research Ethics', *Qualitative Health Research*, 22 (5) pp. 708-718.

Danta, M., Brown, D., Bhagni, S., Pybus, O., Sabin, C., Nelson, M., Fisher, M., Johnson, A., (2007). 'Recent epidemic of acute hepatitis C virus in HIV-positive men who have sex with men linked to high-risk sexual behaviours'. *AIDS,* **21** (8), pp. 983 -991.

Davidson, L. (2008) '"Recovery" as a response to oppressive social structures', *Chronic Illness*, **4,** pp.305–306

Davidson, L., Chinman, M., Sells, D., & Rowe, M. (2006). 'Peer support among adults with serious mental illness: A report from the field.' *Schizophrenia Bulletin*, **32,** pp. 443 – 450.

Davidson, L and Rowe, D. (2007)' Recovery from versus recovery in serious mental illness: One strategy for lessening confusion plaguing recovery', *Journal of Mental Health*, **16** (4) pp. 459 – 470.

Davis, A. (1999) *A Disabled Person's Perspective on Prenatal Screening,* available at: http://disability-studies.leeds.ac.uk/files/library/Davis-A-Disabled-Person.pdf [accessed 1st June 2013].

Davis, M., Bolding, G., Hart, G., Sherr, L., and Elford, J. (2004) 'Reflecting on the experience of Interviewing online; perspectives from the Internet and HIV study in London', *AIDS Care*, **16** (8). pp. 944-952.

Davis, M. and Rhodes, T. (2004) 'Beyond Prevention? Injecting drug user narratives about hepatitis C,' *International Journal of Drug Policy*, **15,** pp. 123-131.

Davis, M., Rhodes, T., & Martin, A. (2004). 'Preventing hepatitis C: "Common sense", "the bug" and other perspectives from the risk narratives of people who inject drugs' *Social Science & Medicine*, **59** (9), pp. 1807-1818

Day, C., Ross, J., Dolan, K. (2003) 'Hepatitis C discrimination among heroin users in Sydney: drug user or Hepatitis C discrimination?' *Drug and Alcohol Review*, **22**, pp. 317-321.

Day, C., Jayasuriya, R., & Stone, G. (2004) 'Hepatitis C-related discrimination in New South Wales' *Australian Health Review*, **27** (2) pp.57-60.

Day C.A., Topp L., Iversen J., Maher L., (2008) 'Blood-borne virus prevalence and risk among steroid injectors: results from the Australian Needle and Syringe Program Survey', *Drug Alcohol Review*, **27** (5) pp. 559-561.

Deacon, R. M., Mooney-Somers, J., Treloar, C., and Maher, L., (2013) 'At the intersection of marginalised identities: lesbian, gay, bisexual and transgender people's experiences of injecting drug use and hepatitis C seroconversion', *Health and Social Care in the Community*, **21** (4) pp. 402-410.

Deal, M. (2003) 'Disabled people's attitudes towards other impairment groups', *Disability & Society* **18** (7) pp. 897-910.

DeCertau, M. (1984) *The Practice of Everyday Life*, California, University of California Press.

Deegan, P. (1988) 'Recovery; the lived experience of rehabilitation', *Psychosocial Rehabilitation Journal* **11** (4) pp. 11-19.

Delvechio-Good, M. J., Good, B.J., Schaffer, C., Lind, S.E. (1990) 'American Oncology and the Discourse on Hope,' *Culture, Medicine and Psychiatry*, **14**, pp. 59-79.

Demery, R., Thirlaway, K., and Mercer, J. (2012) 'The experiences of university students with a mood disorder', *Disability and Society*, **27** (4) pp.519-533.

Department of Health (2002a) *Hepatitis C Strategy for England*, available at: http://www.nhs.uk/hepatitisc/SiteCollectionDocuments/pdf/hepatitis-c-action-plan-for-england.pdf [accessed 1st July, 2013].

Department of Health (2002b) *Health Service Circular Hepatitis C Infected Healthcare workers*, available at; http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_d h/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4012217.pdf [accessed 1st June 2013].

Department of Health (2004) *Hepatitis C Action Plan for England*, available at: http://www.nhs.uk/hepatitisc/SiteCollectionDocuments/pdf/hepatitis-c-action-plan-for-england.pdf [accessed 1st June 2013].

Department of Health (2009) *Essential information for professionals and guidance on testing*, available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_40979 33 [accessed 1 August 2009].

Department of Health (2010) *Equity and Excellence; Liberating the NHS*, London, The Stationery Office.

Department of Health, Macmillan Cancer Support and Health Improvement (2012) *National Cancer Survivorship Initiative Vision*, available at: http://www.ncsi.org.uk/wp-content/uploads/NCSI-Vision-Document.pdf [accessed 1st June 2013].

Department of Health, Macmillan Cancer Support and Health Improvement (2013) *Living with and Beyond Cancer; Taking Action to Improve Outcomes*, available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181054/9333-TSO-2900664-NCSI_Report_FINAL.pdf [accessed 1st June 2013].

Department for Health Social Services and Public Safety (2007) *Action Plan for the Prevention, Management and Control of Hepatitis C in Northern Ireland,* available at: http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Resources/Reports/Northern%20Ireland%20Action%20Plan%20for%20the%20management%20and%20control%20of%20hepatitis%20C%202007.pdf (accessed 1st March 2012).

Department for Work and Pensions (2008) *Raising expectations and increasing support: reforming welfare for the future,* available at: http://www.employabilityinscotland.com/media/82436/raising-expectations-and-increasing-support-reforming-welfare-for-the-future.pdf [accessed 1st June 2013].

Department for Work and Pensions (2009) *Care and Mobility Considerations*, available at: http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/a-z-of-medical-conditions/viral-hepatitis-hepatitis-a-b/care-and-mobility/ [accessed 1st June 2013].

Department for Work and Pensions (2010). *Employment and Support Allowance: Help if you are ill or disabled,* available at: http://www.dwp.gov.uk/docs/dwp1001.pdf, [accessed 14th September 2011].

Department for Work and Pensions (2010). *Universal Credit: Welfare that Works* available at: http://www.dwp.gov.uk/docs/universal-credit-full-document.pdf, [accessed 30th September 2011].

Department for Work and Pensions (2011) *Personal Independence Payment - Policy briefing note,* available at: https://www.gov.uk/government/publications/introduction-to-personal-independence-payment-policy-briefing-note [accessed 3rd October, 2013].

Department for Work and Pensions (2012*) Impact Assessment: Disability Living Allowance Reform,* available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/220176/dla-reform-wr2011-ia.pdf [accessed 1st June 2013].

Department for Work and Pensions (2013) Housing Benefit Size Criteria Factsheet, available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/229364/factsheet-hbsssc1.pdf [accessed 1st November 2013].

Department for Work and Pensions (2013) Improving the Work Capability Assessment, available at: https://www.gov.uk/government/policies/simplifying-the-welfare-system-and-making-sure-work-pays/supporting-pages/improving-the-work-capability-assessment,[accessed 30th December 2013].

Department for Work and Pensions (2013) Housing Benefit Cap factsheet, available at: http://www.dwp.gov.uk/docs/benefit-cap-factsheet.pdf [accessed 1st June 2013].

DeRaeve, L. (1997) 'Positive Thinking and Moral Oppression and Cancer Care' , *European Journal of Cancer Care,* **6,** pp. 249-256.

Derrida, J. (1981) *Dissemination*, London, Althone Press.

De Wolfe, P. (2002) 'Private Tragedy in Social Context? Reflections on Disability, Illness and Suffering', *Disability and Society*, **17,** 3, pp. 255–267.

De Wolfe, P. (2012) 'Reaping the benefits of sickness? Long term illness and the experience of welfare claims', *Disability and Society,* **27** (5) pp. 617-630.

Dickson-Swift, V. James, E.L. Kippen, S and Liamputong, P. (2006) 'Blurring Boundaries in Qualitative Health Research on Sensitive Topics', *Qualitative Health Research*, **16, (**6), pp. 853-871.

DiGiacomo, S. (1992) 'Metaphor as Illness; postmodern dilemmas in the representation of the body, mind and disorder', *Medical Anthropology; cross cultural studies in Health and Illness*, **14,** (1), pp. 109-137.

Disability Benefits Consortium (2013) *Disability Benefits Consortium; our objectives*, available at: http://disabilitybenefitsconsortium.wordpress.com/our-objectives/ [accessed 2nd June 2012].

Disability and Carers Service (2011) *Disability Living Allowance claim form for people aged 16 years or over,* available at: https://www.gov.uk/dla-disability-living-allowance-benefit/overview [accessed 1st October 2011]

Dixon-Woods M., Fitzpatrick R., Roberts K. (2001) 'Including qualitative research in systematic reviews: opportunities and problems', *Journal of Evaluation in Clinical Practice*, **7** (2) pp.125-133.

Doab, A., Treloar, C. and Dore, G., J. (2005) 'Knowledge and Attitudes about Treatment for Hepatitis C Virus and barriers to treatment among current Injecting Drug Users', *Clinical Infectious Diseases*, **40,** pp.313-320.

Doerrbecker, J. Behrendt, P. Mateu-Gelabert, P. Ciesek, S. Riebesehl, N. Wilhelm, C. Steinmann, J. Pietschmann, T. and Steinmann, E. (2013) 'Transmission of Hepatitis C Virus Among People Who Inject Drugs: Viral Stability and Association With Drug Preparation Equipment', *The Journal of Infectious Diseases,* **207** (2) pp. 281-287.

Doerrbecker, J. Friesland, M. Ciesek, S. Erichsen, T.J. Mateu-Gelabert, P. Steinmann, J. Steinmann, J. Pietschmann, T. and Steinmann, E. (2011) 'Inactivation and Survival of Hepatitis C Virus on Inanimate Surfaces' *The Journal of Infectious Diseases,* **204** (12) pp.1830-1838.

Dolan, M. (1998) *The Hepatitis C Handbook*; second edition, London Catalyst Press.

Dolan, K., Larney, S., Jacka, B., Rawlinson, W. (2009) 'Presence of hepatitis C virus in syringes confiscated in prisons in Australia', *Journal of Gastroenterology and Hepatology,* **24** (10) pp.1655-1657.

Dore, G. Law, M. McDonald, M and Kaldor, J.M (2003) 'Epidemiology of hepatitis C virus infection in Australia', *Journal of Clinical Virology,* 26, (2) pp. 171–184

Douglas, M. (1966) *Purity and Danger: An analysis of the Concepts of Pollution and Taboo,* London, Routledge and Keegan Paul.

Drake, R. F. (1997) ' "What am I doing here?" Non-disabled people and the disability movement', *Disability and Society*, 12 (4) pp. 643-645.

Drayton, J. (2013) 'Bodies-in-Life/Bodies-in-Death: Social Work, Coronial Autopsies and the Bonds of Identity', *British Journal of Social Work*, pp.1-18, doi:10.1093/bjsw/bct011.

DrugScope (2009) *Awareness of Hepatitis C transmission risks low as new campaign launched*, available at: www.drugscope.org.uk/newsandevents/currentnews pages/Hep_C_awareness_campaign.htm (accessed 1 August 2009).

D'Souza R.F., Glynn M.J.,, Alstead E., Osonayo C., Foster G.R. (2004) 'Knowledge of chronic hepatitis C among East London primary care physicians following the Department of Health's educational campaign', *QJM; An International Journal of Medicine*, **97** (6) pp. 331-336.

Duckett, P.S. (1998) ' "What are you doing here?" Non-disabled people and the disability movement; a response to Fran Branfield', *Disability and Society*, **13** (4) pp. 625-628.

Duff, C. (2012) 'Book review essay; After methods, after subjects, after drugs, *Contemporary Drug Problems,* **39,** Summer 2012. Pp. 265-287.

Duffin, J. (2004a) *Livers and Lovers; disease concepts in History, Canada,* University of Toronto press.

Duffin, J. (2004b) 'The Body Multiple; ontology in medical practice (review)', *Journal of the History of Medicine and the Allied Sciences,* **59** (2) pp. 319-321.

Duncan, C.J.A. Stewart, E. Fox, R. (2012) 'Improving targeted screening for hepatitis C in the UK Primary care practitioners can play an important role' *British Medical Journal*, **345** (6525) doi: 10.1136/bmj.e6525.

Dunne, A. & Quayle, E. (2001) 'The impact of iatrogenically acquired HCV on the wellbeing and relationships of a group of Irish women' *Journal of Health Psychology,* **6**, pp.679-692.

Dunne, E. A. & Quayle, E. (2002) 'Pattern and process in disclosure of health status in women with iatrogenically acquired HCV', *Journal of Health Psychology*, **7,** pp. 555-582.

Dumit, J. (2006) 'Illnesses you have to fight to get: Facts as forces in emergent uncertain illnesses' *Social Science and Medicine*, **62,** pp. 577-590.

Dusheiko, G and Burney, T. (2013) 'Hepatitis C treatment: Interferon free or interferon freer?' *Lancet Infectious Diseases*, Published online March 15, 2013 http://dx.doi.org/10.1016/S0140-6736(13)60636-4

Dwyer, R; Fraser,S; Treloar, C (2011) 'Doing things together? Analysis of health education materials to inform hepatitis C prevention among couples', *Addiction Research and Theory*, **19**, (4) pp. 352-361.

Dyer, S. and Demeritt, D. (2009) 'Un-ethical Review? Why it is wrong to apply the medical model of research governance to human geography', *Progress in Human Geography*, pp. 46-64.

Edlin, B. R. (2002) 'Prevention and Treatment of Hepatitis C in Injection Drug Users', *Hepatology,* 36 (5 Suppl 1) pp. S210–S219.

Edlin, B.R. (2011) 'Test and treat this silent killer' *Nature,* **474,** 9 June 2011 pp. 18-19.

Edlin, B., Seal, K., Lorvick, J., Kral, A., Ciccarone, D., Moore, L., and Lo B.. (2001) 'Is it justifiable to withhold treatment for Hepatitis C from illicit drug users?' *New England Journal of Medicine,* **345,** pp. 211-214.

Edwards, J. and Boxall, K. (2010) 'Adults with cystic fibrosis and barriers to employment', *Disability and Society,* **25** (4) pp.441-453.

Ehrenreich, B. (2008) *Smile or Die: How Positive Thinking Fooled America and the World,* London, Granta Publications.

Ehsahni, J., Trang, V. and Karvelas, M. (2006) 'Exploring the need for hepatology nurses and allied health professionals in Victorian liver clinics', *Australian Health Review,* **30** (2), pp. 211–18.

Ellard, J. (2007) " There is no profile it is just everyone": The challenge of targeting hepatitis C education and prevention messages to the diversity of current and future injecting drug users, *International Journal of Drug Policy,* **18,** pp. 225-234.

Elmir, R., Schmeid, V., Jackson, D., Wilkes, L. (2011) 'Interviewing people about potentially sensitive topics', *Nurse Researcher,* **19,** 1, pp. 12-16.

El-Zayadi, A. R. (2008) 'Hepatic Steatosis: A benign disease or silent killer?' *World Journal Gastroenterology,* **14,** 26, pp. 4120-4126.

Engelberg, M. (2006) *Cancer Made me a Shallower Person: A memoir in comics,* London, HarperCollins.

Etkin, N.L. (1992) '"Side Effects": Cultural Constructions and Reinterpretations of Western Pharmaceuticals', *Medical Anthropology Quarterly,* **6** (2) pp.99-113.

Ettore, E. (2007) ' Bodies, drugs and reproductive regimes' in Ettore, E. (ed) *Culture, Bodies and the Sociology of Health,* Aldershot, Ashgate.

Evans, M., Donelle, L. and Hume-Loveland, L. (2013) 'Social support and online postpartum depression discussion groups: A content analysis', *Patient Education and Counselling,* **87,** pp.405-410.

Evans, A., Linzey, D. and Booth, J. (2012) 'PMO-014 An innovative model for improving access to and uptake of testing and treatment for patients with chronic hepatitis C in the substance misuse community', *Gut,* **61:** A78.

Evans-Brown, M., Dawson, R.T., Chandler, M., and McVeigh, J. (2009) 'Use of Melanotan I and II is unlicensed unregulated and potentially harmful', *British Medical Journal,* 21 February, **338** pp.424-425.

Everson, G.T (2012) *Curing Hepatitis C; current and future options for treatment,* Hatherleigh Press.

Evon, D., Esserman, D.A., Ramcharran, D., Bonner, J.E. Fried, M.W. (2011) 'Social support and clinical outcomes during antiviral therapy for chronic hepatitis C', *Journal of Psychosomatic Research,* **71,** pp. 349-356.

Exchange Supplies (2009) *HIV and hepatitis C survival in used syringes*, available at: http://www.youtube.com/watch?v=e5xgKaX8z78 [accessed 12th November 2009].

Expert Patients Programme (2012) *Lottery back self-management for people with Hepatitis C in Bristol*, available at: http://www.expertpatients.co.uk/news-events/news-releases/lottery-back-self-management-people-hepatitis-c-bristol [accessed 1st June 2013].

Farrell G, Comiskey C. (2013) 'Dualities of Living With HIV/HCV Co-Infection: Patients' Perspectives From Those who are Ineligible for or Nonresponsive to Treatment', *Journal of the Association of Nurses in AIDS Care,* doi: 10.1016/j.jana.2012.10.005. [Epub ahead of print]

Faye, B., & Irurita, V. (2003) 'Balancing perspective: The response to feelings of being condemned with the hepatitis C virus', *Journal of Substance Use,* **8** (2), pp. 92-103.

Fatemilehin, I and (1999) ' "You've got to have a Chinese Chef to cook Chinese food!" Issues of power and control in the provision of mental health services', *Journal of Community and Applied Social Psychology,* **9,** pp. 101-117.

Feilzer, M (2009) 'The importance of telling a good story: An experiment in public criminology', *The Howard Journal,* **48** (5) pp.472-484.

Ferguson, H. (2013) 'What can the unemployed teach us about work?' *Continuum; Journal of Media and Cultural Studies,* **27** (2) pp. 311-322.

Ferguson A. and Thomas-MacLean R., (2009) 'Messy Methodological Musings: Engaging in "Successful" Qualitative Health Research', *Aporia ,* **1** (4) pp.7-15.

Ferri, C., Antonelli A., Mascia, A.T., Sebastiani,M., Fallahi, P., Ferrari D., Pileri, S.A., Zignego, A.L., (2007) 'HCV-related autoimmune and neoplastic disorders: the HCV syndrome', *Digestive and Liver Disease,* **39,** Suppl. 1 S13-S21.

Findlay P.A. (2014) Social Work Practice in the Chronic Care Model: Chronic Illness and Disability Care, Journal of Social Work, 14 (1) pp.83-95.

Finkelstein, V. (1980*) Attitudes and Disabled People,* available at: http://disability-studies.leeds.ac.uk/files/library/finkelstein-attitudes.pdf [accessed 1st June, 2013].

Finkelstein, V. (1996) *Modelling Disability,* available at: http://disability-studies.leeds.ac.uk/files/library/finkelstein-modelling-disability.pdf [accessed 1st June 2013].

Finkelstein, V. (2005) Reflections on the Social Model of Disability: The South African Connection, available at: http://disability-studies.leeds.ac.uk/files/library/finkelstein-Reflections-on-the-Social-Model-of-Disability.pdf [accessed 1st June 2014].

Finch, J. (1993) ' "It's Great to Have Someone to Talk To": Ethics and Politics of Interviewing Women', in M. Hammersley (ed) *Social Research: Philosophy, Politics and Practice,* pp. 166–80. London: Sage.

Forton D.M., Alsop J.M., Main, J. Foster, G.R. Thomas, H. C. Taylor-Robinson I. (2001) 'Evidence for a cerebral effect of the hepatitis C virus', *Lancet* **358,** (9275) pp. 38-39.

Foster, D. (2007) 'Legal Obligation or Personal Lottery? Employee experiences of disability and the negotiation of adjustments in the public sector workplace', *Work Employment and Society,* **21** (1) pp. 67-84.

Foster, G. (2008) 'Injecting drug users with chronic Hepatitis C: should they be offered antiviral therapy?' *Addiction*, **103,** pp.1412-1413.

Foster, G. (2013) *Live Chat: Graham Foster Q and A,* available at: http://www.hepctrust.org.uk/Get+Involved/LiveChat/Graham+Foster+online+now [accessed 1st June 2013].

Francisco's, A. (2012) *An Overview of Extra hepatic Manifestations of Hepatitis C,* available at: http://www.hcvadvocate.org/hepatitis/factsheets_pdf/Extrahepatic.pdf [accessed 13th July 2013].

Fraenkel, L., McGraw, S., Wongcharatrawee, S., and Garcia-Tsao, G. (2006) 'Patients 'experiences related to anti-viral treatment for hepatitis', *Patient Education and Counselling*, **62**, pp.148-155.

Frank, A. (1997) *The Wounded Storyteller; body illness and ethics*, London, Chicago University Press.

Fraser, S. (2004) 'It's your life!': Injecting Drug Users, Individual Responsibility and Hepatitis C Prevention,' *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, **8**, pp.199-221.

Fraser, S. (2006) 'The Chronotope of the Queue: Methadone maintenance treatment and the production of time space and subjects', *International Journal of Drug Policy,* **17**, pp.192-202.

Fraser, S. (2008) 'Getting Out in the "Real World": Young Men, Queer and Theories of Gay Community', *Journal of Homosexuality*, **55** (2) pp. 245-264.

Fraser, S. (2010a). 'More than one and less than many: Materialising hepatitis C and injecting drug use in self-help literature and beyond,' *Health Sociology Review* **19** (2) pp.230-244.

Fraser, S. (2010b) 'Hepatitis C and the limits of medicalization and biological citizenship for people who inject drugs', *Addiction Research and Theory*, **18** (5) pp. 544-556.

Fraser, S. (2011) 'Beyond the potsherd'; the role of injecting drug use related stigma in shaping hepatitis C' in Fraser, S and Moore, D. (Eds) *The Drug Effect; health crime and society*, Cambridge, Cambridge University Press, pp. 91-106

Fraser, S. (2012) 'Silences and Signals: The politics of medical progress on hepatitis C', seminar given at Lancaster University, UK, 26th June 2012

Fraser, S. (2013) 'The missing mass of morality: A new fit pack design for hepatitis C prevention in sexual partnerships', *International Journal of Drug Policy*, **24,** pp.212-219.

Fraser, N. and Gordon, L. (1994) 'A Genealogy of Dependency: Tracing the History of a Keyword in the US Welfare State', *Signs*, **19** (2) pp. 306-339.

Fraser, S. and D. Moore (2008). "Dazzled by unity? Order and chaos in public discourse on illicit drug use " *International Journal of Drug Policy,* **66,** pp. 740-752.

Fraser, S. and Moore, D. (2011) 'Harm reduction and hepatitis C: On the ethics and politics of prevention and treatment', *Addiction Research and Theory*, **19** (4) pp. 375-379.

Fraser, S. and C. Treloar (2006). "'Spoiled Identity' in Hepatitis C infection: The binary logic of despair," *Critical Public Health*, **16** (2) pp. 99-110

Fraser, S. and Seear K. (2011) *Making Disease, Making Citizens: the politics of hepatitis C,* Aldershot, Ashgate.

Fraser, S. and K. Valentine (2006). 'Making Blood Flow: Materialising Blood in Body Modification and Blood Borne Virus Prevention,' *Body and Society*, **12**(1) pp.97-119.

Fraser, S. and Valentine, K. (2008) *'Substance and substitution: methadone subjects in liberal societies'* Basingstoke, Palgrave Macmillan.

Frazer K., Glacken M., Coughlan B., Staines A. and Daly L. (2011) 'Hepatitis C virus in primary care: survey of nurses' attitudes to caring' *Journal of Advanced Nursing,* **67** (3), pp. 598–608.

Frazer K., Glacken M., Coughlan B., Staines A. and Daly L. (2011) 'Hepatitis C virus infection in primary care: survey of registered nurses' knowledge and access to information' *Journal of Advanced Nursing*, **67** (2), pp.327–339.

Freeman, A. J., Dore, G.J., Law, M.G., Thorpe, M., Von Overbeck, J., Lloyd, A.R,. Marinos, G. and Kaldor, M.J. (2001) 'Estimating Progression to Cirrhosis in Chronic Hepatitis C Virus Infection', *Hepatology,* **34** (4) pp. 809-816.

Freud, D. (2013) *Universal Credit, Personal Independence Payment, Jobseeker's Allowance and Employment and Support Allowance (Decisions and Appeals) Regulations 2013: Motion to Approve,* available at: http://www.publications.parliament.uk/pa/ld201213/ldhansrd/text/130213-0003.htm, [accessed 1st June 2013].

Fried, M.W. (2002) 'Side effects of hepatitis C therapy and their management', *Hepatology*, **36** s237-s244.

Froggatt, K. (1998) 'The place of metaphor and language in exploring nurses emotional work' *Journal of Advanced Nursing*, **28**,(2) pp. 332-338.

Fry, M. and Bates, G.(2012) The task of self- managing hepatitis C: The significance of disclosure, *Psychology & Health,* Vol.27(4), 460-474.

Fumaz, C.R., Muoz-Moreno, J.A., Molto, J., Ferrer, M.J., Lopez-Blazquez, R., Negredo, E., Paredes R, Gómez G, Clotet B. (2008). 'Sustained antiretroviral treatment adherence in survivors of the pre-HAART era: Attitudes and beliefs' *AIDS Care,* **20** (7), pp. 796-805.

Furedi, F. (2006) 'Save Us From the Politics of Behaviour' (Spiked Online) http://www.spiked-#online.com/index.php/site/article/1638 [accessed 01/02/2012].

Gagnon, M. (2009) 'Re-Thinking the Corporeality of HIV/AIDS in the Post- HAART Era: A Critical Perspective,' *Aporia*, **1** (3) pp. 18-27.

Galindo, L. Maginnis, T. Wallace, G. Hansen, A, Sylvester, D. (2007) 'Education by Peers is the Key to Success', *International Journal of Drug Policy,* **18**, (5), pp.411-416.

Galvani, S. (2007) 'Refusing to Listen: Are We Failing the Needs of People with Alcohol and Drug Problems?' *Social Work Education*, **26** (7) pp. 697-707.

Galvani, S. and Hughes, N. (2010) 'Working with Alcohol and Drug Use: Exploring the Knowledge and Attitudes of Social Work Students', *British Journal of Social Work,* **40**, pp.946-962.

Galvani, S. Hutchinson, A. and Dance, C. (2013) 'Identifying and Assessing Substance Use: Findings from a National Survey of Social Work and Social Care Professionals', *British Journal of Social Work*, Advanced Access published March 13 2013, pp. 1-19.

Garthwaite, K. (2009) 'What a performance! Exploring the reflexive roles of the researcher and the researched within health and illness narratives', *ENQUIRE,* November 2009, pp. 110-133.

Garthwaite, K. (2011) 'The language of shirkers and scroungers? Talking about illness, disability and coalition welfare reform,' *Disability and Society* **26** (3): pp. 369-372.

Garthwaite, K., Bambra, C. & Warren, J. (2013) 'The unwilling and the unwell'? Exploring stakeholders' perceptions of working with long term sickness benefits recipients' *Disability and Society,* DOI:10.1080/09687599.2012.758032.

Genovese, B. (2004) 'Thinking inside the Box: The Art of Telephone Interviewing', *Field Methods*, **16** (2) pp.215-226.

Gibbs, A. (1997) *Social Research Update19: Focus Groups*, University of Surrey, available at: http://sru.soc.surrey.ac.uk/SRU19.html [accessed 3rd October 2012].

Gifford, S., O'Brien, M., Bammer, G., Banwell, C., & Stoove, M. (2003) 'Australian women's experiences of living with hepatitis C virus: Results from a cross-sectional survey' *Journal of Gastroenterology and Hepatology*, **18**, pp.841-850.

Gifford, S., O'Brien, M., Smith, A., Temple-Smith, M., Stoove, M., Mitchell, D., Jolley, D. (2005). 'Australian men's experiences of living with hepatitis C virus: Results from a cross-sectional survey' *Journal of Gastroenterology and Hepatology*, **20**, pp.79-86.

Gilbert, L. K., Peterson, R. S., and Scanlon, K.E., (2010) 'Promoting Sexual Health among MSM Online: A Hepatitis Campaign Comparison', *Journal of Gay and Lesbian Social Services*, **22** (4) pp.446-462.

Gill, M., Atiq, M., Sattar, S., and Khokhar, N. (2005) 'Psychological implications of hepatitis C virus diagnosis', *Journal of Gastroenterology and Hepatology*, **20**, pp. 1741-1744.

Giraudon, I., Ruf, M., Maguire, H., Charlett, A., Ncube, F., Turner, J., et al. (2008) 'Increase in diagnosed newly acquired hepatitis C in HIV-positive men who have sex with men across London and Brighton, 2002-2006: Is this an outbreak?' *Sexually Transmitted Infections*, **84** (2), pp. 111-115.

Glacken, M., Kernohan, G., & Coates, V. (2001) 'Diagnosed with hepatitis C: Descriptive exploratory study', *International Journal of Nursing Studies*, **38**, pp.107-116

Glacken, M., Coates, V., Kernohan, G., & Hegarty, J. (2003) 'The experience of fatigue for people living with hepatitis C'. *Journal of Clinical Nursing*, **12** (2), pp.244-252.

Goffman, E. (1963) *Stigma; notes on the management of a spoiled identity,* London, Penguin.

Golden, J., Conroy, R. M., O'Dwyer, A., Golden, D. & Hardouin, J. (2006)' Illness related stigma, mood and adjustments to illness in persons with Hepatitis C', *Social Science and Medicine*, **63**, pp.3188-3198.

Goodley, D. (2011) *Disability Studies; an interdisciplinary introduction,* London, Sage.

Goodley, D. and Tregaskis, C. (2005) 'Disability Research by Disabled and Non-Disabled People: Towards a Relational Methodology of Research Production', *International Journal of Social Research Methodology,* **8,** (5), pp. 363-374.

Goytia, E.J., Lounsbury, D.W., McCabe, M., Weiss, E., Newcomer, M., Nelson, D.J., Brennessel, D., Rapkin, B.D., Kemeny, M.M., (2009) 'Establishing a General Medical Output Clinic for Cancer Survivors in a Public City Hospital Setting', *Journal of General Internal Medicine*, **24** (Supplement 2) 451-455.

GOV.UK (2013) *'Benefits and Credits: Budgeting Loans'* available at: https://www.gov.uk/budgeting-loans [accessed 1st October 2013].

Gow, P. J., and Mutimer, D. (2001) 'Regular Review: Treatment of Chronic Hepatitis C', *British Medical Journal,* **323,** pp.1164-1167.

Greater Manchester Hepatitis C Strategy Group, (2006) *Greater Manchester Hepatitis C Strategy,* (online) http://greatermanchesterhepc.com/document_repository/ (accessed 01/03/2012).

Green, A. and I. Shuttleworth (2010). 'Local differences, perceptions and incapacity benefit claimants: implications for policy delivery' *Policy Studies* **31** (2) pp. 223-243.

Grewal, I., S. Joy, Swales, J. and Woodfield, K. (2002) *Disabled for Life? attitudes towards and experiences of disability in Britain*, available at: http://research.dwp.gov.uk/asd/asd5/rrep173.pdf, [accessed 15th September, 2011]..

Grinyer, A. (2002) *The anonymity of research participants: assumptions, ethics and practicalities*, Social Research Update 36, University of Surrey, available at: http://sru.soc.surrey.ac.uk/SRU36.pdf [accessed 30th October 2012].

Grinyer, A. (2009) *Life after Cancer in Adolescence and Young Adult: the experience of survivorship,* London, Routledge.

Groessl, E., Weingart, K.R., Kaplan, R.M., Clark ,J, A., Gifford, A.l, Ho, S.L. (2008) 'Living with Hepatitis C: Qualitative Interviews with Hepatitis C-infected Veterans', *Journal of General Internal Medicine,* **23** (12) pp. 1959–1965.

Groessl E.J., Weingart K.R., Gifford A.L., Asch S.M, Ho SB. (2011) 'Development of the hepatitis C self-management program', *Patient Education and Counselling* **83** (2) pp. 252-255.

Grogan A, Timmins F. (2010) 'Patients' perceptions of information and support received from the nurse specialist during HCV treatment', *Journal of Clinical Nursing*,**19** (19-20) pp. 2869-2878.

Grover, C. and Piggott, L. (2005) 'Disabled people, the reserve army of labour and welfare reform' *Disability & Society.* 20 (7) pp. 705-717.

Grover, C. and Paylor, I. (2010) 'No one written off? Welfare work and problem drug use', *Drugs Education Prevention and Policy,* **17** (4) pp. 315-332.

Grover, C. and L. Piggott (2007) 'Social security, employment and Incapacity Benefit: critical reflections on a new deal for welfare,' *Disability and Society,* **22** (7) pp. 733-746.

Grover, C. and L. Piggott (2010) 'From Incapacity Benefit to Employment and Support Allowance: social sorting, sickness and impairment and social security,' *Policy Studies,* **31** (2) pp. 265-282.

Grover, C. and Piggott, L. (2012) 'Disability and Social (In)Security: Emotions Contradictions of Inclusion and Employment and Support Allowance', *Social Policy and Society,* DOI:10.1017/S147476412000619.

Grover, C. and Soldatic, K. (2012)' Neoliberal Restructuring disabled people and social (in)security in Australia and Britain', *Scandinavian Journal of Disability Research,* DOI:10.1080/15017419.2012.724446.

Grow J.M. and Christopher S.A. (2008) 'Breaking the silence surrounding hepatitis C by promoting self-efficacy: hepatitis C public service announcements,' *Qualitative Health Research,* **18** (10) pp. 1401-1412.

Grue, J. (2012) 'The Rejected Category: ME, CFS, and the Theorization of Disability, Impairment, and Chronic Illness, paper presented at the 6th Biennial Disability Studies Conference', Lancaster University 11-13 September.

Grundy G. and Beechng, N., (2004) 'Understanding social stigma in women with hepatitis C', *Nursing Standard,* **19** (4) pp.35-39.

Guasp, A. (2012) *Gay and Bisexual Men's Health Survey,* Stonewall, available at: http://www.stonewall.org.uk/documents/stonewall_gay_mens_health_final_1.pdf [accessed 1st July 2013].

Guillemin, M., and Gillam, L. (2004) 'Ethics, reflexivity and ethically important moments in research' *Qualitative Inquiry,* **10,** pp. 261-280.

Guise, J., McVittie, C. McKinlay, A. (2009) 'A discourse analytic study of ME/CFS (Chronic Fatigue Syndrome) sufferers' experiences of interactions with doctors', *Journal of Health Psychology,* **15** (3) pp. 426-435.

Gupta, L., Shah, S. and Ward, J.E. (2006) 'Education and health service needs of Australian general practitioners in managing hepatitis C', *Journal of Gastroenterology and Hepatology,* **21** pp.694-699.

Guttorm, Hanna Ellen (2012) 'Becoming-(a)-Paper, or an Article Undone: (Post-)Knowing and Writing (Again), Nomadic and So Messy', *Qualitative Inquiry,* 18 (7) pp. 595-605.

Habib, S.E. and Adorjany, L.V.(2003) 'Hepatitis C and injecting drug use: The realities of stigmatisation and discrimination,' *Health Education Journal*, **62** (3) pp. 256-265.

Hagan H., Thiede H., Weiss N.S., Hopkins S.G., Duchin J.S., Alexander E.R., (2001) 'Sharing of drug preparation equipment as a risk factor for hepatitis C'. *American Journal of Public Health*, **9**, pp.42–6.

Halding, A., Heggal, K., Wahl, A. (2011) 'Experiences of self-blame and stigmatisation for self-infliction among individuals living with COPD', *Scandinavian Journal of Caring Sciences*, **25**, pp. 100-107.

Halliday J, Klenerman P, Barnes E (2011) Vaccination for hepatitis C virus: closing in on an evasive targetExpert Rev Vaccines. 2011 May;10(5):659-72..

Halse, C. and Honey, A. (2007) 'Rethinking ethics review as institutional discourse', *Qualitative Inquiry*, **13** (3) pp. 336-352.

Hammersley, M. (2006) 'Are Ethics Committees Ethical?', *Qualitative Researcher*, **2**, (Spring 2006) pp. 4-7.

Hammersley, M. (2010) 'Reproducing or Constructing? Some questions about transcription in social research', *Qualitative Research*, **10 (**5) pp. 553-569.

Hammond, C. (2002). 'A poorly understood condition: Disability Living Allowance and People with CFS/ME,' *Social Policy & Administration*, **36** (3) pp. 254-274.

Hampson, H. and Thomas, M. (2003) 'Lone Researchers at sea; gender risk and responsibility', *Qualitative Research***, 3** (2) pp. 165-189.

Hanna, P. (2012) 'Using internet technologies (such as Skype) as a research medium: a research note', *Qualitative Research*, **12** (2) pp. 239-242.

Harraway, D. (1991) Situated knowledges: the science question in feminism and the privilege of partial perspective, Feminist Studies, 14, 3, 575-599.

Harrington, M. (2010). *An Independent Review of the Work Capability Assessment,* available at: http://www.dwp.gov.uk/docs/wca-review-2010.pdf. [accessed 15th September, 2011].

Harrington, M. (2012) *An Independent Review of the Work Capability Assessment* available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/70123/wca-review-2012.pdf [accessed 1st June 2013].

Harris, J. and McElrath, K. (2012) 'Methadone and Social Control: Institutionalized Stigma and the Prospect of Recovery', *Qualitative Health Research*, **22** (6) pp. 810-824.

Harris, M. (2005) 'Living with Hepatitis C: the medical encounter', *New Zealand Sociology*, **20,** pp.419.

Harris, M. (2009a) 'Injecting, Infection, Illness: Abjection and Hepatitis C Stigma', *Body and Society*, **15** (4) pp.33-51.

Harris, M. (2009b) 'Relapse to Injecting Drug Use; a hepatitis C treatment concern', *Contemporary Drug Problems,* **36,** 12.

Harris, M. (2009c) 'Troubling biographical disruption: Narratives of unconcern about hepatitis C diagnosis' *Sociology of Health & Illness* **31** (7) pp. 1028–1042.

Harris, M. (2010) 'Negotiating the Pull of the Normal; embodied narratives of living with hepatitis C in New Zealand and Australia', University of New South Wales, Unpublished PhD thesis accessed online [01/07/2012].

Harris, M., Jolly, E., Martin, A., Wells, H., Rhodes, T. (2012a) *Barriers and facilitators to hepatitis C treatment for people who inject drugs: A qualitative study,* World Health Organisation Regional Office for Europe available at: http://www.euro.who.int/__data/assets/pdf_file/0011/179750/Barriers-and-facilitators-to-hepatitis-C-treatment-for-PWID-A-qualitative-study-June-2012-rev-4.pdf [accessed 1st May 2013].

Harris, M. and Rhodes, T. (2012a) 'Methadone diversion as a protective strategy: The harm reduction potential of generous constraints', *International Journal of Drug Policy,* http://dx.doi.org/10.1016/j.drugpo.2012.10.003

Harris M, and Rhodes T. (2012b) 'Venous access and care: harnessing pragmatics in harm reduction for people who inject drugs', Addiction, 107 (6), pp. 1090-1096.

Harris M., Rhodes T., Martin A. (2013) 'Taming systems to create enabling environments for HCV treatment: negotiating trust in the drug and alcohol setting', *Social Science and Medicine,* **83** pp.19-26.

Harris, M. Treloar, C. Maher, L. (2012b) 'Staying Safe from Hepatitis C: Engaging with Multiple Priorities', *Qualitative Health Research,* **22** (1), pp.31-42.

Harrow, A., Wells, M,. Barbour, R.S., and Cable, S. (2008) 'Ambiguity and uncertainty: the on-going concerns of male partners of women treated for breast cancer', *European Journal of Oncology Nursing,* **12** (4) pp. 349-56.

Hathaway, A D and Tousaw, K. I (2008) 'Harm reduction headway and continuing resistance: Insights

from safe injection in the city of Vancouver', *International Journal of Drug Policy,* **19,** pp. 11-16.

HCV Action (2012*) Hepatitis C Adult Services Commissioning Toolkit,* HCV Action available at: http://www.hcvaction.org.uk/Resources/HCV%20Action/Resources/Commissioning%20Tools/The%20 Hepatitis%20C%20Commssioning%20Toolkiit.pdf [accessed 1st June 2013].

Health Protection Agency (2008) *Hepatitis C in the UK: The Health Protection Agency Annual report* London, Health Protection Agency Centre for Infections.

Health Protection Agency (2012) *Hepatitis C in the UK: The Health Protection Agency Annual Report,* London, Health Protection Agency available at: http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317135237219 [accessed 1st July 2013].

Heathcote, J. and Main ,J. (2005) 'Treatment of Hepatitis C', *Journal of Viral Hepatitis,* **12** (3) pp. 223-235.

Hellard, M. E. and Wang, H-S, J. (2009) 'The Role of General Practitioners in Managing and Treating Hepatitis C', *Medical Journal of Australia,* **191,** (10) pp. 523-524.

Hentz, P. (2002) 'The Body Remembers ; grieving and a circle of time', *Qualitative Health Research* **12**, 2, pp. 161-172.

Hepatitis Australia (2008) *Moving on after treatment; a post treatment guide for people with hepatitis C,* Hepatitis Australia, available at: http://www.hepatitiswa.com.au/assets/files/pdfs/Movingon.pdf [accessed 01/07/2012].

Hepatitis C Trust (undated) *The UK vs. Europe; Losing the Fights Against Hepatitis C*, available at, http://www.hepctrust.org.uk/NR/rdonlyres/CA675E63-1A8C-4D99-B5D2-D3E5A98F6842/0/213_TheUKvsEurope.pdf [accessed 31st July 2012].

Hepatitis C Trust (2009) *Hepatitis C: Out of Control. An audit of Strategic Health Authority hepatitis C governance,* London, The Hepatitis C Trust, available at: http://www.hepctrust.org.uk/NR/rdonlyres/F065663C-2D16-4A32-8ED4-EABE1DF0BD65/0/FINALOutofControlwithnewSEscore.pdf (accessed 5th April 2012).

Hepatitis C Trust (2010a) *Diagnosing viral hepatitis in the community; a 3 month pharmacy testing pilot,* available at: http://www.hepctrust.org.uk/Resources/HepC/HCV%20Reports/Trust/Diagnosing%20viral%20hepatitis%20in%20the%20community%20A%203%20month%20pharmacy%20testing%20pilot.pdf [accessed 15th January 2011].

Hepatitis C Trust (2010b) *Post treatment survey report*, London, The Hepatitis C Trust available at: http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Resources/Reports/Post%20Treatment%20Survey%20Report%202010.pdf (accessed 4th April 2011).

Hepatitis C Trust (2011a) *Awareness Posters*, available at: http://www.hepctrust.org.uk/News_Resources/resources/Posters [accessed 1st June 2011].

Hepatitis C Trust (2011b) *Benefits: an Introduction*, available at: http://www.hepctrust.org.uk/Support/Benefits/Benefits+introduction [accessed 12th October 2011].

Hepatitis C Trust (2012) *Considering Treatment*, http://www.hepctrust.org.uk/Treatment/Considering+Treatment/Considering+treatment [accessed 4th January 2012].

Hepatitis C Trust (2013a) *Update from the Hepatitis C Trust, Issue 15*, available at: http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Resources/The%20Hepatitis%20C%20Trust%20PDF%20Jan%202013.pdf [accessed 30th January 2013].

Hepatitis C Trust (2013b) *The Trust joins forces with Terrence Higgins Trust for support courses,* available at: http://www.hepctrust.org.uk/News_Resources/news/2013/March/The+Trust+joins+forces+with+Terrence+Higgins+Trust+for+support+courses [accessed 1st July 2013].

Hepatitis C Trust (2013c) *Opportunity Knocks? An audit of hepatitis C services during the transition,* London, The Hepatitis C Trust available at: http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Resources/Reports/Opportunity%20knocks%20audit.pdf (accessed 19th May, 2013).

Hepatitis C Trust (2013d) *Capital Challenge: Tackling Hepatitis C in London,* London, The Hepatitis C Trust, available at http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Resources/Reports/CapitalchallengetacklinghepatitisCinLondon.pdf (accessed 16th May 2013).

Hepatitis C Trust (2013e) *The hepatitis C 'talk test treat' roadshow,* http://www.hepctrust.org.uk/Get+Involved/World+Hepatitis+Day/World+Hepatitis+Day+2013/Roadshow [accessed 30th July, 2013]

Hepatitis C Trust (2013f) *Scotland's Hepatitis C Odyssey*, available at: http://www.hepctrust.org.uk/News_Resources/news/2013/June/Hepatitis+C+Odyssey+in+Scotland [accessed 11th July, 2013].

Hepatitis Scotland (2013) *World Hepatitis Day Scotland 2013*, available online: http://www.hepatitisscotland.org.uk/world-hepatitis-day-2013-and-b/ [accessed 13th July 2013].

HIV Scotland and Hepatitis Scotland (2012) *People living with hepatitis C and HIV: Their views on welfare reform*, available at: http://www.hepatitisscotland.org.uk/publications-policy/people-living-with-hepatitis-c-and-hiv/ (accessed 2nd January 2013).

Hepgul N., Kodate N., Anderson JE., Henderson M., Ranjith G., Hotopf M., Pariante CM. (2012) 'Understanding clinical risk decision making regarding development of depression during interferon-alpha treatment for hepatitis-C: a qualitative interview study' *International Journal of Nursing Studies,* 49 (12) pp.1480-1488

Hepworth., J., & Krug, G. (1999) 'Hepatitis C: A socio-cultural perspective on the effects of a new virus on a community's health' *Journal of Health Psychology* **4** (2), pp. 237-24.

Herek, G..M., Capitiano, J.P., and Widaman, K.F (2002) 'HIV-Related Stigma and Knowledge in the United States: Prevalence and Trends, 1991-1999', *American Journal of Public Health,* **92,** (3) pp. 371-377.

Her Majesty's Government (1995) *The Disability Discrimination Act, 1995* available at: http://www.legislation.gov.uk/ukpga/1995/50 [accessed 1st July 2013].

Her Majesty's Government (2010) *Equality Act 2010; chapter 15*, available at: http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf [accessed 1st June 2013.]

Her Majesty's Government (2011). 'Equality Act 2010 Guidance: guidance on matters to be taken into account in determining questions relating to the definition of disability' available at: http://odi.dwp.gov.uk/docs/law/ea/ea-guide-2.pdf [accessed 15th April 2013].

Hertz, R. (1997) 'Introduction: Reflexivity and Voice' in Hertz, R. (Ed) Reflexivity and Voice, London, Sage, pp.vii-3.

Herzlich, C. and Pierret, P. (1987) Illness and self in society, Baltimore Johns Hopkins University Press.

Hezode, C. (2012) 'Bocepravir and Telepravir for the treatment of chronic hepatitis C: safety management and clinical practice', *Liver International*, February, 2012 pp. 32-38.

Hirsch, J. (2006) 'An Anniversary for Cancer Chemotherapy', *Journal of the American Medical Association,* September 27 2006, **296** (12) pp. 1518-1520.

Hochschild, A. (1979). 'Emotion work, feeling rules and social structure', *American Journal of Sociology*, **85**, pp. 551–575..

Hodge, N. (2005) 'Reflections on diagnosing autistic spectrum disorders' *Disability and Society* **13**,(2) pp. 345-349.

Hodkinson, P. (2005) "Insider Research" in the study of youth cultures, Journal of Youth Studies, 8 (2) pp. 131-149.

Hodgkinson, K., Butow, P., Hunt, G.E., Wyse, R. Hobbs, R.M. (2007) 'Life after cancer: couples' and partners' psychological adjustment and supportive care needs,' *Supportive Care in Cancer,* **15,** (4), pp 405-415.

Holloway, I and Biley, F (2010) 'Being a Qualitative Researcher', *Qualitative Health Research,* **21** (7) 968-975.

Holt, A. (2010) 'Using the Telephone for Narrative Interviewing; a research note', *Qualitative Research*, **10** (1) pp. 113-121.

Hopwood, M. (2009) *Recovery from Hepatitis C treatment*, National Centre in HIV Social Research, The University of New South Wales, available at:
http://nchsr.arts.unsw.edu.au/media/File/Recovery_from_hepatitis_C_treatments.pdf[accessed 1st July 2011].

Hopwood, M. N., Brener, L and Wilson, H., (2012) 'Vaccine, transmission and treatment: an exploratory study of viral hepatitis knowledge among attendees at a metropolitan Australian university', *Drugs - Education Prevention and Policy*, **19**, (4) pp. 346 - 350

Hopwood, M. (2013) 'Perspectives of a self-selected sample of former patients on the long term health outcomes of interferon based hepatitis C treatments: an exploratory study', *Psychology Health and Medicine,* DOI:10.1080/1354806.2013.774429.

Hopwood, M. Bryant, J. and Brener, L. (2010) 'Evolving Knowledge and Practice: Hepatitis C and Illicit Drug Use', *Contemporary Drug Problems*, **37,** Winter 2010 pp. 543-547.

Hopwood M, Nakamura T, Treloar C. (2010) 'Disclosing hepatitis C infection within everyday contexts: implications for accessing support and healthcare', *Journal of Health Psychology,* **15** (6) pp. 811-818.

Hopwood, M. and Southgate, E. (2003) 'Living with Hepatitis C: A Sociological Review', *Critical Public Health,* **13,** (3) pp. 251-267.

Hopwood, M. & Treloar, C. (2003*) The 3D Project: Diagnosis, Disclosure and Discrimination - Living with Hepatitis C*, National Centre for HIV Social Research, University of New South Wales.

Hopwood, M., & Treloar, C. (2004) 'Receiving a hepatitis C-positive diagnosis', *Internal Medicine Journal,* **349,** pp. 526-531.

Hopwood, M. and Treloar, C. (2005) 'The Experience of Interferon Based treatments for Hepatitis C infection,' *Qualitative Health Research*, **15,** (5) pp. 635-646.

Hopwood, M and Treloar, C. (2007) 'Pre-treatment preparation and management of interferon –based therapy for hepatitis C virus infection', *Journal of Advanced Nursing*, **59** (3) pp. 248-254.

Hopwood, M. and Treloar, C. (2008) 'Resilient coping: Applying adaptive responses to prior adversity during treatment for hepatitis C infection' *Journal of Health Psychology*, **13** (1), pp. 17-27.

Hopwood, M., Treloar, C., and Bryant, J. (2006) 'Hepatitis C and injecting-related discrimination in New South Wales, Australia,' *Drugs: Education, Prevention and Policy*, **13** (1), pp. 61-75

Hopwood, M., Treloar, C. and Redsull, L. (2006) *Experiences of hepatitis C treatment and its management: What some patients and health professionals say* (Monograph 4/2006), National Centre in HIV Social Research, The University of New South Wales.

Houston, D. and C. Lindsay (2010). 'Fit for Work? Health, employability and challenges for the UK Welfare reform agenda ' *Policy Studies* **31** (2) pp. 133-142.

Hughes, B. (1999) 'The Constitution of Impairment: modernity and the aesthetic of oppression' *Disability and Society*, **14,** (2) pp. 155-172.

Hughes, B. (2000) 'Medicine and the Aesthetic Invalidation of Disabled People', *Disability and Society*, **15** (4) pp. 555-568.

Hughes, B (2009) 'Disability activisms: social model stalwarts and biological citizens', Disability and Society, **24** (6) pp. 677-688.

Hughes, B. (2012) 'Civilising Modernity and the Ontological Invalidation of Disabled People', in Watson, N., Roulstone, A., and Thomas, C. (Eds) *Routledge Companion to Disability Studies*, London, Routledge pp. 17-32.

Hughes, N. Closs, S.J. and Clarke, D. (2009) 'Experiencing cancer in old age: A Qualitative Systematic Review' *Qualitative Health Research,* **19,** (8) pp. 1139-1153.

Hughes, B. and Paterson, K. (1997) 'The Social Model of Disability and the Disappearing Body: towards a sociology of impairment', *Disability and Society*, **12** (3) pp. 325-340.

Hulse, G.K. (1997) 'Australia's public health response to HIV and HCV: a role for 'affected' Communities', *Drug and Alcohol Review*, **16** pp.171-176.

Humphrey, J. C. (2000) 'Researching disability politics, or, some problems with the social model in practice', *Disability and Society,* **15** (1) pp 63-85.

Hunt, N. and Derricott, J. (2001) 'Smack heads, crack heads and other junkies: Dimensions of the stigma of drug use' in Mason, T., Carlisle, C., Watkins, C. and Whitehead, E. (Eds.) *Stigma and Social Exclusion in Healthcare,* London Routledge.

Hutchinson, S.A., Wilson, M.E., Wilson, H.S. (1994) 'Benefits of Participating in Research Interviews', *IMAGE; Journal of Nursing Scholarship.* **26** (2) pp. 161-166.

Irvine, A., (2011) 'Duration, dominance and depth in telephone and face-to-face interviews: a comparative exploration', *International Journal of Qualitative Methods*, **10,** (3) pp. 202-220.

Irvine, A. Drew, P. and Sainsbury, R. (2012) ' "Am I not answering your questions properly?" Clarification adequacy and responsiveness in semi structured telephone and face to face interviews', *Qualitative Research*, published online 5 April 2012, DOI: 10.1177/1468794112439086 pp.1-20

IRAS, (2011). *Welcome to the Integrated Research Application System (IRAS),* available at; https://www.myresearchproject.org.uk/Signin.aspx [accessed 30th September 2012].

Islam, M. M., Topp, L., Day, C. A., Dawson, A. and Conigrave, K. M. (2012) 'The accessibility, acceptability, health impact and cost implications of primary healthcare outlets that target injecting drug users: A narrative synthesis of literature'. *International Journal of Drug Policy*, **23** (2), pp.94–102.

Iversen, J., Wand, H., Gonnermann, A. and Maher, L. (2010) 'Gender differences in hepatitis C antibody prevalence and risk behaviours among people who inject drugs in Australia 1998-2008', *International Journal of Drug Policy,* **21** pp. 471-476.

Jackson, E. J. (2005) 'Stigma, Liminality and Chronic Pain: mind-body borderlands', *American Ethnologist,* **32**, (3), pp. 332 -353.

Jafari, S., Copes, R., Baharlou S., Etminan, M. and Buxton, J. (2010) 'Tattooing and the risk of transmission of hepatitis C: a systematic review and meta-analysis', *International Journal of Infectious Diseases,* **14**, e928–e940.

Janke E A., McGraw S., Garcia-Tsao G., and Fraenkel L (2008) 'Psychosocial issues in hepatitis C: a qualitative analysis', *Psychosomatics,* **49 (**6) pp.494-501.

Jairath, N. (1999) ' Myocardial Infarction patients use of metaphors to share meaning and communicate underlying frames of experience', *Journal of Advanced Nursing*, **29**, (2) pp. 283-289.

Jasen, P. (2009) 'From 'silent killer' to 'whispering disease': Ovarian cancer and the uses of metaphor', *Medical History*, **53,** pp. 489-512.

Jenkinson, K.M., Temple-Smith, M., Lavery, J. Gifford, S.M and Morgan, M. (2008) 'Dentists Perspectives on Infection Control in Relation to Blood-borne Viruses', *Australian Journal of Primary Health,* **14** (1) pp. 82-89.

Jenner, A. and Scott, A. (2007) 'Circulating beliefs, resilient metaphors and faith in biomedicine: Hepatitis C patients and interferon combination therapy' *Sociology of Health & Illness*, **30**, pp. 197-216.

Jensen, D.M (2011) 'A New Era of Hepatitis C Therapy Begins', *New England Journal of Medicine*, (**364**) 13, pp. 1272-1273.

Johnson, B. (1981) 'Translator's Introduction' in Derrida, J. (1981) *Dissemination*, London, Althone Press, pp. vii-xxxiii.

Johnson, J. L., Botroff, J. L., Browne, A.J., Grewal,S., Hilton, A.B., and Clarke, H. (2004) 'Othering and Being Othered in the Context of Health Care Services', *Health Communication*, **16** (2) pp. 255-271.

Joinson, A.N. (2005) 'Internet Behaviour and the Design of Virtual Methods' in Hine, C. (ed) *Virtual Methods; issues in Social Research on the Internet,* Oxford, Berg. pp.21-35.

Jootun, D., McGhee, G., and Marland, G.R. (2009) 'Reflexivity: Promoting rigour in qualitative research', *Nursing Standard*, **23** (23) pp. 42-46.

Jost, J.J., Goldsamdt, L.A., Harocopos, A., Kobrak, P. Clatt, M. C. (2010) 'Hepatitis C knowledge among new injection drug users', *Drugs education prevention and policy*, **17** (6) pp. 821-834.

Jutel, A. (2009) 'A Sociology of Diagnosis: a preliminary review', *Sociology of Health and Illness*, **31** (2) pp. 278-299.

Jutel, A. and Nettleton, S. (2011) 'Towards a sociology of diagnosis', *Social Science and Medicine*, **73**, pp. 793-800.

Kadushin, A. (1990) *The Social Work Interview; a guide for human service professionals,* New York, Columbia University Press.

Kaiser, K . (2008) 'The meaning of the survivor identity for women with breast cancer' *Social Science and Medicine,* **67,** pp. 79-87.

Kavanaugh, K., & Ayres, L. (1998) '"Not as bad as it could have been": Assessing and mitigating harm during research interviews on sensitive topics', *Research in Nursing and Health,* **21**, pp.91-97.

Keane, H. (2008) 'Pleasure and discipline in the uses of Ritalin', *International Journal of Drug Policy*, **19**, pp. 401-409.

Keane, H. (2011) 'Drugs that work: pharmaceutical and performance self-management' in Fraser, S. and Moore, D. (eds) *The Drug Effect; Health Crime and Society,* Melbourne, Cambridge University Press, pp. 106-121.

Keane, H. (2013) 'Categorising Methadone; addiction and analgesia', *International Journal of Drug Policy,* http://dx.doi.org/10.1016/j.drugpo.2013.05.007

Keene J.M. (2001) 'An International Social Work Perspective on Drug Misuse Problems and Solutions: Reviewing Implications for Practice', *Journal of Social Work,* **1** (2) pp. 197-199.

Keith, L. (1996) 'Encounters With Strangers: The public's responses to disabled women and how this affects our sense of self', in J. Morris (ed) *Encounters With Strangers: Feminism and Disability*, London: Women's Press, pp. 69-88.

Kent Health Protection Unit (2007) *Management of Hepatitis C in Kent and Medway Guidelines and Local Services,* available at:
http://www.medwaycommunityhealthcare.nhs.uk/_uploads/documents/policies/clinical/management-of-hepatitis-c-tended-2010_combined.pdf [accessed 1st June 2013].

Kenyon, S. and Hawker, E. (1999) 'Once would be enough: Some reflections on the issue of safety for lone researchers', *International Journal of Social Research Methodology*, **2,** (4) pp.3133-327.

Kerruish, A. (1995) 'Basic Human Values; The Ethos of Methodology', *Journal of Community and Applied Psychology,* **5**, pp. 121-143.

King, S. (2008) *Pink Ribbons Inc.: Breast Cancer and the Politics of Philanthropy*, Minnesota , University of Minnesota Press.

Kingfisher, C.P. (1998) 'How Providers Make Policy: An Analysis of Everyday Conversation in a Welfare Office', *Journal of Community and Applied Social Psychology*, **8,** pp.119-136.

Kirby, T. and Thorber-Dunwell, M. (2013) 'High-risk drug practices tighten grip on London gay scene', *The Lancet*, **381**, January 12, pp.101-102.

Kitchin, R. (1998) 'Out of Place', Knowing One's Place: Space power and the exclusion of disabled people, *Disability and Society*, **13** (3) pp. 343-356.

Kitchin, R. Shirlow, P. Shuttleworth, I. (1998) 'On the Margins: Disabled people's experience of employment in Donegal, West Ireland', *Disability and Society*, **13** (5) pp.785-806.

Kitchin, R. (2000) 'The Researched Opinions on Research: disabled people and disability research', *Disability and Society*, **15,** (1), pp. 25-47.

Kitzinger, J. (1995) 'Qualitative Research: Introducing focus groups', *British Medical Journal,* 311 pp. 299.-302.

Klapper P.E. (2009) 'Guidelines for Laboratory Testing of Patients with Hepatitis C in Greater Manchester' The Association of Greater Manchester Primary Care Trusts, Manchester.

Klawiter, M. (2008*) Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* Minnesota, University of Minnesota Press.

Knight, S. (2013) 'Hepatitis C: the cure?', Financial Times, 15th March 2013, available at: http://www.ft.com/cms/s/2/542ad524-8b77-11e2-b1a4-00144feabdc0.html#ixzz2Yez73AnU [accessed 17th March 2013].

Knox, R. (2013) '$1,000 Pill For Hepatitis C Spurs Debate Over Drug Prices' available at: http://www.wbur.org/npr/256885858/-1-000-pill-for-hepatitis-c-spurs-debate-over-drug-prices [accessed 30th December 2013].

Kock, T. and Harrington, A. (1998) 'Reconceptualising rigour: the case for reflexivity' *Journal of Advanced Nursing,* **28** (4) pp.882-890.

Körner H, Treloar C. (2006) 'Representations of people with HIV and hepatitis C in editorials of medical journals: discourses and interdiscursive relations', *Communication & Medicine,* 3 pp. 15–25.

Korner, H. (2010) 'Negotiating treatment for hepatitis C: interpersonal alignment in the clinical encounter' *Health*, **14** (3) pp. 272-91.

Kowdley K.V., Lawitz, E., Crespo, I., Hassanein, T., Davis, M.N., DeMicco, M., Bernstein, D.E., Afdhal, N., Vierling, J.M., Gordon, S.C., Anderson, J.K., Hyland, R.H., Dvory-Sobol, H., An, D., Hindes R.G., Albanis, E., Symonds, W.T., Berrey, M.M, Nelson, D.R., Jacobson I.M. (2013) 'Sofosbuvir with pegylated interferon alfa-2a and ribavirin for treatment-naive patients with hepatitis C genotype-1 infection (ATOMIC): an open-label, randomised, multicentre phase 2 trial' *The Lancet*, **381** (9883) pp. 2100-7.

Kramer, J.R., Kanwal, F., Richardson, P., Mei, M., El-Serag, H.B., (2012) 'Gaps in the achievement of effectiveness of HCV treatment in national VA Practice', *Journal of Hepatology*, **56** pp. 320-325.

Kristeva, J. (1982) *Powers of Horror: An Essay on Abjection*, New York, Columbia University Press.

Krueger, R.A. and Casey, M. (2000) *Focus Groups: A Practical Guide for Applied Research*, 3rd Edition, London, Sage.

Krug, G. (1995) 'Hepatitis C: Discursive domains and epistemic chasms', *Journal of Contemporary Ethnography,* **24** (3), pp. 299-322.

Krug, G. and Hepworth, J. (1999) 'Hepatitis C: A socio-cultural perspective on the effects of a new virus on the community health', *Journal of Health Psychology*, **4** (2), pp. 237-246.

Kumari- Campbell, F. (2009) *Contours of Ableism; the production of disability and ableism*, Basingstoke, Palgrave Macmillan.

Kuppers, P. (2004) 'Visions of Anatomy: Exhibitions and Dense Bodies,' *Differences: A Journal of Feminist Cultural Studies* **15** (3) pp. 123-156.

LaCom, C. (2007) 'Filthy Bodies, Porous Boundaries: The Politics of Shit in Disability Studies', Disability Studies Quarterly, **17** (2).

Lakoff, G and Johnson, M (1980) *Metaphors we live by*, London, University of Chicago Press.

Lancashire Drug and Alcohol Action Team, (2011) *Lancashire Hepatitis C strategy*, personal communication.

Larance B, Degenhardt L, Copeland J, Dillon P. (2008) 'Injecting risk behaviour and related harm among men who use performance- and image-enhancing drugs', *Drug and Alcohol Review*, **27** (6) pp.679-686.

Law, J. (2004) *After Method; Mess in Social Science Research,* London, Routledge.

Law, J. (2006) *Making a mess with method*, available at: http://www.heterogeneties.net/publications/Law2006MakingaMesswithMethod.pdf [accessed 2nd November 2011].

Law, J. and Singleton, V. (2005) 'Object Lessons', *Organisation*, 12 (3) pp. 331-355.

Leavitt, M. (2010) 'The Poison Cure', *The Humanist*, January– February 2010 pp. 38-39.

Leavitt, M. (2011) *The Poison Cure: A Memoir of Hepatitis C Infection and Treatment,* Personal Communication.

Lee, R.M. and Renzetti, C.M. (1993) 'The Problems of Researching Sensitive Topics; an overview and introduction. ' in Renzetti, C.M. and Lee, R.M. (eds) *Researching Sensitive Topics*, London, Sage pp.3-14.

Lekas, H, Siegel K. and Leider, J. (2011) 'Felt and Enacted Stigma Among HIV/HCV-Coinfected Adults: The Impact of Stigma Layering', *Qualitative Health Research,* **21** (9) pp.1205-1219.

Lekas, H. Siegel, K. and Leider, J (2012) 'Challenges Facing Providers Caring for HIV/HCV-Coinfected Patients', *Qualitative Health Research*, **22** (1) pp.54-66.

Lekas, H. Siegel, K. and Scrimshaw, E.W. (2006) 'Continuities and Discontinuities in the Experiences of Felt and Enacted Stigma Among Women With HIV/AIDS', *Qualitative Health Research* **16** (9), pp. 1165-1190.

Lemoine, M. Girard, P.M. Thursz, M. and Raguin, G. (2012) 'In the Shadow of HIV/AIDS: Forgotten disease in sub Saharan Africa: Global health issues and funding agency responsibilities', *Journal of Public Health Policy,* **33**, (4) pp.. 430-438.

Leonard, L., Derubeis, E., Pelude, L., Medd, E., Birkett, N. & Seto, J. (2008) 'I inject less as I have easier access to pipes': Injecting and sharing of crack-smoking materials, decline as safer crack smoking devices are distributed,' *International Journal of Drug Policy*, **19,** pp. 255-264.

Lenton, E, Fraser, S. Moore, D and Treloar, C. (2011) 'Hepatitis C, love and intimacy: Beyond the 'anomalous body' *Drugs, Education Prevention and Policy*, **18,** (3) pp. 228-236 .

Liang, T.J and Ghany, M. G. (2013) 'Current and Future Therapies for Hepatitis C', *New England Journal of Medicine*, **368**, pp.1907-1917.

Lightman, E. Vick, A. Herd, D. Mitchell, A. (2009) 'Not Disabled Enough: Episodic Disabilities and the Ontario Disability Support Programme', *Disability Studies Quarterly*, **29** (3).

Lingsom, S. (2008) 'Invisible Impairments; Dilemmas of concealment and disclosure', *Scandinavian Journal of Disability Research,* **10**, (1), pp.2-16.

Lloyd, C. (2010) *Sinning and sinned against: The stigmatisation of problem drug users.* London: The UK Drug Policy Commission (UKDPC).

Lok A.S., Gardiner D.F, Lawitz E, Martorell, C. Everson, G.T. Ghalib, R, Reindollar, R. Rustgi, V. McPhee, F. Wind-Rotolo, M. Persson, A. Zhu, K. Dimitrova, D. Eley, T. Guo, T. Grasela, D. and Pasquinelli, C. (2012) 'Preliminary study of two antiviral agents for hepatitis C genotype 1', *New England Journal of Medicine,* **(366)** pp. 216 –224.

London Joint Working Group for Substance Misuse and Hepatitis C (2012) *Tackling the Problem of Substance Misuse, Health Inequality and Hepatitis C: a consensus for London*, London Joint Working Group, available at: http://www.smmgp.org.uk/download/others/other077.pdf [accessed 1st July 2012].

London Joint Working Group for Substance Misuse and Hepatitis C (2013) NHS England abandons Liver Strategy – LJWG response, London Joint Working Group, available at: http://ljwg.org.uk/wp-content/uploads/2013/12/NHS-England-abandons-Liver-Strategy.pdf [accessed 10th January 2014].

Lorig, K. (2002) 'Partnerships between expert patients and physicians', *The Lancet* **359** (9309), pp.314-315.

Loveday, S. and Dore, G.J, (2009), 'Improving quality of life for people with hepatitis C', in Dore G, Temple-Smith M, Lloyd A (ed.), *Hepatitis C: An Expanding Perspective*, IP Communications, East Hawthorn, pp. 172 - 180

Lupton, D. (2003) *'Medicine as Culture; illness, disease and the body in western societies'* London, Sage.

Lyon, D. (2001) 'Facing the future: Seeking ethics for everyday surveillance,' *Ethics and Information Technology* **3** (3) pp. 171-171.

Lyon, D. (2003) 'Surveillance as social sorting: computer codes and mobile bodies' in Lyon, D. (ed) *Surveillance as Social Sorting: privacy, risk and digital discrimination,*. London, Routledge: 13-30.

Mack, H. (2007) *Evaluating Harm Reduction Responses to Hepatitis C*, Norwich, Social Work Monographs.

Macmillan Cancer Support (2011a). *Welfare Reform Bill Commons Report Stage Briefing*, Macmillan Cancer Support.

Macmillan Cancer Support (2011b) ' *New toolkit helps employers support people with cancer at work'*, available at:
http://www.macmillan.org.uk/Aboutus/News/Latest_News/Newtoolkithelpsemployerssupportpeoplewithcanceratwork.aspx [accessed 16th November 2011].

Macmillan Cancer Support (2012a) *What Our Brand is about*, (Macmillan Online) http://be.macmillan.org.uk/AboutOurBrand/Whatourbrandisabout/Whatourbrandisabout.aspx [accessed 1st February 2012].

Macmillan Cancer Support (2012b) *'Cancer Survivorship'* available at;
http://www.macmillan.org.uk/Documents/HowWeCanHelp/Get_support/nursingtimessurvivorshipsupplement.pdf [accessed 20th October 2013].

Macmillan Cancer Relief, (2004) *The Unclaimed Millions*, London, Macmillan Cancer Relief.

Maher L, White B, Donald A, Bates A, Enriquez J, Pham S, Liao L (2010a) 'Using ethnographic fieldwork to inform hepatitis C vaccine preparedness studies with people who inject drugs', *International Journal of Drug Policy*. **21** pp. 194-201.

Maher L., White B., Hellard M., Madden A., Prins M., Kerr T., Page K. (2010b) 'Candidate hepatitis C vaccine trials and people who inject drugs: challenges and opportunities', *Vaccine*, **28** (45) pp.7273-7278.

Malacrida, C. (2010). 'Income Support in Canada and the UK: different but much the same' *Disability and Society* **25** (6) pp. 673-686.

Malik, S. (2012) *Disabled people face unlimited unpaid work or benefit cuts*, The Guardian (online) http://www.guardian.co.uk/society/2012/feb/16/disabled-unpaid-work-benefit-cuts ; [accessed 12th February, 2012].

Mann A.G., Trotter C.L., Balogun M.A., Ramsay M.E., (2008) 'Hepatitis C in ethnic minority populations in England', *Journal of Viral Hepatitis*, **15** (6) pp. 421-426.

Manns, M.P. and Cornberg, M. (2013) 'Sofosbuvir: the final nail in the coffin for hepatitis C?', *The Lancet Infectious Diseases*, **13** (5) pp. 378-379.

Manns, M. P. Foster, R.G. Rockstroh J.G. Zeuzem S. Zoulim, F. and Houghton, M. (2007) 'The way forward in HCV treatment – finding the right path', *Nature Reviews Drug Discovery*, 6, December 2007, pp. 991-1000.

Marcellin F., Préau M., Dellamonica P., Ravaux I., Kurkdji P., Protopopescu C., Carrieri M.P., Spire B. (2007) 'Adding HCV treatment to HIV treatment in HIV-HCV co-infected patients: the impact on the different dimensions of fatigue and self-reported side effects', *Journal of Pain and Symptom Management*, **34** (4) pp.413-21.

Marks, D. (1999) *Disability: Controversial Issues and Psychosocial Perspectives*, London, Routledge.

Marsh, S. (2012) *Diary of a Benefit Scrounger: work consultation*, available at: http://diaryofabenefitscrounger.blogspot.co.uk/2012/10/work-consultation.html [accessed 1st June 2013].

Martin, E. (2006) 'The Pharmaceutical Person', *Biosocieties*, **1** (3) pp. 273-288.

Mateu-Gelabert, P., Treloar, C., Calataud, V. A., Sandoval, M., Valderama-Zurein, J. C., Maher, L., Rhodes, T. & Friedman, S. R. (2007) 'How can Hepatitis C be prevented in the long term?' *International Journal of Drug Policy*, **18**, pp. 338-340.

Matthews, G.V., and Dore, G.J. (2008) 'HIV and hepatitis C coinfection'. *Journal of Gastroenterology & Hepatology*, **23** (7), pp. 1000- 1008.

Mason, M. (1990) 'Internalised Oppression', in Reiser, R. and Mason, M. (eds) (1990) *Disability Equality in Education*, London: ILEA, available at: http://disability-studies.leeds.ac.uk/files/library/Mason-Michelene-mason.pdf [accessed 1st June 2013].

Mason, J. (2002) *Qualitative Researching*, London: Sage Publications

Mason, J. (2011) 'Facet Methodology: the case for an inventive research orientation', *Methodological Innovations Online*, **6** (3) pp. 75-92.

McAllister, J. Beardsworth, G. Lavie, E. MacRae, K. Carr, A. (2013) 'Financial Stress Is Associated With Reduced Treatment Adherence in HIV-infected Adults in a Resource-rich Setting', *HIV Medicine*, **14** (2) pp. 120-124.

McCartney, M. (2011). "Well Enough to Work?" *British Medical Journal (overseas and retired doctors edition)* **342** (7792) pp. 308-309.

McCauley, A. (1994) 'Viewpoint editorial; ethics of research in native communities', *Canadian Family Physician*, **40,** (November 1994) pp. 1898 – 1890.

McCreaddie, M., Lyons, I., Horsburgh, D., Miller, M. and Frew, J. (2011) 'The Isolating and Insulating effects of hepatitis C: A substantive grounded theory', *Gastroenterology Nursing*, **34**, (1) pp. 49-59.

McDonach, E., Barbour, R.S., Williams, B. (2009) 'Reflections on applying for NHS ethical approval and governance in a climate of rapid change; prioritising process over principles', *International Journal of Social Research Methodology*, **12**, (3), pp. 227-241.

McDonald, M., Crofts, N. and Kaldor, J. (1996) 'Transmission of Hepatitis C Virus; Rates routes and co-factors', *Epidemiologic Reviews*, **18,** (2) pp.137-148.

McFarland, L., Barlow, J. and Turner, A. (2009) 'Understanding Metaphor to facilitate emotional expression during a chronic disease self-management course', *Patient Education and Counselling*, **77,** pp. 255-259.

McKeown, C. and Gibson, F. (2007) 'Determining the political influence of nurses who work in the field of hepatitis C: A Delphi survey', *Journal of Clinical Nursing*, **16,** pp. 1210-1221.

McHutchison, J.G., Ware, J.E. Jr. Bayliss, M.S., Pianko, S., Albrecht, J.K., Cort, S., Yang, I., Neary, M.P. (2001) 'The effects of interferon alpha-2b in combination with ribavirin on health related quality of life and work productivity', *Journal of Hepatology,* **34** (1) pp.140-147.

McHutchison, J.G., Lawitz, E.R., Shiffman, M. L., Muir, A.J., Galler, G.J., McCone, J., Nyberg, L., Lee, W. M., Ghalib, R.H., Schiff, E.R., Galati, J.S., Bacon, B.R., Davis, M.N., Mukhopadhyay, P. Koury, K., Noviello, S., Pedicone, L.D., Brass, C.A., Albrecht, J.A., Sulkowkski, M. S. for the IDEAL study team (2009) 'Peginterferon Alfa-2b or Alfa-2a with Ribavirin for Treatment of Hepatitis C Infection', *New England Journal of Medicine,* **361,** pp. 580-593

McMenamin M.B., Jackson A.D., Lambert J., Hall W., Butler K., Coulter-Smith S., McAuliffe F.M. (2008) 'Obstetric management of hepatitis C-positive mothers: analysis of vertical transmission in 559 mother-infant pairs', *American Journal of Obstetrics and Gynaecology*, **199,** pp. 315.e1-315.e5.

McNally, S. Temple-Smith, M. and Pitts, M. (2004) *Making Decisions about Hepatitis C Treatment,* available at: http://www.hep.org.au/documents/04MakingDecisions-400KB.pdf [accessed 13th July 2012].

McNally, S., Temple-Smith, M., Sievert, W. and Pitts, M. (2006) 'Now, later or never? Challenges associated with Hepatitis C treatment', *Australian and New Zealand Journal of Public Health*, **30** (5), pp. 422–7.

McVeigh J., Beyond C. and Bellis M.A. (2003) 'New challenges for agency based syringe exchange schemes: analysis of 11 years of data (1991-2001) in Merseyside and Cheshire, United Kingdom', *International Journal of Drug Policy,* **14,** pp. 399-405.

Measham, F. and Moore, K (2006) 'Reluctant Reflexivity; Implicit insider knowledge and the development of Club Studies', in Sanders, B. (ed) *Drugs, Clubbing and Young People; Sociological and Public Health perspectives,* Aldershot, Ash gate, pp. 13-26.

Meenaghan, A., O'Herlihy, A., Durand, M., Farr, H., Tulloch, S. and Lelliott, P. (2007) 'A 55 kg paper mountain: The impact of new research governance and ethics processes on mental health services research in England', *Journal of Mental Health* **16** (1) pp. 149 – 155.

Mellor, N. (1998). 'Notes from a Method,' *Educational Action Research* **6** (3) pp. 453-470.

Mellor, N. (2001). 'Messy Method: The unfolding story,' *Educational Action Research,* **9** (3) pp.465-484.

Mehta, S., H. , Thomas, D., L., Sulkowski, M. S., Safaein, M., Vlhlaov, D. & Strathdee, S. A. (2005) 'A framework for understanding factors that affect access and utilisation of treatment for Hepatitis C virus infection among HCV mono infected and HIV/HCV co-infected injection drug users' *AIDS,* **19**, pp. 179-189.

Mendelson, C. (2003) 'Gentle hugs listservs as sources of support for women with lupus', *Advances in Nursing Science*, **26,** pp. 299-306.

Mendelson, C. (2006) 'Managing a medically and socially complex life: women living with Lupus' Qualitative Health Research, **16**, (7) pp. 982-987.

Mendelson, C. (2009) 'Diagnosis; a liminal state for people living with Lupus' *Healthcare for Women International,* **30**, pp. 390-407.

Micaleff, J..M., Kaldor, J.M., Dore, G.J., (2006) 'Spontaneous viral clearance following acute hepatitis C infection; a systematic review of longitudinal studies', *Journal of Viral Hepatitis* **13** (1) pp. 34-41.

Midtgaard, J., Hansen, M. J,. and Grandjean, B. (2009) 'Modesty and recognition; a qualitative study of the lived experience of anal cancer' *Support Care Cancer*, **17,** pp. 1213-1222.

Miller, D. (2006) 'The Politics of Metaphor', *Theory, Culture and Society*, **23** (2-3) pp. 63-65.

Miller, E.R. McNally, S. Wallace J. and Schilichthorst, M. (2012) ' The on-going impacts of hepatitis c - a systematic narrative review of the literature', *BMC Public Health* **12** (672).

Milner, R. (2007) 'Race, Culture, and Researcher Positionality: Working Through Dangers Seen, Unseen, and Unforeseen', *Educational Researcher,* **36 (**7) pp. 388-400.

Minuk G.Y., Gutkin A., Wong S.G., Kaita K.D., (2005) 'Patient concerns regarding chronic hepatitis C infections', *Journal of Viral Hepatitis*, 12 (1) pp. 51-57.

Minkin, L. (1997*) Exits and Entrances: Political Research as a Creative Art*, Leicester, Perpetuity Press.

Mitchell, and Irvine, A. (2008) 'I'm Okay, You're Okay?: Reflections on the Well-Being and Ethical Requirements of Researchers and Research Participants in Conducting Qualitative Fieldwork Interviews', *International Journal of Qualitative Research Methodology,* **7** (4) pp.31-44.

Moffatt, S., Noble, E. and Exeley, C. (2010) ' "Done more for me in a fortnight than anybody's done in all my life" how welfare rights advice can help people with cancer' *BMC Health Services Research*, **10**.

Mol, A. (1999) 'Ontological Politics: a word and some questions' in Law J. and Hassard, J. (eds) *Actor Network Theory and After*, Oxford, Blackwell pp. 74 - 89.

Mol, A. (2002) *The Body Multiple; Ontology in medical practice*, Durham, Duke University Press.

Mol, A. and M. de Laet (2000). 'The Zimbabwe Bush Pump: Mechanics of a Fluid Technology,' *Social Studies of Science*, **30** (2) pp.225-263.

Mol, A and Law J. (2002) 'Complexities; an introduction' in Law, J. and Mol, A. (Eds) *Complexities: social studies of knowledge practices,* Durham and London, Duke University Press, pp. 1-22.

Mol, A. and J. Law (2005). 'Guest Editorial: Boundary Variations: An Introduction,' *Environment and Planning: Society and Space*, **23,** pp. 637-642.

Monnet E., Collin-Naudet E., Bresson-Hadni S., Minello A., Di Martino V., Carel D., Jooste V., Gagnaire A., Evrard P., Obert-Clerc B., Miguet J.P., Hillon P. (2006) 'Place of residence and distance to medical care influence the diagnosis of hepatitis C: a population-based study', *Journal of Hepatology*, **44** (3) pp. 499-506.

Montagne, M. (1996) 'The Pharmakon Phenomenon: cultural conceptions of drugs and drug use' in Davis, P. (ed) *Contested Ground: Public Purpose and Private Interest in the Regulation of Prescription Drugs,* New York, Oxford, Oxford University Press, pp. 11-25.

Moore, G., A, , Hawley, D., A & Bradley, P. (2008) Hepatitis C: Studying stigma. Gastroenterology Nursing, 31, 346-352.

Moore, G. A., Hawley, D. A. and Bradley, P. (2009) 'Hepatitis C: Experiencing stigma' *Gastroenterology Nursing,* **32,** (2) pp. 94-104.

Moore, K. and Measham, F. (2012) ' The Silent "G": A Case Study in the Production of "Drugs" and "Drug Problems' *Contemporary Drug Problems* **39** (3) pp. 565-590

Morris, J. (1991) *Pride against Prejudice: Transforming Attitudes to Disability, A personal politics of disability*, London, The Women's Press.

Morris, J (2011) 'Rethinking disability policy', Joseph Rowntree Foundation available at: http://www.jrf.org.uk/publications/rethinking-disability-policy, [accessed 10th June 2012].

Morris, K. (2011) 'Tackling hepatitis C: A tale of two countries', *The Lancet*, **377,** (9 April), pp. 1227-1228.

Morris-Colton, B (2011) 'Recovery as a process of decolonisation? History, politics and experience' Paper presented at 'Distress or Disability? Symposium held at Lancaster University 15-16th November 2011, Lancaster UK.

Moser, I. (2008) 'Making Alzheimer's disease matter: Enacting, interfering and doing politics of nature', *Geoforum*, **39,** pp. 98-110.

Motability (2013a) 'Understanding the scheme' available at: http://www.motability.co.uk/understanding-the-scheme/ [accessed 1st July 2013].

476

Motability (2013b) 'Lord Sterling's statement on transitional support package', available at: http://www.motability.co.uk/understanding-the-scheme/pip-and-motability/lord-sterling-transitional-support-package [accessed 20th October 2013].

Moulton, M. (2011) 'More than a liver' Social Work's contribution to the wellbeing of people undergoing treatment for Hepatitis C', *Journal of Social Work Practice in the Addiction*, **11**, pp. 40-59.

Mueller, P.K., and Houser, J.A., and Riddle, M.D., (2010) 'Regarding Disability: Perceptions of Protection under the Americans with Disabilities Act', in Barnartt, S.A. (ed) *Disability as a Fluid State*, Bingley, Emerald Publishing

Muhkerjee, S. (2011) *The Emperor of All Maladies; a cultural history of cancer*, London, Fourth Estate.

Munoz-Plaza C. E., Strauss, S., Astone-Twerrell, J., Des Jarlais, D., Gwadz, M., Hagan, H., Osborne, A. & Rosenblum, A. (2008) 'Exploring drug users attitudes and decisions regarding Hepatitis C treatment in the US', *International Journal of Drug Policy*, **19,** pp.71-78.

Munoz-Plaza, C.M., Strauss, S.M., Tiburcio, N., Astone-Twerrell, J. M., Des Jarlais, D., Gwadz, M., Hagan, H., Osborne, A. and Rosenblum, A. (2010) 'Perspectives on the hierarchy of HIV and hepatitis C disease; consequences for drug treatment programmes', *Journal of Drug Issues*, **40** (2) pp. 517- 535.

Munoz-Sastre, M-T., Bacq, Y. Mullet, E. and Clay-Sorum, P. (2002) 'Misconceptions regarding hepatitis C in the French public', *Preventative Medicine*, **34** pp.596-599.

Murphy, M.B. and Fitzpatrick, J. (2011) 'Illness Intrusiveness of a Hepatitis C Diagnosis: A Pilot Study and Implications for Practice', *The Journal for Nurse Practitioners*, **7** (1) pp.46-50.

Murphy, R., Scheer, J., Murphy, Y. and Mack, R. (1988) 'Physical disability and social liminality; a study in the rituals of adversity', *Social Science and Medicine,* **26** (2) pp. 235-242.

Morse, J. (1998) 'Designing funded qualitative research'. In Denzin, N. and Lincoln,Y. (eds) *Strategies of Qualitative Inquiry*. California, Sage, pp. 56 –85.

Natale, A.P., Biswas, B., Urada, L,. and Scheyett, A.M (2010) 'Global HIV and AIDS: Calling all Social Work Educators,' *Social Work Education: The International Journal*, **29** (1) pp.27-47.

National AIDS Trust (2009) Working with HIV, available at: http://www.nat.org.uk/media/Files/Publications/Aug-2009-Working-with-HIV.pdf [accessed 1st October 2011].

National AIDS Trust (2010) *The Work Capability Assessment; A call for evidence,* available at http://www.nat.org.uk/Media%20library/Files/Policy/2010/NAT_Response_WCAreview.pdf [accessed 11th October 2011].

National AIDS Trust (2011) *Personal Independence Payment: draft assessment criteria (Response from NAT)*availableat:http://www.nat.org.uk/Media%20library/Files/Policy/2011/PIP_assessment_NAT_res ponse.pdf [accessed 11th October 2011].

National AIDS Trust (2012) *Hepatitis C and HIV Co-infection,* London, National AIDS Trust. Available at http://www.nat.org.uk/media/Files/Publications/Jan-2012-Hepatitis-C-and-HIV-co-infection.pdf (accessed 4th April 2013).

National AIDS Trust (2013) *HIV and Injecting Drug Use,* London, National AIDS Trust, available at: http://www.nat.org.uk/media/Files/Policy/2013/HIV_and_Injecting_Drug_Use_Report_2013.pdf [accessed 1st July 2013].

National Cancer Action Team (2010) *Holistic Needs Assessment for people with cancer: A practical guide for healthcare professionals,* NHS, available at: http://www.ncsi.org.uk/wp-content/uploads/Holistic-Needs-Assessment-practical-guide.pdf [accessed 1st June 2013].

National Institute for Clinical Excellence (2006*) Peginterferon alpha with ribavirin for the treatment of mild chronic Hepatitis C,* available at: http://www.nice.org.uk/nicemedia/live/13180/50856/50856.pdf [accessed 14th January 2013].

National Institute for Clinical Excellence (2012a) *Bocepravir for treatment of chronic genotype 1 hepatitis C,* available at: http://guidance.nice.org.uk/TA253/Guidance/pdf/English. [accessed 1st June 2013].

National Institute for Clinical Excellence (2012b) *'Telapravir for treatment of chronic genotype 1 hepatitis C,* available at: http://www.nice.org.uk/nicemedia/live/13717/58946/58946.pdf [accessed 1st June 2013].

National Institute for Clinical Excellence (2012c) *Hepatitis B and C: Ways to promote and offer testing to people at increased risk of infection,* available online, http://publications.nice.org.uk/hepatitis-b-and-c-ways-to-promote-and-offer-testing-to-people-at-increased-risk-of-infection-ph43. [accessed 1st July 2013].

National Treatment Agency for Substance Use, (2012) *Making Recovery a Reality; the public health future of drug and alcohol treatment,* http://www.nta.nhs.uk/uploads/regionaleventspresentationcondensed.pdf [accessed 19th December 2012].

Neale, J. Tomkins C. and Sheard, L. (2008) 'Barriers to accessing generic health and social care services: a qualitative study of injecting drug users', *Health and Social Care in the Community,* **16** (2) pp.147-154.

Nelson, P.K., Mathers, B.M., Cowie, B., Hagan, H., Des Jarlais, D., Horyniak, L., Degenhardt, L. (2011) 'Global epidemiology of hepatitis B and hepatitis C in people who inject drugs: results of systematic reviews', *The Lancet,* **378**, pp.571–83.

Nettleton, S. (2006) ' "I just want permission to be ill": Towards a sociology of medically unexplained symptoms', *Social Science and Medicine,* **62,** pp. 1167-1178.

NHS Choices (2012a) *Hepatitis C; the more you know the better* available at http://www.nhs.uk/hepatitisc/southasian/Pages/default.aspx [accessed 9th December 2012].

NHS Choices (2012b) *Lupus* available at: http://www.nhs.uk/Conditions/lupus/Pages/Introduction.aspx [accessed 1st June 2013].

NHS Choices (2012c) *Fibromyalgia* available at:
http://www.nhs.uk/conditions/fibromyalgia/Pages/Introduction.aspx [accessed 1st June 2013].

NHS Choices (2012d) Hepatitis C: Workplace tips, available at: http://www.nhs.uk/hepatitisc/living-with-it/Pages/workplace-tips.aspx [accessed 1st July 2013].

NHS Choices (2013) *Hormone Replacement Therapy – HRT* available at:
http://www.nhs.uk/conditions/hormone-replacement-therapy/pages/introduction.aspx [accessed 1st June 2013].

NHS Health Scotland (undated) Hepatitis C: Taking Control, available at:
http://www.healthscotland.com/uploads/documents/4947-HepCTakeControl.pdf [accessed 20th October 2013].

Norman, J., Walsh N.M., Mugavin, J., Stoové, M., Kelsall, J., Austin, K. and Lintzeris, N. (2008) 'The acceptability and feasibility of peer worker support role in community based HCV treatment for injecting drug users', *Harm Reduction Journal* **5** (8).

Norredam, M and Album, D. (2007) 'Prestige and its significance for medical specialties and diseases', *Scandinavian Journal of Public Health*, **35** pp.655–661.

Novick, G. (2008) 'Is there a bias against telephone interviewing in Qualitative Research?' *Research in Nursing and Health,* **31**, pp. 391-398.

Novick, D.M. and Kreek, M.J. (2008) 'Critical Issues in the treatment of hepatitis C virus infection, in methadone maintenance patients', *Addiction*, **103** (6) pp.905-18.

Oakley, A. (1981) 'Interviewing Women; a contradiction in terms' in Roberts, H. (ed) *Doing Feminist Research,* London, Routledge, Keegan and Paul. Pp. 30-62.

O'Brien, G.V. (2009) 'Metaphors and the pejorative framing of marginalised groups: Implications for Social Work education', *Journal of Social Work Education*, **45**, (1), pp. 29-46.

O'Brien, A. P. Cross, W.M. Higgs, P. Munro, I. Bloomer, M. J. Chou, K. (2010)' Australians living with and managing hepatitis C', *Issues in Mental Health Nursing,* **31** (8) pp.520-524.

O'Brien, S. Day, C. Black, E. and Dolan ,K. (2008) 'Injecting Drug Users Understandings of Hepatitis C', *Addictive Behaviors*, **33**, pp.1602-1605.

Ogawa LM, Bova C. (2009) 'HCV treatment decision-making substance use experiences and hepatitis C treatment decision-making among HIV/HCV Coinfected Adults', *Substance Use and Misuse.* **44** (7) pp. 915-933.

Oliver, M. (1990) *The Politics of Disablement*, Basingstoke, Palgrave Macmillan.

Oliver M. (1996) Defining Impairment and Disability: issues at stake, in Barnes, C. and Mercer, G. (eds) Exploring the Divide, Leeds, The Disability Press, pp. 29-54.

Oliver, M. (1992) 'Changing the Social Relations of Research Production? Disability, Handicap and Society', **7**,(2) 101-114.

Oliver, M. (1997) 'Emancipatory Research; realistic goal or impossible dream? In Barnes, C and Mercer, G. (eds) *Doing Disability Research,* Leeds, The Disability Press, pp. 15-32.

Oliver M. (2004) ' The Social Model in Action: If I had a hammer.' In Barnes, G and Mercer, C. (eds) Implementing the Social Model of Disability: theory and research, Leeds, The Disability Press. Pp.18-31.

Oliver, M Sapey, B. and Thomas, P. (2012) *Social Work with Disabled People,* fourth edition, Basingstoke, Palgrave Macmillan.

Olsen, A. Banwell, C. and Dance, P. (2009) 'Internal of Infernal Devices: Experiences of Contraception Among Australian Women Living with Hepatitis C', *Healthcare for Women International,* **30,** pp. 456-474.

Olsen, A. Banwell, C. Dance, P. (2013) 'Reinforced Biographies Among Women Living With Hepatitis C', *Qualitative Health Research,* .**23** (4), pp.531-540

Opdenakker, Raymond (2006) 'Advantages and Disadvantages of Four Interview Techniques in Qualitative Research', *Forum: Qualitative Social Research,* **7** (4).

Orgel, M., Paylor, I. & Tibbs, C. (2005) *Attitudes and Knowledge about Hepatitis C amongst Patients and Staff of Community Addiction Services and Hepatitis C Clinics: A Comparative Study between an Outlying Area in North West England and a Major Urban Area'.* (personal communication).

Owen, G. (2008) An 'elephant in the room'? Stigma and hepatitis C transmission among HIV-positive 'serosorting' gay men, *Culture, Health & Sexuality,* **10** (6) pp. 601-610.

Owen, G and Catalan, J. (2012) ' "We never expected this to happen": narratives of ageing with HIV among gay men living in London, UK', *Culture, Health and Sexuality,* **14** (1) pp. 59-72.

Oxford English Dictionary (2013) *Indolent,* available at: http://www.oed.com/ [accessed 1st July, 2013].

Oxlad M., Wade T.D., Hallsworth L., Koczwara B. (2008) '"I'm living with a chronic illness, not dying with cancer': a qualitative study of Australian women's self-identified concerns and needs following primary treatment for breast cancer", *European Journal of Cancer Care* **17,** pp.157–166.

Oxtoby, K. (2009) 'Hep C: Fighting back', *Drink and Drugs News,* 6-7.

Padfield, M and Proctor, I. (1996) 'The effect of the interviewer's gender on the interviewing process: a comparative inquiry', *Sociology,* **30** (2) pp.355-366.

Paff Ogle, J. Tyner, K, Schofield-Tomschin, S. (2011) 'Watching over Baby; Expectant Parenthood and the Duty to be Well', *Sociological Inquiry,* **81,** (3) pp.285-309.

The Papworth Trust (2011). *Changes to Disability Living Allowance Survey Results: A Summary,* available at: http://www.papworth.org.uk/downloads/dlasurveyresultssummary_110830174513.pdf, [accessed 14th September 2011].

Parker, R and Aggleton, P. (2003)' HIV and AIDS related stigma and discrimination: a conceptual framework and implications for action', *Social Science and Medicine,* **57,** pp 13-24.

Paterson, B.L. Butt, G. and McGuiness, L. and Moffat, B. (2006) 'The Construction of Hepatitis C as a Chronic Illness', *Clinical Nursing Research,* **15** (3) pp. 209-224.

Paterson, B., L. , Backmund, M., Hirsch, G. & Yim , C. (2007) 'The depiction of stigmatisation in research about Hepatitis C', *International Journal of Drug Policy,* **18**, pp. 364-373.

Paterson B., Hirsch G., Andres K. (2013) 'Structural factors that promote stigmatization of drug users with hepatitis C in hospital emergency departments', *International Journal of Drug Policy,* doi: 10.1016/j.drugpo.2013.01.008.

Paterson, B. and Hopwood M. (2010) 'The Relevance of Self-Management Programmes for People with Chronic Disease at Risk for Disease-Related Complications' in Kralik,D., Paterson, B. and Coates, V. (eds*.), Translating Chronic Illness Research into Practice,* Oxford, Wiley-Blackwell, pp. 111 – 142.

Paterson, B. L. Gregory, D. Thorne, S. (1999) 'A Protocol for Researcher Safety', *Qualitative Health Research,* **9,** (2), pp.259-269.

Paterson, K., and Hughes, B. (1999) 'Disability studies and phenomenology: The carnal politics of everyday life' *Disability and Society,* **14** (5), pp. 597-610.

Patrick, R. (2011) 'Disabling or Enabling? The Extension of Work Related Conditionality to Disabled People', *Social Policy and Society,* **10,** (3) pp. 309-320.

Patrick, R. (2012) 'All in it together? Disabled People, the Coalition and welfare to work', *Journal of Poverty and Social Justice,* **20** (3) pp. 307-322

Paylor, I. (2009) *Blood Borne Viruses and substance use in the social work curriculum,* Higher Education Academy Subject Centre for Social Policy and Social Work (SWAP), available at: http://www.swap.ac.uk/docs/infosheets/is_subusebbv.pdf [accessed 4th April 2013].

Paylor, I. and Mack, H. (2010) 'Gazing into the Scarlet Crystal Ball; Social Work and Hepatitis C', *British Journal of Social Work,* **40,** 7, pp.2291-2307.

Paylor, I. and Orgel, M. (2004) 'Sleepwalking through an epidemic – why social work should wake up to the threat hepatitis C', *British Journal of Social Work,* **34,**(6), pp. 897-906.

Pears, E. (2010) 'Hepatitis C virus infection: risk factors diagnosis and management', *Nursing Standard,* **25,** (15-17) pp. 49-56.

Peckover, S. and Chidlaw, R. (2007) 'Too frightened to care? Accounts by district nurses working with clients who misuse substances', *Health and Social Care in the Community,* **15** (3) pp. 238-245.

Perrillo, R., Rothstein, K.D., Rubin, R., Alam, I., Imperial, J., Harb, G., Hu, S., Klaskala, W. (2004) 'Comparison of quality of life, work productivity and medical resource utilization of peginterferon alpha 2a vs the combination of interferon alpha 2b plus ribavirin as initial treatment in patients with chronic hepatitis C', *Journal of Viral Hepatitis,* **11** (2) pp. 157-165.

Persson, A. (2004) 'Incorporating Pharmakon: HIV, Medicine and Body Shape Change', *Body and Society,* **10** (4) pp. 45-67.

Persson, A. (2006) 'Facing HIV: Body Shape Change and the (In) Visibility of Illness', *Medical Anthropology*, **24**, pp. 237-264.

Persson, A. and Newman, C. (2008) 'Making monsters: heterosexuality, crime and race in recent Western media coverage of HIV', *Sociology of Health and Illness*, **30** (4) pp.632-644.

Persson, A. Race, K. and Wakeford, E. (2003) 'HIV Health in Context: Negotiating Medical Technology and Lived Experience', *Health*, **7** (4) pp. 397-415.

Peters, M. G and Terrault, N. A. (2002) 'Alcohol and hepatitis C', *Hepatology*, **36**, S220-S225.

Peterson, J.L., Rintamaki, L.S., Brashers, D.E., Goldsmith,D.J., Neidig, J. (2012) 'The Forms and Functions of Peer Social Support for People Living With HIV', *Journal of the Association of Nurses in AIDS Care*, **23**, (4) pp. 294-305.

Phelan, J.C. Link, B.G. and Dovidio, J (2008) Stigma and Prejudice: One animal or two? Social Science and Medicne, 67, pp. 358-367.

Piggott, L. and Grover, C. (2009) 'Retrenching Incapacity Benefit', *Social Policy and Society*, **8**, (2) pp. 159-170.

Pilgrim, D. (2008) ''Recovery and current mental health policy, *Chronic Illness*, **4**, pp. 295-304.

Pinder, R., Petchey, R., Shaw, S. and Carter, Y. (2005) What's in a care pathway? Towards a cultural cartography of the new NHS' *Sociology of Health and Illness*, **27** (6) pp. 759-779.

Pisani, E. (2009) *The Wisdom of Whores: Bureaucrats, Brothels and the Business of AIDS*, London, Granta.

Platt, M. W. and Gifford, S.M (2003) 'Promoting health through promoting work: the dilemmas of disclosure in the workplace for employers and for Australian women living with hepatitis C', *Health Promotion Journal of Australia*, **14** (3) pp. 180 – 186.

Plumb, A. (1994) 'Distress or disability?' In Anderson, J. Sapey, B. and Spandler H. (eds) Distress or Disability? Proceedings of a symposium held at Lancaster University Lancaster, UK, 15th-16th November 2011 pp. 4-14.

Plumb, A. (2011) 'Incorporation, or not, of MH survivors into the disability movement', in Anderson, J. Sapey, B. and Spandler H. (eds) Distress or Disability? Proceedings of a symposium held at Lancaster University Lancaster, UK, 15th-16th November 2011 pp. 18-24.

Pockros, P.J., (2010) 'New direct-acting antivirals in the development for hepatitis C virus infection', *Therapeutic Advances in Gastroenterology*, **3** (3) pp. 191–202.

Price, S. and Goyette, J. (2003) 'Role of psychiatrists in the care of patients with Hepatitis C and HIV/AIDS', *Psychiatric Quarterly*, **74** (3), pp. 261–76.

Porter, L.K (2009) 'After HCV Treatment: A Hepatitis C Support Programme Guide', available at: http://www.hcvadvocate.org/hepatitis/factsheets_pdf/After%20treat_09.pdf [27th July 2013].

Poynard, T., Bedossa, P. and Opolon, P. (1997) 'Natural history of liver fibrosis progression in patients with chronic hepatitis C', *The Lancet*, **349,** (9055) pp. 825-832.

Price, S. and Goyette, J. (2003) 'Role of psychiatrists in the care of patients with Hepatitis C and HIV/AIDS', *Psychiatric Quarterly*, **74** (3), pp. 261–76.

Priestley, M. (1997) 'Who's Research? A Personal Audit' In Barnes, C and Mercer, G. (eds) *Doing Disability Research*, Leeds, The Disability Press, pp. 88-108.

Pugh, J. (2008) 'Hepatitis C and the Australian news media: a case of 'bad blood'' *Continuum: Journal of Media and Cultural studies,* **22**, pp.385-394.

Punch, M. (1994) 'Politics and Ethics in Qualitative Research' in Denzin, N.K. and Lincoln, Y.S. (eds) *Handbook of Qualitative Research*, London, Sage, pp.83-97.

Race, K. (2001) 'The Undetectable Crisis; Changing Technologies of Risk', *Sexualities,* **4** (2) pp. 167-189.

Readhead S, Ahmed A, Jenkins H, Nicholls, M. Berry, P. Shafi, S. Foster, G.R. Ala. A. (2012) A prospective pilot study of the utility of finger prick dry blood spot testing (DBS) in mosques - a model for chronic viral hepatitis related community screening, health promotion and accessing health care in the UK Pakistani population, *Hepatology*, **56**, 1095A-1096A

Reed-Gibson, P. and Lindberg, A. (2007) 'Work accommodation for people with multiple chemical sensitivity', *Disability and Society,* **22,** (7) pp. 717-732.

Reeve, D. (2002) 'Negotiating Psycho-emotional Dimensions of Disability and their Influence on Identity Constructions' *Disability and Society*, **17** pp. 493-508.

Reeve, D. (2004) Psycho-emotional dimensions of disability within relationships between professionals and disabled people, paper presented at Disability Studies: Putting Theory into Practice, Lancaster University, 26-28 July.

Reeve, D. (2006) 'Towards a psychology of disability: the emotional effects of living in a disabling society' in Goodley, D. and Latham, R. (eds) *Disability and Psychology: Critical Introductions and Reflections,* London, Palgrave, pp. 94-107.

Reeve, D. (2008) *Negotiating psycho-emotional disablism in everyday life*, Lancaster Unpublished PhD Thesis.

Reeve, D. (2012a) 'Psycho-Emotional Disablism; The Missing Link?' in Watson, N. Roulstone, A. And Thomas, C. (Eds) *Routledge Companion to Disability Studies*, London, Routledge, pp. 78-92.

Reeve, D (2012b) 'Preparation for Practice: Can Philosophy Have a Place in Helping Students Incorporate the Social Model of Disability Within Their Praxis?' *Social Work Education: The International Journal* , **31** (2) pp.227-234.

Reeve, D. and Soldatic, K. (2012) 'The arrival of the 'brown envelope': The embodied experience of welfare reform in the UK', paper presented at 6th Biennial Disability Studies Conference, Lancaster University, 11-13 September.

Resnick I., Brener L., Treloar C., Hull P., (2012) 'Health worker attitudes toward peer workers in hepatitis C prevention', *Psychology of Health and Medicine*, **17** (6) pp. 659-66.

Rethink Mental Illness (2013*) Unfair WCA,* available at: https://www.rethink.org/get-involved/campaigns/unfair-wca [accessed 14th June 2013].

Rhodes, T., Davis, M. & Judd, A. (2004) 'Hepatitis C and its risk management among drug injectors in London: renewing harm reduction in the context of uncertainty,' *Addiction*, 99 (5) pp. 621-633.

Rhodes, P., Nocon, A. Small,N. and Wright, J. (2008) 'Disability and Identity: the challenge of epilepsy,' *Disability and Society,* **23** (4) pp.385-395.

Rhodes T. & Treloar, C. (2008) 'The social production of Hepatitis C risk among injecting drug users: a qualitative synthesis', *Addiction*, **103,** pp. 1593-1603.

Rice, C. (2011) 'Miles to go before we sleep', *Nature,* **474,** (9th June 2011) S8.

Richardson, L. (2001) 'Writing as a Method of Inquiry' in Denzin, N and Lincoln, Y. (eds) *The Qualitative Inquiry Reader,* London, Sage, pp. 39-50.

Richmond, J. Dunning, P. Desmond, P. (2004) 'Hepatitis C: A medical and social diagnosis', *Australian Nursing Journal,* 73,

Richmond, J., Dunning, T.L. and Desmond, P. V. (2007) 'Health professionals attitudes towards caring for people with hepatitis C', *Journal of Viral Hepatitis*, **14.** pp. 624-632.

Richmond, J. (2008) *Do you C what I C? National Hepatitis C needs assessment 2008: A report on the information and support needs of people living with hepatitis C in Australia,* Hepatitis Australia, available at: http://www.hepatitisaustralia.com/research/ [accessed 1st June 2013].

Ricoeur P. (2003) *The Rule of Metaphor; the creation of meaning in language*, 3rd edition, London, Routledge.

Rolland, M (2008) *Integrated Care Pathway for Nurse-led treatment of Hepatitis C Patients*, Blackpool, Fylde and Wyre Hospitals NHS Trust.

Rose, K. (1998) 'The telephone as a data collection instrument in a qualitative study of informal carers of terminally ill cancer patients', *European Journal of Oncology Nursing,* **2** (1) pp.59-61.

Rott, L. (2010) ' "Why does growth hurt?" The dual role of normalisation and stigmatisation in the experience of growth hormone treatment' in Barnartt, S. (ed) *Disability as a Fluid State*, UK, Emerald, pp. 253-277.

Roulstone, A. (2003) 'The Legal Road to Rights? Disabling Premises, Obiter Dicta and the Disability Discrimination Act, 1995.' *Disability and Society*, **18** (2) pp.117-131.

Roulstone, A. Gradwell, L, Price J. and Child, L. (2003) *Thriving and Surviving at Work,* Joseph Rowntree Foundation, available at: http://www.jrf.org.uk/sites/files/jrf/jr147-work-disabled-people.pdf [accessed 1st June 2013].

Roulstone, A. (2004) 'Disability, Employment and the Social Model' in Barnes, C and Mercer, G. (eds)

Disability Policy and Practice: Applying the Social Model, Leeds, The Disability Press: 18-34.

Roulstone, A. (2011) 'Current barriers facing disabled people in Britain,' available at: http://cdsmmu.posterous.com/pages/downloads, [accessed 31st August 2011].

Roulstone, A. (2012) 'Stuck In The Middle With You': Towards Enabling Social Work with Disabled People,' Social Work Education 31, (2), pp. 142–154

Roulstone, A. and Barnes, C. (2005) ' The challenges of a work first agenda for disabled people' in Roulstone, A. and Barnes, C. (eds) Working Futures? Disabled people, policy and social inclusion, Bristol, Policy press, pp.17-28.

Roulstone, A., Thomas, C. and Watson, N (2012) 'The Changing Terrain of Disability Studies', in Watson, N., Roulstone, A. And Thomas, C. (Eds) Routledge Companion to Disability Studies, London, Routledge pp. 3-11.

Rowe, W, Rowe, J. Malowaniec, L. (2000) 'Hepatitis C: Mental Health Issues', Canadian Journal of Public Health, 91 (supplement 1) S41-S44.

Roy, E., Nonn, E., Haley, N., & Cox, J. (2007) 'Hepatitis C meanings and preventative strategies among street-involved young injection drug users in Montreal'. International Journal of Drug Policy, 18, pp. 397-405.

Royal College OF General Practitioners (2007) Guidance on the prevention testing treatment and management of Hepatitis C in primary care, available at: www.smmgp.org.uk/download/guidance/guidance003.pdf [accessed 20 February 2009].

Royston, S. (2012) 'Understanding Universal Credit,' The Journal of Poverty and Social Justice,20 (1) pp. 69-86.

Sampson, H., Bloor, M. and Fincham, B. (2008) 'A Price Worth Paying? Considering 'cost' of reflexive research methods and the influence of feminist ways of 'doing'', Sociology, 42 (5) pp.919 – 933.

Sampson, H. and Thomson, M. (2003) 'Lone researchers at sea: gender, risk and responsibility', Qualitative Research, 3 (2) pp. 165-189.

Samuels, E.J. (2003) 'My Body, My Closet: Invisible Disability and the Limits of Coming-Out Discourse', GLQ: A Journal of Lesbian and Gay studies, 9 (1-2) pp. 233-255.

Sanabria, E. (2009) 'Alleviative Bleeding: Bloodletting, Menstruation and the Politics of Ignorance in a Brazilian Blood Donation Centre', Body and Society, 15: pp.123-144.

Sanders, T. (2005) ' Researching the Online Sex Work Community' in Hine, C (ed) Virtual Methods: Issues in Social Research on the Internet, Oxford, Berg. pp. .67-81.

Sayce, L. (1998) 'From Psychiatric Patient to Citizen; Overcoming Discrimination and Social Exclusion,' Basingstoke, Palgrave Macmillan.

Scambler, G. and Hopkins, A. (1986) 'Being epileptic: coming to terms with stigma', *Sociology of Health and Illness,* **8,** pp. 26-43.

Scambler, G. (2004) 'Re-framing Stigma: Felt and Enacted Stigma and Challenges to the Sociology of Chronic and Disabling Conditions', *Social Theory and Health,* **2** pp. 29-46.

Schaefer, M. Schwaiger, M. Garkisch, A. Pich, M. Hintzpeter A, Uebelhack, R. Heinz, A. van Froemmel, F, Berg, T. (2005) 'Prevention of interferon-alpha associated depression in psychiatric risk patients with chronic hepatitis C', *Journal of Hepatology,* **42** (6) pp.793–798.

Schmid-Buci,S. Halfens, R. Dassen, T. and van der Borne, B. (2011) 'Psychosocial problems and needs of post treatment patients with breast cancer and their relatives', *European Journal of Oncology Nursing,* **15** pp. 260-266.

Schon, U. (2010) 'The power of identification: peer support in recovery from mental illnesses, *Scandinavian Journal of Disability Research,* **12** pp.283-290.

Schostak, J. F., and Barbour, R. (2005) 'Interviewing and Focus Groups', in: B. Somekh and C. Lewin, *Research Methods in the Social Sciences,* London, Sage

Scottish Executive (2006) *Hepatitis C Action Plan for Scotland: Phase I; September 2006 – August 2008,* available at: http://www.scotland.gov.uk/Publications/2006/09/15093626/0 [accessed 2nd November 2011].

Scottish Government (2008) *Hepatitis C Action Plan for Scotland: phase II; May 2008 - March 2011,* available at: http://www.scotland.gov.uk/Publications/2008/05/13103055/0, [accessed 2nd November 2011].

Scottish Government (2011) *Sexual Health and Blood Borne Virus Framework,* Edinburgh, The Scottish Government, available at: http://www.scotland.gov.uk/Publications/2011/08/24085708/0 [accessed 19th May 2012].

Seddon, T. (2006) 'Drugs, Crime and Social Exclusion', *British Journal of Criminology,* **46,** pp. 680-705.

Seeff LB. (2002) 'Natural history of chronic hepatitis C', *Hepatology,* **36** (5 Suppl 1) S35-46.

Seear, K., S. Fraser and Lenton, E. (2010) 'Guilty or Angry? The politics of emotion in accounts of Hepatitis C transmission. *Contemporary Drug Problems* **37** (Winter 2010) pp.619-638.

Seymour, W. (2001)' In the flesh or online? Exploring qualitative research methodologies', *Qualitative Research,* **1** (2) pp. 147 – 168.

Sgorbini M., O'Brien L., Jackson D. (2009) 'Living with hepatitis C and treatment: the personal experiences of patients', *Journal of Clinical Nursing* **18** (16) pp. 2282-2291.

Shah, S. (2006) 'Sharing the World; the researcher and the researched', *Qualitative Research,* **6,** (2) pp. 207-220.

Shakespeare, T. (1996). 'Disability, Identity and Difference' in Barnes, C. and Mercer, G. (eds) *Exploring the Divide,* Leeds, The Disability Press: 94-113.

Shakespeare T. Thompson, S. and Wright, M. (2010) 'No Laughing Matter: medical and social experiences of restricted growth', *Scandinavian Journal of Disability Research*, **12,** (1) pp. 19-31.

Shepard, C.W., Finelli, L., Alter, M.J. (2005) 'Global epidemiology of hepatitis C virus', *The Lancet Infectious Diseases,* **5**, pp. 558-567.

Shildrick, M. (1997) *Leaky Bodies and Boundaries; feminism postmodernism and bioethics*, London, Routledge.

Shildrick, M. and Price, J. (1999) 'Openings on the body; A critical introduction', in Price, J and Shildrick, M. (eds) *Feminist Theory and the Body; a Reader,* London, Routledge, pp.1-14.

Shivkumar, S. Peeling, R. Jafari, Y. Joseph, L. Pant Pai, N. (2012) 'Accuracy of Rapid and Point-of-Care Screening Tests for Hepatitis C: A Systematic Review and Meta-analysis', *Annals of Internal Medicine* **157** (8) pp. 558-566.

Shuy, R.W. (2003) 'In–person versus telephone interviewing' in Holstein, J. and Gubrium, J.F. (eds) *Inside Interviewing; new lenses new concerns* London, Sage, pp. 537-555.

Siegel, K., Dean, L. and Scrimshaw, E. (1999) 'Symptom Ambiguity Among Late Middle Aged and Older Adults with HIV', *Research on Ageing*, **21** (4) pp. 595-618.

Silverman, D. (2000) *Doing Qualitative Research: A Practical Handbook,* London: Sage Publications

Silverman, D. (2001) *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction,* 2nd Edition, London: Sage Publications.

Simmonds, L. & Coomber, R. (2009) 'Injecting drug users: A stigmatised and stigmatising population', *International Journal of Drug Policy*, **20,** pp. 121-130.

Sinclair, J. (2005) *Autism Network International: the development of a community and its culture* Autism Network International, available at: http://www.autreat.com/History_of_ANI.html, [accessed 20th January 2012].

Sinclair, M., McPherson, S., Bor, R., Orban, L. (2011) 'Another dragon in the kitchen: Psychological experiences of hepatitis C treatment among HIV-hepatitis C co-infected gay men', *Counselling and Psychotherapy Research*, **11** (3) pp.228236.

Singleton, V. (1996). 'Feminism, Sociology of Scientific Knowledge and Postmodernism: Politics, Theory and Me.' *Social Studies of Science* **26** pp. 445-468.

Slavin, S. Batrouney, C. and Murphy, D. (2007) 'Fear appeals and treatment side effects? An effective combination for HIV prevention', *AIDS Care,* **19** (1) pp.130-137.

Small, N and Rhodes, P (2000) *Too Ill to Talk? User Involvement in Palliative Care*, London, Routledge.

Smart, C. (2009) 'Shifting Horizons: Reflections on qualitative methods.' *Feminist Theory* **10,** (3) pp. 1-14.

Smart, C. (2010) 'Working Paper #13 Disciplined Writing; On the problem of writing sociologically' Morgan Centre, University of Manchester, Available:

http://www.socialsciences.manchester.ac.uk/morgancentre/realities/wps/13-2010-01-realities-disciplined-writing.pdf [accessed 3rd October 2011].

Smith, B.J., Bauman, A. E., Chen, J., Loveday, S., Costello, M., Mackie, B., and Dore, G. J.(2006) 'Hepatitis C in Australia: Impact of a Mass Media Campaign' *American Journal of Preventive Medicine,* **31** (6) pp.492-498.

Smye, V., Brownie, A.J,. Varcoe, C. and Josewksi, V. (2011) 'Harm reduction methadone maintenance treatment and the root causes of health and social inequalities, An intersectional lens in a Canadian context', *Harm Reduction Journal,* **8** (17).

Smythe, E. A., Ironside, P.M., Sims, S.L., Swenson, M.M., and Spence,D.G. (2008) 'Doing Heidiggerian hermeneutic research; a discussion paper', *International Journal of Nursing Studies,* **45,** pp. 1389-1397.

Sontag. S, (1991) *Illness as Metaphor and AIDS and its Metaphors,* London, Penguin.

Soldatic, K. and Chapman, A. (2010) 'Surviving the Assault? The Australian Disability Movement and the Neoliberal Workfare State, Social Movement Studies'; *Journal of Social Cultural and Political Protest,* **9** (2) pp.139-154.

Soldatic, K., Reeve, D., Morgan, H. and Grover, C. (2012) *Britain's disabled people are being abandoned by the state Open Democracy,* 19th April 2012, available at http://www.opendemocracy.net/ourkingdom/karen-soldatic-donna-reeve-hannah-morgan-chris-grover/britains-disabled-are-being-abandon [accessed 1st June 2013].

Soldatic, K. and Pini, B.(2009) 'The three Ds of welfare reform; disability, disgust and deservingness', *Australian Journal of Human Rights,* **15** (1) pp. 77-96.

Spandler, H. and Calton, T. (2009) 'Psychosis and Human Rights: Conflicts in Mental Health Policy and Practice', *Social Policy and Society,* **8,** pp. 245-256.

Sparrow and Owen (2012) *Politics Live Blog: Boris Johnson Victory Rally at Conservative Conference,* available at: http://www.theguardian.com/politics/blog/2012/oct/08/osborne-speech-conservative-conference-live-blog?commentpage=1#block-50727e98c0e3aacd18e2f8e6&guni=Article:in_body_link [accessed 1st July 2013].

Squire, C. (2010) 'Being naturalised being left behind: the HIV citizen in the era of treatment possibility' *Critical Public Health,* **20,** (4) pp. 401-427.

St. Pierre, E. A. (1997) 'Circling the text: Nomadic writing practices' *Qualitative Inquiry,* **3** (4) pp. 403-417.

Stacey, J. (1997) *Teratologies; a cultural study of Cancer,* London, Routledge.

Stanley, L. and Wise, S. (1979) 'Feminist research, feminist consciousness and experiences of sexism', *Women's Studies International Quarterly,* **2** (3), 359-374.

Stanley, L. and Wise, S. (1993) *Breaking Out Again: Feminist Ontology and Epistemology,* New edition, London, Routledge.

The Stationery Office (2005) *Disability Discrimination Act 2005,* (online) http://www.legislation.gov.uk/ukpga/2005/13/pdfs/ukpga_20050013_en.pdf) [accessed 1st July, 2013].

Stedman, C (2013) 'Current prospects for interferon free treatment of hepatitis C in 2012', *Journal of Gastroenterology and Hepatology,* **28**, pp.38-45.

Stephens, N. (2007) 'Collecting data from elites and ultra-elites: telephone and face to face interviews with macroeconomists,' *Qualitative Research,* **7** (2) pp.203-216.

Stephens, P. (2012*) Bridging the Gap: why some people are not offered the medicines that NICE recommends,* IMS Health, available at: http://www.imshealth.com/ims/Global/Content/Insights/IMS%20Institute%20for%20Healthcare%20I nformatics/NICE%20report/IMS_Health_Bridging_the_Gap_2012.pdf [accessed 1st June 2013].

Sternhell, P. Landstra, J. Andersson-Noorgard, K. (2012) 'H2M: a GP-focused multidisciplinary team for patients living with HIV and hepatitis C', *Australasian Psychiatry* **20,** (3) pp. 220-224.

Stevens, A. (2011) *Drugs Crime and Public Health: The Political Economy of Drug Policy,* London: Routledge.

Stevens, I. and Cox, P. (2008) Complexity Theory: Developing new understandings of child protection in field settings and residential child care, British Journal of Social Work, 38 (7) pp. 1320-1336.

Stevens I. and Hasslett, P. (2012) Non linear perspectivesof risk in social care;using complexity theory and social geography to move the focus from individual pathology to the complex human environment, European Journal of Social Work, 15 (4) pp.503-513.

Stevenson –Turner, K and Mayes, D. (2011) 'Three relapses in one year; my story of recovery with bi-polar disorder' in Anderson, J. Sapey, B and Spandler, H. (eds) *Distress or Disability?* Proceedings of a symposium held at Lancaster University Lancaster, UK, 15th-16th November 2011 pp. 39-42.

Stewart, E. (2012) *Testing for Hepatitis C Web Seminar,* 31st July 2012 http://www.ustream.tv/recorded/24377218 [accessed 1st August 2012].

Stewart, B.J., Mikocka-Walus, A. A., Harley, H., Andrews, J. M. (2012) 'Help-seeking and coping with the psycho-social burden of chronic hepatitis C: A qualitative study of patient, hepatologist and counsellor perspectives', *International Journal of Nursing Studies,* **49** (5), pp.560-569.

Stiker, H.J. (1999) *A History of Disability,* Michigan, University of Michigan Press.

Stoddard Holmes, M. (2006) ' Pink Ribbons and Public Private Parts: On not imagining Ovarian Cancer', *Literature and Medicine,* **25,** (2), pp. 475-501.

Stone, D. (1986) *The Disabled State,* Philadelphia, Temple University Press.

Stone, D. (1978-1979) 'The Deserving Sick: Income Maintenance Policy Towards the Ill and Disabled', *Policy Sciences,* **10,** pp. 133-155.

Stone, S. Crooks, V.A. Owen M. (2013) 'Going through the back door: Chronically ill academics' experiences as 'unexpected workers' *Social Theory and Health* pp. 1-24.

Strathdee, S.A. and Pollini, R.A. (2007) 'A 21st Century Lazarus; the role of safer injection sites in harm reduction and recovery', *Addiction,* **102** (6) pp. 848-849.

Strauss, E., & Teixeira, M. (2006) 'Quality of life in hepatitis C' *Liver International,* **26** , pp. 755-765.

Sturges, J.E. and Hanrahan, K.J. (2004)' Comparing telephone and face to face interviewing; a research note,' *Qualitative Research,* **4,** (1) pp. 107-118.

St. Pierre, E. A. (1997) 'Methodology in the fold and the eruption of transgressed data', *Qualitative Studies in Education,* **10**, pp. 175-189.

Su, J., Brook, R.A., Kleinman,, N.L., Corey-Lisle, P. (2010) 'The impact of hepatitis C virus infection on work absence, productivity, and healthcare benefit costs' *Hepatology,* **52** (2) pp. 436-442.

Suarez, A. E. and Shindo,, A. A. (2008) 'Silence and Stigma: the Hepatitis C Virus (HCV) Epidemic'availableat:http://www.sssp1.org/file/AgendaforSocialJustice/Agenda_For_Social_Justice_2 008_Chapter_11.pdf.[accessed 13th July 2012].

Sutton, R. and Treloar, C. (2007) 'Chronic illness experiences, clinical markers and living with Hepatitis C', *Journal of Health Psychology,* **12** (2), pp. 330–40.

Swan, T. (2013) *New drugs pipeline,* available at: http://www.hepctrust.org.uk/News_Resources/news/2013/July/New+drugs+pipeline [accessed 28th July 2013].

Swann, D., Long, J., Carr, O., Flanagan, J., Irish, H., Keating, S., Keaveney, M., Lambert, J., McCormick, P.A., McKiernan, S., Moloney, J., Perry, N. and Cullen, W. (2010) 'Barriers to and Facilitators of Hepatitis C Testing, Management, and Treatment Among Current and Former Injecting Drug Users: A Qualitative Exploration', *AIDS Patient Care and STDs,* **24** (12) pp.753-782.

Szasz, T. (1974) *Ceremonial Chemistry: the ritual persecution of drugs, addicts and pushers,* London, Routledge and Keegan Paul.

Sylvestre, D., L. & Zweben, J. E. (2007) 'Integrating HCV services for drug users: A model to improve engagement and outcomes,' *International Journal of Drug Policy,* **18**, pp. 406-410.

Tait J. M., McIntyre P.G., McLeod S., Nathwani D., Dillon J.F. (2010) 'The impact of a managed care network on attendance, follow-up and treatment at a hepatitis C specialist centre,' *Journal of Viral Hepatitis,* **17** (10) pp.698-704.

Taintedblood (undated) *Background* available at: http://www.taintedblood.info/background.php [accessed 2nd July 2013].

Takeda, A. (2012) 'Reflexivity: unmarried Japanese male interviewing married Japanese women about international marriage', *Qualitative Research,* **13** (3) pp.285-298.

Taylor, S. (2004) ' The Right Not To Work: Power and Disability', *The Monthly Review*, 55 (10) March, available at: http://monthlyreview.org/author/sunnytaylor [accessed 3rd January 2011].

Taylor, A., Fleming, A., Rutherford, J., Goldberg, D. (2004) *Examining the injecting drug use practices of injecting drug users in Scotland*, Effective Interventions Unit, available at: http://www.scotland.gov.uk/Publications/2004/02/18871/32889 (accessed 23rd March 2010).

Taylor, S. (2012) 'One participant said…': the implications of quotations from biographical talk', *Qualitative Research*, **12**, (4),pp. 388-401.

Teague, W., Hepworth, J., & Krug, G. (1999). 'Support for patients with hepatitis C: An exploratory qualitative study of medical specialists' perceptions', *Australian and New Zealand Journal of Public Health,* **23** (2) pp. 201-204.

Temple-Smith, M., Gifford, S., & Stoove, M. (2004) 'The lived experience of men and women with hepatitis C: Implications for support needs and health information', *Australian Health Review*, **27** (2) pp. 46-56.

Temple -Smith, M. (2008) 'Commentary by Temple-Smith', *Western Journal of Nursing Research,* **30**, pp. 222-224.

Temple -Smith M., Jenkinson, K., Lavery, J., Gifford, S. M. & Morgan, M. (2006) 'Discrimination or discretion? Exploring dentists views on treating people with Hepatitis C', *Australian Dental Journal* 51, 318-323.

Temple-Smith, M., Jenkinson, K., and Wallace, J. (2012) 'Hepatitis C related discrimination in pharmacy based opioid replacement therapy programs: Does it exist?' *Australian Pharmacist*, **31**, (6) pp. 494-497.

Terrault N.A., Dodge J.L., Murphy E.L., Tavis J.E., Kiss A., Levin T.R., Gish R.G., Busch M.P., Reingold A. L., Alter M. J. (2013) 'Sexual transmission of hepatitis C virus among monogamous heterosexual couples: the HCV partners study,' *Hepatology*, **57** (3) pp. 881-889.

The College of Social Work (2011) *Mission Statement*, available at: http://www.tcsw.org.uk/about-us/mission-statement/ [accessed 3rd April 2011].

Thein, H.H. and Dore, G.J. (2009) 'Natural history of hepatitis C virus infection', in Dore G, Temple-Smith M, Lloyd A (ed.) *Hepatitis C: An Expanding Perspective,* East Hawthorn, IP Communications, pp. 76 – 89.

Thein, H.H., Maruff, P., Krahn, M.D., Kaldor J.M., Koorey D.J,, Brew B.J, Dore G.J. (2007) 'Improved cognitive function as a consequence of hepatitis C virus treatment', *HIV Medicine*, 8 (8) pp.520-528.

Thomas, C. (1999) *Female Forms; experiencing and understanding disability,* Buckingham, Open University Press.

Thomas, A. and R. Griffiths (2010)' Disability Living Allowance and Work: Exploratory research and evidence review,' available at: http://research.dwp.gov.uk/asd/asd5/report_abstracts/rr_abstracts/rra_648.asp. [accessed 14th September 2011].

Thomas, C. (2004) 'Developing the Social Relational in the Social Model of Disability; a theoretical agenda, in Barnes, C and Mercer, G. (eds) Implementing the Social Model of Disabiltiy: Theory and Research, Leeds, The Disability Press, pp. 32-47.

Thomas, C. (2007) *Sociologies of Disability and Illness; contested ideas in Disability Studies and Medical Sociology,* Basingstoke, Palgrave Macmillan.

Thomas, C., Morris, S.M. and Harman, J. C. (2002) 'Companions through cancer: the care given by informal carers in cancer contexts', *Social Science and Medicine* **54** pp. 529–544.

Thomas, C., Morris, S. Soothill, K., McIllmurray, M., Francis, B. Harman, J. (2001) *What are the psychosocial needs of cancer patients and their main carers? A study of user experience of cancer services with specific reference to psychosocial need,* Institute for Health Research at Lancaster University, available at:
http://www.lancs.ac.uk/shm/dhr/publications/carolthomas/the%20psychosocial%20needs%20report.pdf [accessed 1st February 2011].

Thompson, S.J., and Demerath, N..J. (1952) 'Some Experiences with the Group Interview', *Social Forces,* **31** (2) pp. 148-154.

Thompson, S., Hernberger, F., Wade, E. and Crofts,N., (1996) 'Hepatitis C through tattooing: A case report', *Australian and New Zealand Journal of Public Health,* **20** (3) pp. 317-318.

Tierney, S. (2001).'A Reluctance to be Defined 'Disabled'. How Can the Social Model of Disability Enhance Understanding of Anorexia,' *Disability and Society,* **16** (5) pp. 749-764.

Tompkins, C.N.E., Wright, N.M.J., and Jones, L. (2005) 'Impact of a positive hepatitis C diagnosis on homeless injecting drug users: a qualitative study', *British Journal of General Practice,* **55,** pp.263-268

Travis J., Roeder K., Walters H., Piette J., Heisler M., Ganoczy D., Valenstein M., and Pfeiffer P. (2010) 'Telephone-based mutual peer support for depression: a pilot study' *Chronic Illness,* **6** (3) pp. 183-191.

Treichler, P. (1999*) How to have theory in an epidemic: Cultural Chronicles of AIDS,* Chicago, Duke University Press.

Treloar, C., and Abelson, J. (2005) 'Information exchange among injecting drug users: a role for an expanded peer education workforce,' *International Journal of Drug Policy,* **16** (1), pp. 46-53.

Treloar, C., Byron, P., McCann, P. and Maher, L. (2010) ' "Fitness for duty" Social, organisational and structural influences on the design and conduct of hepatitis C vaccine trials involving people who inject drugs', *Vaccine,* **28** (32), pp.5228-5236

Treloar, C. and Fraser, S. (2009). 'Hepatitis C treatment in pharmacotherapy services: Increasing treatment uptake needs a critical view,' *Drug & Alcohol Review,* 28,(4) pp.436-440.

Treloar, C. and Fraser, S. (2004) 'Hepatitis C; blood models of the body: new directions for public health,' *Critical Public Health,* **14,** pp. 377-389.

Treloar, C., Fraser, S., Kippax, S., Rosengarten, M., Waldby, C., Valentine, K., Haire, D. and Murphy, B. (2003) *Blood Awareness in Hepatitis C prevention,* Sydney, National Centre for HIV and Social Research.

Treloar, C. and Holt, M. (2008) 'Drug treatment clients' readiness for Hepatitis C treatment: Implications for expanding treatment services in drug and alcohol settings', *Australian Health Review,* **32** (3), pp. 570–576.

Treloar, C., Hopwood, M. and Loveday, S. (2002) 'Hepatitis C- related discrimination in healthcare' *Medical Journal of Australia,* **177,** pp. 233-234.

Treloar, C. and Hopwood, M. (2004) 'Infection Control in the Context of Hepatitis C Disclosure: Implications for the Education of Healthcare Professionals' *Education for Health,* **17,** pp.183-191.

Treloar, C., and Hopwood, M. (2008). "Look, I'm fit, I'm positive and I'll be all right, thank you very much": Coping with hepatitis C treatment and unrealistic optimism, *Psychology, Health and Medicine,* **13** (3), pp. 360-366

Treloar, C. Hull, P. Bryant, J. Hopwood, M. Grebely, J. Lavis, Y. (2011)' Factors associated with hepatitis C knowledge among a sample of treatment naïve people who inject drugs', *Drug and Alcohol Dependence* **116** (1), pp.52-56.

Treloar, C., Laybutt, B., Jauncey, M., van Beek, I., Lodge, M., Malpas, G., Carruthers, S. (2008) 'Broadening discussions of "safe" in hepatitis C prevention: A close-up of swabbing in an analysis of video recordings of injecting practice,' *International Journal of Drug Policy,* **19** (1) pp. 59-65.

Treloar, C., Rance, J., Laybutt, B. and Crawford, S. (2010) 'Working with the "hierarchy of the underworld": Insights for communication skills training with peer educators', *Contemporary Drug Problems,* **37,** Winter 2010, pp. 639-656.

Treloar, C., Rance, J., Laybutt, B., and Crawford, S. (2012) 'Structural constraints on the training of peer educators in hepatitis C prevention', *Health Education Research,* **27** (2) pp. 248-257.

Treloar, C. and Rhodes, T. (2009) 'The lived experience of Hepatitis C and its treatment; a qualitative synthesis' *Qualitative Health Research* **19** (9) pp.1321-1334.

Treloar, C., Newland, J., Harris, M., Deacon, R. and Maher, L. (2010) 'A diagnosis of hepatitis C: Insights from a study on patients experiences', *Australian Family Physician,* **39** (8) pp.589-592.

Treloar, C., valentine, k. and Fraser, S. (2011) 'Social Inclusion and hepatitis C: exploring new possibilities for prevention', *Journal of Anti Infective Therapy,* **9** (4) pp.397-404.

Trigg, M. E (2012) 'Emerging treatment advances in chronic hepatitis C', *Community Oncology,* doi:10.1016/j.cmonc.2012.03.010.

Tucker, M. (2013) Costs for Hepatitis C Treatment Skyrocket, available at: http://www.medscape.com/viewarticle/814295 [accessed 30th December 2013].

Turner, V. (1966*). Forest of Symbols: Aspects of Ndembu Ritual,* New York, Cornell University Press.

Turner, B. (2003). 'Social Fluids: Metaphors and Meanings of Society,' *Body and Society* **9** (1) pp.1-10.

Tyler, I. (2008) 'Chav Mum Chav Scum: Class disgust in contemporary Britain,' *Feminist Media Studies* 8 (1) pp. 17-33.

Tyler, I. and Bennett, B. (2010) 'Celebrity Chav' Fame, femininity and social class', *European Journal of Cultural Studies,* **13,** (3) pp. 875-393.

Uddin, G., Shoeb, D., Solaimann, S., Marley, R., Gore, C., Ramsay, M., Harris, R., Ushiro-Lumb, I, Moreera, S., Alam, S., Thomas, H.C., Kahn, S,. Watt, B., Pugh, R.N., Ramaiah, S., Jervis, R., Hughes, A., Singhal, S., Cameron, S., Carman, W.F. and Foster, G. R. (2010) 'Prevalence of chronic viral hepatitis in people of south Asian ethnicity living in England: the prevalence cannot necessarily be predicted from the prevalence in the country of origin', *Journal of Viral Hepatitis,* **7** (5) pp.327-335.

UK Drug Policy Commission (2011). *Work Capability Assessment: Issues encountered by people with drug problems,* available at: http://www.ukdpc.org.uk/resources/WCA_Y2_submission.pdf, [accessed 30th September 2011].

UPIAS (1976) *Fundamental Principles of Disability,* available at: http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf [accessed 1st June 2013].

Vallet-Pichard A, Pol S. (2006) 'Natural history and predictors of severity of chronic hepatitis C virus (HCV) and human immunodeficiency virus (HIV) co-infection' *Journal of Hepatology,* **44** (1 Suppl) S28-34.

Van der Geest, A., Reynolds, S. and Hardon, A. (1996) 'The Anthropology of Pharmaceuticals: A Biographical Approach', *Annual Review of Anthropology,* **25,** pp.153-78.

Van De Mortel, T. (2002) 'Health Care Workers Knowledge of Hepatitis C and Attitudes Towards Patients with Hepatitis C: A Pilot study' *Australian Journal of Advanced Nursing,* **20,** pp.13-19.

Van De Mortel, T. (2003) 'Registered and Enrolled Nurses Knowledge of Hepatitis C and attitudes towards persons with Hepatitis C,' *Contemporary Nurse,* **16,** pp. 133-144.

Van Genep, A. (1960) *The Rites of Passage London*, Routledge.

Van Oorschot, W. (2006) 'Making the difference in social Europe: deservingness perceptions among citizens of European welfare states', *Journal of European Social Policy,* **16** (1) pp.23-42.

Vernon, A. (1997) 'Reflexivity: Dilemmas of researching from the inside', In Barnes, C and Mercer, G. (eds) *Doing Disability Research,* Leeds, The Disability Press, pp. 158-177.

Vick, A. and Lightman, E. (2010) 'Barriers to employment among women with complex episodic disabilities', *Journal of Disability Policy Studies,* **21** (2) pp.70-80.

Waldby, C. Treloar, C. and Fraser, S., (2004) 'Blood and bio identity: ideas about self-boundaries and risk among blood donors and people with Hepatitis C', Social Science and *Medicine,* **59**, pp.1461-1471.

Waller, L. (2004) 'Living with Hepatitis C: from self-loathing to advocacy', *Medical Journal of Australia,* **180**, pp. 293-294.

Wallis, P. And Nerlich, B. (2005) 'Disease metaphors in the new epidemics: the UK media framing of the 2003 SARS epidemic', *Social Science and Medicine,* **60,** pp.2629-2639.

Warin, J. (2011) 'Ethical mindfulness and reflexivity: managing a research relationship with children and young people in a fourteen year qualitative longitudinal research (QLR) study', *Qualitative Inquiry,* **17,** (9), p. 805-814.

Watling, S. (2011) 'Digital Exclusion; coming out from behind closed doors' *Disability and Society,* **26** (4) 491-495.

Watson, N. (2002) 'Well I know this is going to sound very strange to you, but I don't see myself as a disabled person: identity and disability', *Disability and Society,* **17** (5) pp. 509-527.

Watson, L., Bond, C. and Gault, C. (2003) 'A survey of community pharmacists on prevention of HIV, and hepatitis B and C: Current Practice and attitudes in Grampian', *Journal of Public Health Medicine,* **25** (1) pp. 13-18.

Watts, L. (2012) 'FCJ-139 Sand14: Reconstructing the Future of the Mobile Telecoms Industry', *The Fibreculture Journal,* **20,** pp. 33-57.

Watts, L. and Urry, J (2008) 'Moving methods, travelling times, Environment and Planning' *Society and Space,* **26,** pp. 860-874.

Waverley Care (2013) *Advice and Information,* available at http://www.waverleycare.org/content/adviceandinformation/116/ [accessed 1st June 2013].

Weedon, C. (1997) *Feminist Practice and Poststructrualist Theory,* London, Blackwell.

Weiss, M. (1997) 'Signifying the pandemics: Metaphors of AIDS, Cancer and Heart Disease', *Medical Anthropology Quarterly,* **11** (4) pp. 456-476.

Welsh Assembly Government (2010*) Blood borne viral hepatitis action plan for Wales 2010-2015,* available at: http://wales.gov.uk/topics/health/protection/communicabledisease/publications/blood/?lang=en, (accessed 15th June 2011).

Wendell, S. (1996) *The Rejected Body: Feminist Philosophical Reflections on Disability,* London, Routledge.

Wendell, S. (2006) 'Towards a Feminist Theory of Disability' in Davis, L.J. (ed) *The Disability Studies Reader,* second edition, pp243-257.

Wendell, S. (2001) 'Unhealthy Disabled: Treating Chronic Illness as Disabilities, *Hypatia,* **16,** 4, pp.17-33.

Werner, A. Isaksen, L.W. and Malterud, K. (2004) 'I am not the kind of woman who complains of everything': illness stories on self and shame in women with chronic pain', *Social Science and Medicine,* **59,** pp. 1035-45.

Werner, A. and Malterud, K. (2003) 'It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors', *Social Science and Medicine,* **57,** pp. 1409-14-19.

Whalen, J. (2013) 'As Hepatitis C Spreads, Scotland Steps In', *Wall Street Journal,* 16th May 2013, available at: http://online.wsj.com/article/SB10001424127887323466204578384760850698712.html [accessed from 20th May 2013].

White, B., Day, C., Thein, H., Doab, A., Bates, A., Holden, J., Van Beek, I. and Maher, L. (2008) 'Acceptability of Hepatitis C virus testing methods among drug users' *Drug and Alcohol Review,* **27,** pp. 666-670.

Whiteman, N.K (2010) 'Control and Contingency: Maintaining Ethical Stances in Research,' *International Journal of Internet Research Ethics,* **3** (12) pp.6-22.

Willet, J. and Deegan, M. (2001) 'Disability and Liminality: Rites of Passage and Community in Hypermodern Socieity', *Disability Studies Quarterly,* 21 (3).

Williams, J.(2005) *Understanding Poststructuralism,* Durham, Acumen Publishing.

Williams-Findlay, R. (2011) 'Lifting the lid on Disabled People Against Cuts', *Disability and Society,* **26** (6) 773-778.

Willig, C. (2011) 'Cancer diagnosis as discursive capture: Phenomenological repercussions of being positioned within dominant constructions of cancer', *Social Science and Medicine,* **73,** pp. 897-903.

Willner-Reid, J., Belendiuk, K. A., Epstein, D. H., Schmittner, J. & Preston, K. L. (2008) 'Hepatitis C and human immunodeficiency virus risk behaviors in polydrug users on methadone maintenance,' *Journal of Substance Abuse Treatment,* **35**, pp.78-86.

Wilson, K. and Amir, Z. (2008). 'Cancer and Disability Benefits: a synthesis of qualitative findings on advice and support,' *Psycho-oncology* **17**, pp. 421-429.

Wilson, H and Bryant, B. (2010) 'Perception of Hepatitis C Risk Among Injecting Drug Users Who Obtain Injecting Equipment from Pharmacies in Western Australia', *Contemporary Drug Problems,* **37**, Winter 2010, pp. 599-618.

Wilson, K. and Luker, K.A. (2006) 'At home in hospital? Interaction and stigma in people affected by cancer', *Social Science and Medicine,* **62**, pp. 1616-1627.

Wilson, H., Hopwood, M., Hull, P,. Lavis, Y., Newland, J., Bryant, J. and Treloar, C. (2010) *Treatment decisions: What makes people decide to have treatment for hepatitis C?* ,National Centre for HIV Social Research, University of New South Wales, available at: http://nchsr.arts.unsw.edu.au/media/File/Treatment_decisions.pdf (accessed 18th May 2012).

Winlow, S. and Hall, S. (2012) 'What is an 'Ethics Committee'? Academic Governance in an Epoch of Belief and Credulity', *British Journal of Criminology,* **52** (2) pp. 400-416.

Winter, R., Ngyuen, R., Higgs, P., Armstrong, S., Duong, D., Thach, M.L., Aitken, C. and Hellard, M. (2008) 'Integrating enhanced hepatitis C testing and counselling in research', *International Journal of Drug Policy,* **19,** pp. 66-70.

Woodby, L. L. Williams, B.R. Wittch, A.R. Burgio, K.L. (2011) 'Expanding the Notion of Researcher Distress; The Cumulative Effects of Coding', *Qualitative Health Research,* **21,** 6, pp. 830-838.

Worklife (2013) *Welcome to Worklife,* available at: http://yourworkhealth.com/ [accessed 1st June 2013].

World Health Organisation (2007) 'Chapter Six: Management of Hepatitis C and HIV coinfection; clinical protocol for the WHO European Region', in Eramova, I. Matic, S. and Munz, M. (eds) *HIV/AIDS treatment and care; clinical protocols for the European Region,* pp. 229-267, World Health Organisation, available at:
http://www.euro.who.int/__data/assets/pdf_file/0008/78146/E90840_Chapter_6.pdf [accessed 1st July 2013].

World Health Organisation (2012) *Prevention & Control of Viral Hepatitis Infection: A framework for global action,* available at: http://www.who.int/csr/disease/hepatitis/Framework/en/ [accessed 3rd February 2013].

World Health Organisation (2013*) Hepatitis C Fact Sheet No. 164,* available at: http://www.who.int/mediacentre/factsheets/fs164/en/ [accessed 1st June 2013].

Wozniak, L., Prakash, M., Taylor, M., & Wild, T. (2007) 'Everybody's got it, but … :Situational and strategic participation in normalized HCV discourse among injection drug users in Edmonton, Canada,' *International Journal of Drug Policy,* **18** (5), pp. 388-396.

Yee L. J., Weiss, H.L., Langner, R.G., Herrera, J., Kaslow, R.A., and van Leeuwen D.J. (2001) 'Risk factors for acquisition of hepatitis C virus infection: a case series and potential implications for disease surveillance', *BMC Infectious Diseases* 1 ,8, pp.1691–1696.

Young, J., Parsons, R., Morris, B and Barnett-McCormack, S. (2013) *Emergency Stop: the hidden economic and social costs of welfare reform,* available at http://wearespartacus.org.uk/emergency-stop/ [accessed 1st June 2013].

Zacks, S., Beavers, K., Theodore, D., Doughtery, K., Batey, B., Shumaker, J., Galanko, J., Shreshtha, R. and Fried, M. (2006) 'Social stigmatisation and Hepatitis C virus infection', *Journal Clinical Gastroenterology,* **40** (3), pp. 220–224.

Zanetti, A.R., Tanzi, E., Paccagnini, S., Principi, N., Pizzacolo, G., Caccamo, M.L. D'Amico, E. Cambie, G. Vecchi, L. (1995) 'Mother to Infant transmission of hepatitis C', *The Lancet,* **345,** pp. 289-291.

Zavestocki, S., Brown, P., McCormick,S., Mayer, B., D'Ottavi, M., Lucove, J.C. (2004) 'Patient activism and the struggle for diagnosis: Gulf War illnesses and other medically unexplained physical symptoms in the US', *Social Science & Medicine,* **58,** pp. .61–175.

Zickmund SL, Bryce CL, Blasiole JA, Shinkunas L, LaBrecque DR, Arnold RM. (2006) Majority of patients with hepatitis C express physical, mental, and social difficulties with antiviral treatment, *European Journal Gastroenterology Hepatology,* Apr;18(4):381-8.

Zickmund, S., Hills, S., Barnett, M., Ippolito, L. and Labreque, D. (2004) 'Hepatitis C virus infected patients report communication problems with physicians', *Hepatology*, **39** (4), pp. 999–1007.

Zickmund, S., Ho, E. Y., Masahiro, M., Ippolito, L., and LaBrecque, D.R. (2003) "They Treated Me Like a Leper" Stigmatization and the Quality of Life of Patients with Hepatitis C', *Journal of General Internal Medicine*, **18 (**10) pp. 835–844.

Zucker, D. (2006) 'A Case of Health Disparity: Treatment issues in women with hepatitis C', *Gastroenterology Nursing,* **29** (2) pp.137-141.