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LANCASTER UNIVERSITY DOCTORATE IN CLINICAL PSYCHOLOGY

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Doctoral Thesis

Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis and Fibromyalgia: a Social Model of Disability Perspective

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Statement of Word Count for Thesis Sections

	Abstract	Main Text	Appendices (including tables and references)	Total
Thesis Abstract	284	N/A	N/A	284
Literature Review	147	7,962	6,466	14,575
Research Paper	170	7,984	20,051	28,205
Critical Review	N/A	3,438	290	3,728
Ethics Section	N/A	5,254	2,684	7,938
Total	601	24,638	29,491	54,730

Declaration

This thesis presents work undertaken for the Doctorate in Clinical Psychology at the Division of Health Research at Lancaster University from April 2015 to May 2016. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Rachel Barcroft

Signed: ....

Date: ....

Acknowledgements

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Section Three: Critical Appraisal

Section Four: Ethics Section

Thesis Abstract

This thesis is composed firstly of a literature review focusing on the attitudes of health professionals towards chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) and fibromyalgia. Secondly, a research paper explores the ways in which people living with CFS/ME have experienced psycho-emotional disablism. Finally, a critical appraisal discusses the process of conducting the research as well as its strengths and limitations.

The literature review takes the form of a meta-synthesis regarding the attitudes of healthcare professionals towards CFS/ME and fibromyalgia. A meta-ethnographic approach was used with reciprocal translation producing the following themes: "Feeling hopeless and more hopeless": psychological effects of lack of knowledge; "Your heart sinks when they come in the room": stigma and stereotypes; and "I'm going to be with you through thick and thin": management of the condition. The review highlights the difficulties faced by health professionals regarding the management and diagnosis of both conditions, as well as possible reasons for the negative attitudes held by some professionals.

The research paper, which employed thematic analysis, explores the ways in which people living with CFS/ME have experienced psycho-emotional disablism. Three overarching themes were identified: "fighting to be heard"; "lack of legitimacy" and "feeling invisible". Participants described the discrimination and stigma that they had encountered from many areas of society. Ideas for future research are proposed.

The critical appraisal presents the author's reflections on the research process as well as its strengths and limitations, and the five stages of the process are described as follows: choosing a thesis topic and designing the project; recruitment and research interviews; the interview process; analysis and writing up of the data; and the author's reflections on the project.

Section One: Literature Review

Healthcare Professionals' Attitudes Towards Chronic Fatigue Syndrome/ Myalgic

Encephalomyelitis and Fibromyalgia: A Meta-Synthesis

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Abstract

Objective: To review the qualitative research regarding the attitudes and beliefs of healthcare

professionals towards chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) and

fibromyalgia as well as their attitudes towards the people who live with them.

Methods: A meta-ethnographic approach was used, with reciprocal translation of nine studies

conducted to obtain three over-arching themes.

Results: The following themes were identified: "F*eeling hopeless and more hopeless": psychological*

effects of lack of knowledge; "Your heart sinks when they come in the room": stigma and

stereotypes; and "I'm *going to be with you through thick and thin": m*anagement of the condition.

Conclusions: Although many healthcare professionals displayed empathy towards individual with the conditions, the review highlights the difficulties faced by health professionals regarding the management and diagnosis of both conditions. Possible reasons are discussed, as well as ideas for future research.

Keywords: chronic fatigue syndrome/ myalgic encephalomyelitis, fibromyalgia, health professionals, attitudes, stigma.

A number of illnesses have attracted controversy as valid diagnostic constructs because of their lack of a clear biological aetiology. Such illnesses include chronic fatigue syndrome (often also called myalgic encephalomyelitis; CFS/ME and fibromyalgia (FM; Afari & Buchwald, 2003; Briones-Vozmediano, Vives-Cases, Ronda-Pérez, & Gil-González, **2013;** Komaroff & Buchwald, 1998; **Parra-Delgado & Latorre-Postigo, 2013). However, these types of illnesses** are often as disabling as those caused by identifiable organic disease (Carson et al., 2000). Indeed, CFS/ME can be as disabling as other serious long term conditions such as multiple sclerosis (MS) or rheumatoid arthritis (UK National Institute for Health and Care Excellence [NICE], 2007). In addition, the health related quality

of life (HRQOL) of people living with CFS/ME has been found to be significantly lower than the general population (Hart, Buchwald, Wilks, Sharpe, Nix, & Egle, 2001; Hividberg, Olesen, Petersen, Ehlers, & Brinth, 2015). Perhaps more tellingly, people living with CFS/ME have a lower HRQOL than populations living with MS or stroke. As with people living with CFS/ME, HRQOL in individuals experiencing FM is significantly lower than the general population (Annemans, Le Lay, & Taieb, 2009; Verbunt, Pernot, & Smeets, 2008). Moreover, Fletcher, Booth and Ryan (2015) found that FM can significantly impact on many aspects of people's quality of life (QOL), including their psychological well-being, relationships with family, friends and employers, social activities and occupations.

As well as the similarities regarding reduced QOL, FM and CFS/ME share many other features. Firstly, CFS/ME often co-occurs with FM (Aaron, Burke, & Buchwald, 2000); it has been estimated that around 35% to 75% people living with CFS/ME have also received a diagnosis of FM (Jason, Taylor, & Kennedy, 2000). Secondly, both conditions are seen more frequently in women than men (Gallagher, Thomas, & Hamilton, 2004). The prevalence of fibromyalgia has been estimated at 2-4% and around 0.2- 0.5% for CFS/ME (Garcia-Fructoso, Lao-Villadoniga, Santos, Poca-Dias & Fernandez-Sola, 2008). Additionally, some symptoms of CFS/ME and FM overlap (Åsbring & Närvänen, 2002; Schmaling & Betterton, 2016; White, Speechley, Harth, & Østbye, 2000). For example extreme fatigue (Evengård, Schacterle, & Komaroff, 1999; Goldenberg, Simms, Geiger, & Komaroff, 2005), cognitive difficulties such as 'brain fog' or 'fibro fog' (Cockshell & Mathias, 2010; Park, Glass, Minear, & Crofford, 2001) and sleep disturbances ranging from unrefreshing sleep to insomnia (Fukuda et. al., 1994; Wolfe, Brahler, Hinz, & Hauser, 2013), and muscle and joint pain (Ngian, Guymer, & Littlejohn, 2011; Sim & Madden, 2008). Due to the many similarities in symptoms of FM and CFS/ME there has been a debate regarding whether they are the same condition, or indeed should be reclassified as belonging to one umbrella syndrome (McKay, Duffy, & Martin, 2009).

In addition to the overlapping physical difficulties experienced by people living with them, the two conditions have attracted controversy for similar reasons which will be described here. Research into understanding the cause of each condition continues to be conducted; in FM, it has been hypothesised that a defining feature of the condition is a decreased pain threshold due to the increased reactivity of dorsal horn neurons, known as central sensitisation (Borchers & Gershwin, 2015). Only in recent decades has FM been recognised as a physiological condition rather than one of a psychological nature Craggs-Hinton, 2000; McKay et al., 2009). In CFS/ME, a debate continues relating to biological or psychological factors that may explain the illness (Clarke & James, 2003), however over recent years a biological cause has become more accepted (Barnden, Kwiatek, Crouch, Burnet, & Del Fante, 2016; Hornig et. al., 2015). It has been hypothesised that certain events, e.g. stressful life events or viruses such as glandular fever, can trigger CFS/ME (Bansal, Bradley, Bishop, Kiani-Alikhan, & Ford, 2012; Hatcher & House, 2003).

There is no specific test to diagnose CFS/ME so it is diagnosed by exclusion of other conditions. Several investigations including a full blood count and tests for liver and thyroid function are therefore recommended in order to rule out other conditions (CDC, 2012; NICE 2007), which can take sometimes take years to complete (Wearden et al., 2010). As with CFS/ME, FM cannot be identified by objective examinations such as physiological tests or x-rays (Bernstein, 2016) and the subsequent reliance on subjective reports can also be time-consuming and problematic (Suresh, 2015). Individuals may experience pain that cannot be fully explained by inflammation or damage in tissues (Bernstein, 2016; Clauw, 2015), thus meaning that laboratory tests and scans may show normal results (Suresh, 2015).

Diagnostic criteria for FM was revised in 2010 (Wolfe et al., 2010) and subsequently approved by the American College of Rheumatology, meaning that FM is currently diagnosed using a widespread pain index and symptom severity scale. A diagnosis therefore requires the presence of widespread pain lasting for more than three months, fatigue or unrefreshing sleep, and memory and

other cognitive difficulties. Despite the many physical similarities between CFS/ME and FM, a different emphasis is placed during diagnosis on the severity of different symptoms, e.g., widespread pain across extensive tender points and allodynia for FM (Bradley, McKendree-Smith, & Alarcón, 2000; Wolfe et al., 2010) whereas the major symptoms of CFS/ME are significant levels of fatigue which severely impacts on activity levels (Fukuda et al., 1994). Managing either condition is often as problematic as diagnosis. There is no agreed method for managing FM (Durif-Bruckert, Roux, & Rousset, 2014; Sim & Adams, 2002), and treatment for both CFS/ME and FM is based on symptom management (Drachler et al, 2009; Durif-Bruckert et al., 2014).

Perhaps due to the lack of clear causes, as well as difficulties in diagnosis and management, doubts regarding the legitimacy of either condition have been well documented (Horton-Salway, 1998; Sim & Madden, 2008). People living with FM often report their illness being perceived with scepticism (Cunningham & Jillings, 2006; Sallinen, Kukkurainen, & Peltokallio, 2011) as do those living with CFS/ME (Thomas & Smith, 2005).

It is unsurprising given the negative attitudes from others in society, as well as the physical and cognitive difficulties present, that research indicates psychological difficulties for some living with either condition. For example, for those living with CFS/ME, their employment status, social lives and recreational activities can be negatively impacted (Gray & Fossey, 2003; Soderlund, Skoge, & Malterud, 2000; Ware, 1998). The lack of acceptance from family and loved ones as well as physicians to accept the existence of FM is a further source of distress (Borchers & Gershwin, 2015) and people living with CFS/ME have described annoyance regarding others' lack of understanding of the condition (Larun & Malterud, 2007). Moreover, people living with CFS/ME have reported disbelief and lack of empathy from healthcare providers (Drachler et al., 2009); Whitehead (2006) found that half of the people interviewed felt their physicians were not supportive. Similarly, people living with FM report frustration with healthcare providers (Cranford & King, 2011; Deale & Wessely, 2001) and both report discrimination and stigma in general (Åsbring & Närvänen, 2002).

Unfortunately, this appears to be backed by previous research, in which health professionals

reported a lack of knowledge regarding FM with 23% of family physicians in the same study believing

people living with FM to be malingers (Hayes et al., 2010).

It is not only the discrimination faced by those living with these contested conditions that

appears to be a barrier to successful adjustment to living with such a condition; the ambiguity

regarding the cause of each condition also affects this transition. According to Levanthal's self-

regulation model (1980), an individual is motivated to solve the 'problem' of being ill in order to re-

establish equilibrium in their life. The consequent development of 'illness representations', the

beliefs that individuals hold about their illness, have an important influence in how they understand

their illness as well as the coping skills they go on to develop. One of these - understanding the cause

of a condition - is seen as an important influence in how individuals adjust to living with a long-term

condition, and it in turn affects the coping strategies that they go on to develop. Because the

aetiology of these conditions remains in doubt, this affects how the individual makes sense of living

with a long-term condition. Illness perceptions have been shown to affect psychological outcomes

such as psychological adjustment to the condition, anxiety and depression in a range of long term

conditions (Costa, Vale, Sobra, & Graca Pereira, 2016; Keeling, Bambrough, & Simpson, 2013)

including CFS/ME (Dickson, Toft, & O'Carroll, 2009; Edwards, Suresh, & Lynch, 2001) and FM (Nielson

& Jensen, 2004). In CFS/ME, illness representations, such as beliefs regarding the length of the

condition, control over the condition and cause of the condition, have been associated with

psychological adjustment and well-being (Moss-Morris, Petrie & Weinman, 1996). In particular, a

strong illness identity was associated with a longer illness duration, and believing that the illness had

a psychological cause was related to beliefs that the illness would have serious effects on their life.

Health care professionals play an important role in shaping an individual's illness beliefs, and

in turn, health outcomes (DiMatteo & DiNicola, 1982; Ley, 1979), meaning that their own beliefs are

of particular importance in the management of CFS/ME and FM.

Aim of literature review

It is clear from the research above that from the perspectives of those living with either condition, some members of society, and more specifically, some healthcare professionals are seen as unsupportive and disbelieving regarding the severity and even the existence of their health difficulties. In order to gain an understanding of available studies in this area, this systematic review will synthesise the attitudes of health professionals to CFS/ME and FM in order to appraise attitudes towards people living with either condition from those who are responsible for their healthcare.

A qualitative methodology has been chosen as it will allow for more detailed exploration of the subject matter than a quantitative study would be able to provide, and provides the opportunity to access information that may not be available via quantitative means (Anzules, Haennl, & Golay, 2007).

Other syntheses of qualitative research in the area have been conducted previously. Anderson, Jason, Hlavaty, Porter and Cudia (2012) conducted a synthesis of all available qualitative studies relating to CFS/ME in order to synthesise the major thematic findings. This meta-synthesis included 34 qualitative studies and also included studies including people living with CFS/ME. They identified themes such as identity changes involving a shift in the relationship between the mind and body, and developing coping strategies such as social support and religion. This review included three studies that are included in the current meta-synthesis (Åsbring & Närvänen, *2003; Chew-Graham, Dowrick, Wearden, Richardson, & Peters, 2010;* Raine, Carter, Sensky, & Black, 2004). Similarly, Larun and Malterud (2007) reviewed 20 qualitative studies which described experiences of CFS/ME, however this review also included experiences from patients and thus synthesised quotations and perspectives from both patients and healthcare professionals. In addition, only two of the studies identified in the present review are included in this synthesis (Åsbring & Närvänen, *2003;* Raine et al., 2004). More recently, Bayliss et al. (2014) reviewed 21 qualitative studies with a specific emphasis on barriers to diagnosing and management of CFS/ME. Similarly, this study

included the perspectives of individuals with the condition. The present study is unique in that it

focuses solely on the attitudes of healthcare professionals towards all aspects of the condition and

the individuals with whom they come into contact who live with the condition. In relation to FM, Sim

and Madden (2008) conducted a meta-synthesis of the illness experience of individuals with FM,

however to date there has been no review of the perspectives of professionals working with the

condition. To the author's knowledge, this review is the first to include health professionals'

attitudes towards FM in a meta-synthesis. In addition it includes medical students, the views of

whom have not been reviewed in previously published syntheses. This gives an insight into the

attitudes of future medical professionals, in order to explore how attitudes have developed over the

years.

Finally, within the research, there is a lack of qualitative reviews of studies on FM. The

inclusion of this condition in this review seeks to address this problem.

The research question to be addressed is thus: what are the attitudes and beliefs of

healthcare professionals regarding CFS/ME and FM, and the people who live with them?

Method

The search for relevant studies was conducted in November 2015. The studies included in

this literature were obtained following a search of four databases across a range of health

disciplines: Academic Search Complete, PubMed, Cinahl, PsycINFO. The databases were searched

separately using search terms which included: "Qualitative", "Chronic Fatigue Syndrome", "CFS",

"Myalgic Encephalomyelitis", "ME", "Fibromyalgia", "Perspective", "Belief", "Attitude*", AND

"Doctor", "General practitioner", "GP" and "Healthcare professional" "Physician", Nurse". A more

detailed list of terms and variations is provided in the Appendix. Reference lists of papers in the

same field were also hand-searched.

A total of 1646 studies were obtained across the four databases, which included a large number of duplicates, and after removing duplicates and studies that were immediately considered to be unsuitable (e.g. due to methodology, participant characteristics etc.), a total of 33 studies remained (see Figure 1).

Insert figure 1 here

The following inclusion criteria were applied:

- The study was qualitative and comprised data from interviews or focus groups

- The study was published in English

- The study was published in a peer-reviewed journal

- The study recruited health professionals who provided perspectives on people living with CFS/ME and/or FMS

- The study met baseline quality appraisal criteria.

The following exclusion criteria were applied:

- A mixed method or quantitative methodology was employed and the qualitative data was not extractable

- Unable to separate views of health professionals from those of other populations.

After applying the inclusion and exclusion criteria to each paper, a total of ten papers remained.

Quality appraisal

Different views have been expressed on which studies should be included in a meta-synthesis. For instance, it has been argued that research should not be excluded from a review due

to it being of insufficient quality (Sherwood, 1999), because of concerns that this could lead to

important data being missed. On the other hand, (Campbell et al., 2003) advocate that robust

quality appraisal is necessary to ensure that meta-synthesis is viewed as a credible method within

the field of research. For these reasons, the studies were appraised for quality in order to ensure

studies of a suitably high quality were included**.** Nine studies were included for review. Table 1

(appendix) shows the study characteristics and participant details.

Insert table 1 here

In order to appraise the selected studies for quality, the Critical Appraisal Skills Programme

(CASP) tool was employed (Public Health Resource Unit, 2006). This tool is a checklist consisting of

10 questions designed to assist the researcher in assessing the quality and value of the research. The

first two questions are screening questions requiring a yes or no answer. Due to a lack of clear

statement of the aims of the research, one study was excluded (Horton-Salway, 2002). The

remaining eight questions are designed to help the researcher appraise various aspects of the study

including research design, recruitment strategy and data analysis. Based on a three point rating

system developed by Duggleby et al. (2010), the eight questions were each scored out of three

depending on the amount of detail provided in that area. Items with little or no detail regarding the

justification for that aspect of design or analysis (weak) scored one point, items with a moderate

amount of detail scored two points (moderate) and items providing extensive information and clear

justification regarding that aspect of the study scored three points (strong) (see table 2).

Insert table 2 here

On appraising the final nine studies, few included sufficient information regarding the

researchers' own role and influence in the design, collection and analysis of data, making it difficult

to appraise to what extent their own ideas and beliefs about the subject matter had influenced the

data collection and analysis.

Participants

Data comprised of interviews with a total of 221 health professionals; 179 participants were

interviewed regarding their views on CFS/ME and 42 regarding FM. The disparity in the numbers of

studies reporting on CFS/ME and FM is reflected in the participant numbers for the two conditions.

The smaller number of participants interviewed about FM does mean that data regarding CFS/ME

are more prominent in the findings. This means that it was particularly important during the analysis

phase to ensure that themes identified in the data were not skewed towards the experience of

working with CFS/ME, rather than FM. Similarly it was important to ensure that data regarding FM

was present in the identified themes. Differences in the two conditions are also discussed.

The majority of participants were doctors, particularly family physicians (n =142), however

there were also 15 professionals with specialist knowledge of CFS/ME or FM. Practice nurses (n =34),

medical students (n =21) and one physiotherapist also participated. Two mental health professionals

were interviewed (psychologist n =1; psychiatrist n =1; *Briones-Vozmediano et al., 2013*). Horton et

al. (2010) did not specify in what field the six health care practitioners interviewed in their study

worked. Participants were recruited mainly through purposive sampling; however one study was

unique in that the participants were doctors who were identified by patients as providing

particularly good care (Horton et al., 2010). One study included views on both CFS/ME and FM

(Åsbring & Närvänen, *2003)*.

Results

The selected papers were analysed using the meta-ethnographic approach as described by

Noblitt and Hare (1988). Meta-ethnography seeks to provide an interpretative rather than an

integrative synthesis, combining evidence to develop new concepts (Pope, Mays & Popay, 2007).

This method was selected as it has been identified as being the best developed method for meta-synthesis of qualitative research (Britten et. al, 2002). Meta-ethnography allows for the studies to be assimilated, while preserving the individual nature of each one. After these papers were selected for review, they were read several times to identify key themes, metaphors and concepts that were relevant to the research question. Following the process of reciprocal translation, in which these themes, metaphors and concepts from each study were compared and contrasted with those from the remaining eight studies, a total of eight subthemes were identified, and three over-arching themes (table 3).

Table 3 here

Findings

Three main themes were identified: (1) *"Feeling hopeless and more hopeless": Knowledge of the condition;* (2) "Your heart sinks when they come in the room": Stigma and stereotypes; and (3) "I'm *going to be with you through thick and thin":* Management of the condition.

Theme One: *"Feeling Hopeless and More Hopeless": Psychological Effects of Lack of Knowledge*

A common theme across all the studies related to the knowledge that the health professionals held about either CFS/ME or FM, such as management of the condition, diagnosis or amount of knowledge held in this area. This was illustrated in themes and subthemes such as *understanding the condition* (Chew-Graham et al., 2009), and *limited knowledge but many options* (Stenhoff, Sadreddini, Peters, & Wearden, 2015). This theme included the beliefs about the conditions that the professionals held, as well as the gaps in their knowledge that seemed to have widespread consequences. Professionals' knowledge regarding how people contracted CFS/ME varied from the effects of modern life: *"it's an illness they've got from life" (GP; Chew-Graham et al.,*

2010, p.2), to having a psychological foundation: "I thought it was very much a sort of somatic

presentation of a mental health problem and that was pretty much it" (GP; Chew-Graham et al.,

2010, p.3). Similarly, varying illness beliefs and theories about the type of people affected by FM

*were held by practitioners: "they certainly have particularly deviant personalities'' (*Hellström*,*

Bullington, Karlsson, Lindqvist, & Mattsson, 1998, p. 234). Many practitioners at the start of their

medical careers admitted to knowing nothing about CFS/ME (*Stenhoff et al., p.201*) and even more

experienced workers revealed poorly formed and confusing illness beliefs: *"they have a change in*

their white count levels, they've usually had a virus, a recent viral infection that can trigger

it...depression, I think it's all related to depression" (practice nurse; Chew-Graham et al., 2009, p.5).

This is despite convincing bodies of evidence for both conditions regarding physical, rather than

psychosomatic causes, suggesting that the knowledge many healthcare professionals hold is not

*sufficiently current (*Barnden et al., 2016; *Borchers & Gershwin, 2015;* Hornig et al., 2015).

Given the gaps in knowledge, it is unsurprising that a subtheme that emerged was 'groping

*in the dark' (*Raine et al., 2004*). In both conditions and seen across many roles was the sense that*

professionals felt helpless when seeing people living with either condition. "I do really think that it is

quite intimidating to be … to be presented with or left with a patient … such as this" (medical

student; Stenhoff et al., 2015, p.204). "For the doctor it can be wearying to meet and talk with these

people and this can give a feeling of incompetence and helplessness in the professional function"

*(*Åsbring & Närvänen, *2003, p.715), which leads to professionals "feeling hopeless and more*

hopeless" (GP; Raine et al., 2004).

Professionals who worked with people living with FM appeared to have difficulty in

managing the condition given that it does not fit easily within the biomedical model in which they

were trained. As a consequence of this, they seemed keen to refer service users onto specialist

professionals, such as rheumatologists: "we fairly soon leave the patients to the FM team, so to

speak. Well, it's not a deliberate escape. Others take over" (Hellström et al., 1998, p.235). *However,*

sometimes rheumatologists themselves felt uncertain: "because you don't really know what's happening there...you have few means of knowing what you're doing" (rheumatologist; Briones-Vozmediano et al., 2013, p.201). Gaps that existed in medical training regarding either condition were discussed in themes such as *training needs* (Stenhoff et al., 2015) and by physicians such as those interviewed by Åsbring and Närvänen (2003) and others: "*no, well I, I personally think I've never, had any formal training and never, heard of any, particularly"* (practice nurse, Chew-Graham et al., 2009, p4). Many participants discussed training needs relating to working with CFS/ME, however there was less discussion regarding identified training needs for FM. This may be an area for future research as it is not possible to establish whether there are fewer training needs in general, or because there was less available data due to the smaller number of participants interviewed re FM.

Theme Two: "Your Heart Sinks When They Come in the Room"; Stigma and Stereotypes

Despite many health professionals' ambiguous display of knowledge and the uncertainty regarding the causes and management of the conditions, or perhaps because of this, some of them held strong negative opinions regarding the character or motives of people living with the conditions. In the case of CFS/ME, negative opinions appeared for the most part to be heavily influenced by senior medical staff and clinical tutors: "e*arly on in my training it was referred to as ME ... it was seen as the malingerers' last resort really ... great deal of scepticism and, no time paid to it whatsoever, brushed over"* (practice nurse; Chew-Graham et al., 2009, p.4). This attitude was particularly prevalent in the medical students interviewed, most likely due to their being at a stage of their careers where the attitudes of people holding more power were particularly influential: "GPs will kind of make … comments about how it's just … erm … people are just lazy" (medical student; Stenhoff et al., 2015, p.203).

A common theme across the studies was the refusal of some professionals to acknowledge the existence of CFS/ME, on an individual level: "I don't use the term ME because I think it's

completely without evidence" (GP; Hannon et al., 2012, p.12), to whole services: "you sometimes get whole practices which decide ME doesn't exist" (health care professional; Horton et. al., 2010, p.6). This refusal to acknowledge the condition was not found in the data on FM. Many references were made to the fact that people living with either condition appear to ignore their normal obligation of the sick role i.e. to make every effort to return to a state of health (Raine et al., 2004), with their work ethic called into question (Åsbring & Närvänen, 2003): "there's a part of me that thinks is it something that could be used by patients that want an excuse not to work" (practice nurse, Hannon et al., 2012, p.5). This is consistent with previous research into the experiences of people living with CFS/ME, who are often treated with suspicion and not taken seriously (Åsbring & Närvänen, 2002; Travers & Lawler, 2008).

The negative attitudes held by some professionals were discussed in themes such as *moral judgement of the patients* (Åsbring & Närvänen, 2003). It was felt by many that people may have a particular personality: "a certain personality trait that is chronic fatigue syndrome waiting to happen" (GP; Raine et al., 2004, p2).

It appeared that some clinicians did not feel any empathy regarding the difficulties that this population may experience: "… you think God they are just knackered … like everyone gets knackered no-one like really cares" (medical student; Stenhoff et al., p202). People living with CFS/ME were often compared unfavourably with people experiencing other health difficulties, for instance people living with irritable bowel syndrome (IBS) "are not as heartsinky as people with chronic fatigue" (GP; Raine et al., 2004). This metaphor was echoed by Hannon et al. (2012); "your heart sinks when they come in the room" (GP), indicating the unfortunate labelling given to those living with the condition.

Theme Three: "I'm *going to be with you through thick and thin":* Management of the condition

Challenges in management were acknowledged and these were plentiful. As well as the relational difficulties and lack of knowledge already described, the difficulties in diagnosing the conditions were seen as having a potentially significant impact on the relationship between clinician and individual (Horton et al., 2010); similarly lack of service provision was also an issue. For example, some practitioners identified the short consultation times available and fragmented services or lack of awareness of specialist services were also highlighted (Hannon et al., 2012). Some specifically described the perceived shortcomings of other professionals: "GPs and practice nurses want to do the best for their patients but often they don't know what to do" (CFS/ME specialist; Horton et al., 2012, p.7). The lack of effective medication made management problematic (Briones-Vozmediano et al., 2013) as well as the difficulty faced by doctors when working with these conditions which do not fit the biomedical model (Åsbring & Närvänen, 2003; Hellström et al., 1998; Horton et al., 2010): "… in medicine in general we are taught in a sort of biomedical frame, illnesses like this they sort of err don't fit" (medical student; Stenhoff et al., 2015, p.202). Clinicians were less likely to acknowledge that FM may be a biomedical anomaly (Hellstrom et al., 1998) than they were with CFS/ME. This appears to explain some of the frustration and attitudes of healthcare workers who still attempted to treat FM using this approach. Moreover, accepting and adjusting to life with a long-term condition was recognised as a significant challenge faced by the individual and could be described as a grieving process for many (Horton et al., 2010).

Many healthcare professionals spoke about the tensions that were present in the relationship between themselves and the individual living with the condition, and these difficulties seemed to be present for a number of reasons. In many cases, difficulties arose from both parties violating their usual roles; practitioners may not have the expected knowledge, and the individual might reject their doctor's advice or come to the consultation with their own ideas or management plans (Raine et al., 2004). When this happened, people sometimes showed dissatisfaction and scepticism regarding the clinician's knowledge (Åsbring & Närvänen, 2003) who then felt that their

professionalism, impartiality and authority was being challenged (Briones-Vozmediano et al., 2013, Raine et al., 2004). *Research has established, however, that individuals attending healthcare consultations often expect to be involved in the management of illness as equal partners (Vaartio-Rajalin, Leino-Kilpi, & Puukka, 2014a), and thus those who bring their own ideas to the consultation may be hoping for this type of relationship.*

Other reasons for dissatisfaction with the relationship were related to disagreements over the management and cause of CFS/ME (Raine et al., 2004), as well as due to the difficulties in diagnosing and managing FM (Briones-Vozmediano et al., 2013). Health professionals who were more understanding of the difficulties experienced by this population described the resistance experienced by some of the people who had come to their service: "I do have a patient with ME who said my GP said 'it's in your mind'" (HCP; Horton et al., 2010, p.5). In extreme cases, the relationship broke down completely, leading to some clinicians devising strategies to keep people away: "we have doctors who refuse to see such patients. They say merely, ''I cannot help you, go somewhere else" (doctor; Åsbring & Närvänen, 2003, p.716). Others however did so as a way to protect themselves psychologically from the demands of working with these conditions which are difficult to diagnose and manage (Åsbring & Närvänen, 2003).

Obtaining a diagnosis was seen as useful for some practitioners, however others disagreed. Those who saw it in a positive light felt that "actually making a diagnosis can be quite empowering" (CFS/ME specialist; Hannon et al., 2012, p6) and a relief (Chew-Graham et al., 2009), not least because people felt legitimised by the acknowledgement that they were not making up their difficulties (Briones-Vozmediano et al., 2013). Others felt that it was a last resort because a diagnosis did not offer a clear management pathway (Hannon et al., 2012) and was even considered as potentially harmful (Chew-Graham et al., 2010) as discussed in their theme *potential harm from the label*, as well as problematic and stigmatising (Chew Graham et al., 2009).

Despite the lack of clarity regarding diagnosis and management, the professionals interviewed appeared clearer regarding ways forward to improve management and training, reflected in themes such as *enabling self-management* (Horton et al., 2010). In an ideal situation, management would be individualised (Briones-Vozmediano et al., 2013), with the person understanding their symptoms but not being too symptom-focused (Horton et al., 2010), and with their expectations managed carefully (Horton et al., 2010). Practice nurses saw their role as one of motivation and encouragement (Chew-Graham, 2009). It was felt that specialists needed to provide holistic and flexible support (Horton et al., 2010) and that management should be multi-disciplinary (Briones-Vozmediano et al., 2013). Relevant information from specialist associations should have been provided (e.g. the UK ME Association; Horton et al., 2010).

Regarding psychological support, some practitioners felt it could be useful: "I must admit, my patients who have managed to get to CBT [cognitive behaviour therapy] do seem to have done very well" (GP; Raine et al., 2004, p3). Despite this, some physicians experienced resistance when discussing these strategies (Åsbring & Närvänen, 2003): "their shutters will go up" (GP; Raine et al., 2004, p.2). However, others were unaware of the psychological options (Stenhoff et al., 2015; Raine et al., 2004), and others acknowledged that these options were not suitable for people living with severe CFS/ME, even though they may be most likely to experience psychological difficulties (Horton et al., 2010).

Despite the negative attitudes that appear to prevail across the healthcare professions, a positive relationship between professional and service user was seen as crucial by many. Indeed, many practitioners also displayed empathy when working with this population. This appeared to be expressed as a willingness to be there for an individual in a long term capacity (Åsbring & Närvänen, 2003), while acknowledging that they were unable to offer specific tangible management strategies: *"I think one of the crucial things for these kinds of people is for a doctor to say 'I'm on your side, I'm going to be with you through thick and thin', and for the doctor to accept their relative*

powerlessness, but nonetheless to accompany the patient through this" (GP, Chew-Graham et al.,

*2010, p4). Listening to the person was seen as very important (*Briones-Vozmediano et al., 2013*);*

"patients will often say 'you're the first people that have actually listened to me' (specialist, Horton et

al., 2010, p9). On a more practical note, empowering the individual by giving them responsibility over

their own healthcare and future was seen as an important feature of successful management

*(*Åsbring & Närvänen, 2003*; Horton et al., 2010). This is consistent with research which has found*

that an increased sense of self- control in the management of an illness has been associated with

increased daily functioning (Stewart et al., 2000). Using empathy and good communication was seen

*as an ideal way to provide the necessary information and thus empower people in this way (*Briones-

Vozmediano et al., 2013*; Hellström et al., 1998*; Horton et al., 2010).*

Discussion

This meta-synthesis aimed to explore the attitudes of health professionals regarding two

controversial conditions, CFS/ME and FM, and the people who live with them. Three main themes

were identified: (1) *"Feeling hopeless and more hopeless": psychological effects of lack of*

knowledge; (2) "your heart sinks when they come in the room": Stigma and stereotypes; and (3) "I'm

going to be with you through thick and thin": Management of the condition. This is consistent with

finding from previous reviews (e.g. Bayliss et al., 2014) who also found inconsistent illness beliefs,

friction in health-professional relationships and difficulties in management of CFS/ME.

In synthesising attitudes towards the two conditions, several similarities were found. These

were mainly related to the lack of knowledge of the management of the conditions and also the

absence of up-to-date knowledge of relevant research in the aetiology and presentation of the

illnesses. When discussing either condition, there was a wide range of illness beliefs and theories

relating to the cause, highlighting the need for many healthcare professionals to familiarise

themselves with current research in order to best support individuals who attend their service.

Despite the many similarities presented here, there was however some differences noted between

the two conditions. For instance, while both conditions were viewed negatively by some of the

participants interviewed, there appeared to be more stigma towards the individuals themselves who

were living with CFS/ME than towards those with FM. For example, many studies described the

frustration of professionals relating to the consultations and their helplessness regarding their ability

to offer solutions or satisfactory management plans. However, professionals were more likely to

make negative statements attributing negative personality traits to people living with CFS/ME than

those living with FM (e.g. Raine et al, 2004; Stenhoff et al., 2015). One possible explanation for this is

that CFS/ME is predominantly associated with fatigue, whereas FM is associated with widespread

chronic pain, and some professionals may not consider fatigue to be as serious an impairment. This

is consistent with several studies that reported attitudes that those living with CFS/ME were lazy or

unwilling to work (Chew-Graham et al., 2009; Stenhoff et al., 2015). Pathways for the post-diagnosis

management of CFS/ME and FM also differ, with people with FM often being referred to

rheumatology and those with CFS/ME being offered symptom management in primary care or

access to specialist CFS/ME services if available. As such, professionals spoke about referring people

with FM onto rheumatology, which was often viewed as a relief to be able to transfer their care to

another service. In contrast, people with CFS/ME often had to proactively request referral to

specialist services (Horton et al., 2010).

In terms of attitudes to a diagnosis of either FM and CFS/ME, on the whole clinicians were

slightly more optimistic regarding the usefulness of a diagnosis of FM, with it seen as being either an

opportunity to be offered further treatment (Hellstrom et al., 1998) or to enable the individual to

feel legitimised regarding the nature of their condition (Briones-Vozmediano et al., 2013; Hellstrom

et al., 1998). On the other hand, although some health professionals recognised that a diagnosis

similarly reassured individuals with CFS/ME of the legitimacy of their condition, many professionals

reflected that this advantage was short lived, due to the stigma associated with the condition (Chew-

Graham et al., 2009; Horton et al., 2010) or the lack of follow-up support (chew-Graham et al., 2010;

Hannon et al., 2012).

Given the above findings, is important to consider reasons for the enduring negative

attitudes towards the conditions. CFS/ME is frequently underrepresented in medical textbooks; in a

content analysis of medical textbooks, conditions with lower prevalence rates such as multiple

sclerosis and Lyme disease were found to receive more coverage than CFS/ME (Jason, Paavola,

Porter, & Morello, 2010). Given that some textbooks did not even include the condition, medical

personnel may rely on out of date information, or be vulnerable to being influenced by colleagues

who do not view the condition favourably, as found by Stenhoff et al. (2015).

It appeared from the synthesised studies that while there were undoubtedly professionals

who displayed empathy regarding the severity of the conditions (Briones-Vozmediano et al., 2013;

Horton et al., 2010), unfortunately attitudes and knowledge towards the two conditions appear not

to have made any significant shifts over time. The most recently trained professionals (e.g. Stenhoff

et al., 2015) appeared to be highly influenced by the negative attitudes of senior staff, thus

perpetuating the problematic beliefs towards individuals living with CFS/ME.

The negative opinions about the personality of people living with CFS/ME which some health

professionals held could also be explained through social psychology perspectives. For example,

cognitive dissonance (Elliott & Devine, 1994; Festinger, 1957) is where an individual holds conflicting

beliefs or behaviours, and thus adjusts one of these in order to reduce the discomfort they are

experiencing. In this situation, some health professionals – who are trained in the biomedical model

– hold the belief that they should successfully reduce patients' symptoms; however there is no

diagnostic tool, cure or symptom management for the condition. This leads them to avoid the

patient, or refer them on to another professional, or even belittle the patient so that their failure to

offer any effective treatment holds less importance for them. Alternatively, but in a similar vein,

they may externally attribute the problematic nature of some consultations to the supposed

personality deficiencies of the patients, which then protects their self-esteem (Heider, 1958; Kim,

Dirks, Cooper, & Ferrin, 2006).

It was not possible to separate the attitudes of the different groups of healthcare

professionals interviewed, as both negative attitudes as well as empathic and supportive attitudes,

were present in all groups. It appeared from the synthesised studies that, unfortunately, attitudes

and knowledge towards the two conditions appear not to have made any significant shifts over time,

with the most recently trained professionals (e.g. Stenhoff et al., 2015) appearing to be highly

influenced by the negative attitudes of senior staff, thus perpetuating the problematic beliefs

towards individuals living with CFS/ME.

One of the inclusion criteria was only selecting papers that had been published in peer-

reviewed journals, but despite this it was found that the papers were of variable quality, leading to

one paper to be excluded from the synthesis. There were also methodological flaws found in other

papers, such as a lack of description regarding where the research took place, and how ethical

concerns such as gaining informed consent were addressed. Also lacking from many papers was the

researchers' consideration of their own stance when conducting the research, including critical

examinations of their own roles and beliefs. This means that it is difficult to understand the impact

of researchers' beliefs, i.e. what quotes are used to argue certain points, or how the interviews were

conducted and what questions were asked.

The review process found that many healthcare professionals had empathic views of the

conditions, and saw their role as an empowering and supportive one. Despite this, the presence of

negative and stigmatising beliefs about the conditions were still present in some professions. This

echoed findings of previous studies focusing on individuals' and family members' opinions, where

professionals are reported as labelling individuals as 'malingerers', e.g. Hayes et al. (2010),

Söderberg, Strand, Haapala, and Lundman, (2003) and Whitehead (2006). It has been suggested that

clinicians with low job satisfaction, less experience as well as having a poor understanding of the role

of psychosocial factors in health and illness are more likely to report difficult encounters with patients (Elder, Ricer, & Tobias, 2006), emphasising the need to improve training regarding psychosocial factors. In addition, younger clinicians who experience higher levels of stress are more likely to report high levels of frustration with patients (Krebs, Garrett, & Konrad, 2006).

Currently, it is difficult to establish how the negative attitudes of some health professionals are being perpetuated. For example, it is unclear whether some practitioners hold negative beliefs because their lack of knowledge and training, as well as lack of management options, leaves them feeling inadequate, thus experiencing negative attitudes towards the people who arouse these feelings within themselves. This situation could be viewed as countertransference (the emotional response elicited from the clinician towards the patient; Hughes & Kerr, 2000). Also, as both CFS/ME and FM have no cure, health professionals may feel frustrated or incompetent at their inability to reduce the symptoms of their patients in line with the biomedical training they have received. This would be particularly problematic from the perspective of Leventhal's self-regulation model (1980), as the patient's needs regarding re-establishing equilibrium by recovering from illness are thus not being met, leading to further frustration for all parties. In addition, professionals' negative attitudes regarding the condition itself (e.g. that it cannot be cured or may not even exist) could have a detrimental effect on the patient's development of illness representations and thus psychological adjustment to the condition. Alternatively, those holding a negative belief are unlikely to seek out training and information about a condition in order to educate themselves, and therefore continue to have these attitudes. In this way they are susceptible to being influenced by the opinions of senior staff.

Durif-Bruckert et al. (2014) found that patients create a partnership with their physician for the management of their FM. Sometimes this is done through educating their physician due to concerns that they are ignorant regarding what medication and treatment to prescribe. They also discussed the need to ask carefully selected questions regarding their medication and condition

because they sometimes had doubts regarding their physician's knowledge. Unfortunately, in some situations this can clearly lead to practitioners feeling doubted and challenged. These ruptures in the clinician-patient relationship can also be attributed to a mismatch in expectations especially relating to issues of power.

Several studies reported that some physicians, including whole practices, had made the decision not to diagnose people with CFS/ME due to beliefs around its existence. This means that some people visiting these practices may be unsatisfied with the lack of a diagnosis and seek treatment elsewhere, however this could mean further delay and stress while waiting for relevant investigations to be arranged, and a cost to healthcare services. Some people may stay with the practice but remain undiagnosed, possibly leading to their experiencing distress and reduced HRQOL. It is thus imperative that attitudes to the conditions are improved in order to reduce the stigma so that physicians and other professionals find it acceptable to diagnose this condition, rather than denying its existence.

People living with FM frequently report difficulties with medical staff (Cunningham & Jillings, 2006; Sallinen et al., 2011) as do those living with CFS/ME (Thomas & Smith, 2005), but it is clear that professionals are also having difficulties in these consultations and thus need support.

Several training needs are apparent from the results of the present study. Because of the reluctance of some professionals to receive any relevant training (e.g. Chew-Graham et al. 2009; Stenhoff et al., 2015), any future educational packages should identify particular benefits to the practitioners themselves, e.g. to improve relationships, reduce numbers of consultations and reduce financial costs to health services due to unnecessary investigations (Skaer, 2014) and decrease diagnosis times. More importantly, this could reduce the amount of psycho-emotional disablism experienced by those attending consultations, in turn leading to reduced distress and improved outcomes (Stewart et al., 2000). Good communication, including communication regarding diagnosis and management should be emphasised. Training should be offered to senior staff as it seems that

their opinions are well-respected and influential, so a more sympathetic view of the conditions would be passed down to those with less experience, in turn reducing the negative attitudes experienced by individuals in the form of psycho-emotional disablism. Because many professionals highlighted the lack of time they had, any educational packages should be short and delivered with the least amount of disruption to the practitioners' daily schedules. O'Riordan, Dahinden, Akturk, & Thesen (2011) offer suggestions regarding managing the uncertainty that working with individuals with ambiguous symptoms such as CFS/ME and FM can cause. These include building up relationships with the service user as well as increasing shared decision making during the consultation.

It may be initially perceived that the smaller number of studies regarding attitudes toward FM results from it being viewed as less contentious in reputation or less problematic to manage than CFS/ME, thus requiring less research in this area. However the results of this review suggest that similarly negative attitudes exist around both conditions, as well as the management of them. This means that the inclusion of the data regarding FM is important as the results highlight the need for increased support for staff working with this population in order to improve the care they deliver to this population. Reasons for the difference in numbers of studies for FM and CFS/ME are unclear however there is a prolific team of researchers specifically investigating health professionals' attitudes towards, and ways of working with CFS/ME (i.e. Chew-Graham et al.). However there does not appear to be any equivalent team advocating for better healthcare for those living with FM. This in itself is indicative of the way that FM is often perceived.

Conclusion

The findings of this study highlight the fact that many healthcare professionals feel unconfident when diagnosing and recommending management plans for people living with CFS/ME or FM. In addition, some hold negative views about the conditions themselves as well as their existence, and perhaps more importantly towards those living with them. Despite this, there were

many positive views held, and good communication and empathy were viewed by many to be an

essential part of management. What is also clear is that many professionals' knowledge of the

conditions is very sparse and they would benefit greatly from training that focuses on awareness of

the conditions and the importance of diagnosis. Moreover, any training that is offered to healthcare

professionals should take into account the heavy workloads and time constraints that affect the

professionals.

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* Denotes synthesised study

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Appendix A

No of records identified through database search: n= 1646

No of full text articles assessed in more detail for eligibility:
n = 42

No of full-text articles excluded with reasons: N=33

Quantitative study: n=14

Mixed methods study: n=2

Not English language: n=2

Same cohort as earlier study: n=2

Other professionals: n=1

Clients/ service users: n=8

Not research study: n=2

Insufficient data: n=1

Not meeting quality appraisal standard: n=1

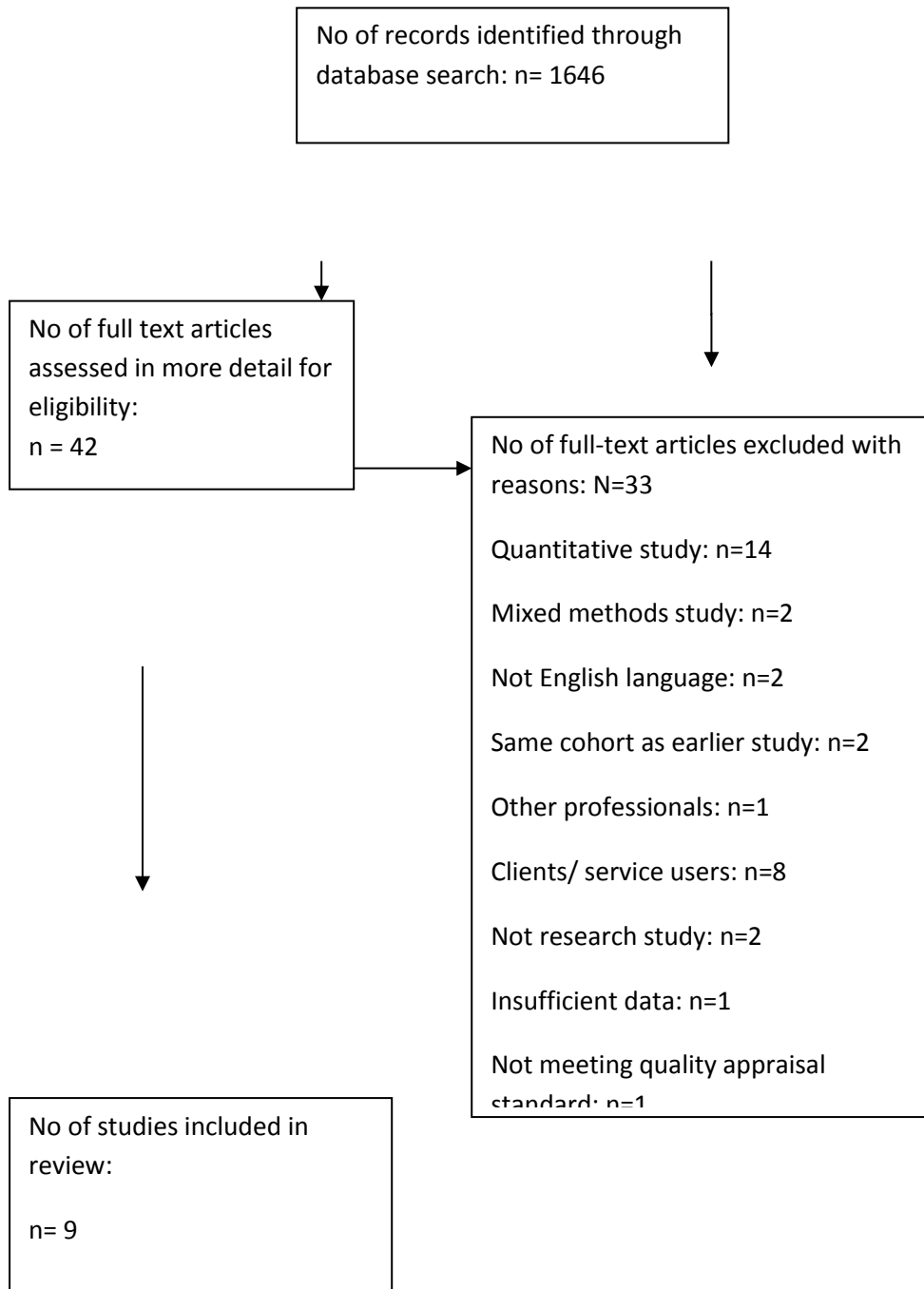No of studies included in review:

n= 9

Figure 1. Flowchart of study selection.

Appendix B

Search terms used to identify papers

Search terms for qualitative papers:

["Qualitative" OR "Interpretative Phenomenological Analysis" OR "IPA" OR "Narrative" OR "Content analysis" OR "Grounded theory" OR "Semi structured interview" OR "Thematic" OR "Hermeneutic"]

Search terms for conditions:

["Chronic Fatigue Syndrome" OR "CFS" OR "Myalgic Encephalopathy" OR "Myalgic Encephalomyelitis" OR "ME" OR "Post Viral Fatigue Syndrome" OR "Fibromyalgia" OR "Fibromyalgia Syndrome" OR "FM" OR "FMS"]

Search terms for perspectives:

["Perspective*" OR "Attitude*" OR "Belief*"]

Search terms for health care professionals:

["Medic" OR "Doctor" OR "Physician" OR "Family practice" OR General practitioner" OR "GP" OR "Nurse" OR "Therapist" OR "Primary Care" OR "Service" OR "Student" "Practitioner" OR "Professional" OR "Healthcare professional"

Table 1
Study Characteristics

Authors, (year), country	N Profession	Condition(s)	Recruitment	Research aim(s)/ questions(s)	Method, analysis
Asbring & Närvänen (2003), Sweden	26 Physicians	Fibromyalgia (13) CFS (13)	Details of physicians were obtained via a patient study.	*How physicians view & categorise patients* *What does CFS/ FMS mean to physicians* *Which strategies do physicians use with these patients?*	*Semi-structured interviews, grounded theory*
Briones-Vozmediano et al. (2013) Spain	9 Health professionals	FMS	Snowball sampling	*To explore three aspects of FMS management- diagnostic approach, therapeutic management and professional-patient relationship*	Discourse analysis
Chew-Graham et al. (2009), UK	29 Practice nurses	CFS	Purposive sampling sent letter	*Explore beliefs about CFS/ME* *Understand their views on their role re management of condition.* Identify any training needs	*Semi-structured interviews, iterative approach.*
Chew-Graham et al. (2010), UK	46 GPs	CFS	Purposive sampling	*Explore GP's beliefs about value of label CFS* *Implications of the diagnosis* *Attitudes toward patients*	*Semi-structured interviews*
Hannon et	18	CFS	Purposive sampling	*Develop education and training*	Thematic

Authors, year, country	N Profession	Condition(s)	Recruitment	Research aim(s)/ question(s)	Method, analysis
al. (2012). UK	9 GPs 5 Practice nurses 4 CFS/ME specialists			*packages to support practitioners in making an early diagnosis of CFS/ME*	
Hellstrom et al. (1998), Sweden	20 10 rheumatologists 10 GPs	FMS	Purposive sampling	Identify their understanding of the phenomenon of FM as well as their relationship to patients	Phenomenological study
Horton et al (2010), UK	6 Healthcare providers	CFS	Practitioners identified by patients as having given particularly effective care	Explore nature of professional best practice	*Semi-structured interviews*, thematic analysis
Raine et al. (2004) UK	46 GPs	CFS (IBS as comparison)	Randomly selected via national GP database	Compare GPs' beliefs about CFS/ME and IBS to explain differences in conditions, to explore implications of their perceptions for the use of psychological treatments	Facilitated group discussion involving case scenarios of patients with CFS/ME or IBS. Grounded theory

Thematic analysis incorporating aspects of grounded theory |
| Stenhoff et al. (2015), UK | 21 Medical students | CFS/ME | Purposive sampling at one university | Investigate medical students' beliefs, attitudes and knowledge of CFS/ME | |

Key: CFS: Chronic fatigue syndrome; FMS: Fibromyalgia syndrome; GP: General practitioner; IBS: Irritable bowel syndrome

Appendix D

Study	Research design	Recruitment strategy	Data collection	Researcher influence	Ethical issues	Data analysis	Findings	Value of research	Total score
Asbring & Närvänen (2003)	2	3	3	2	1	2	2	3	18
Briones-Vozmediano et al. (2013)	3	2	3	1	2	2	3	3	19
Chew-Graham et al. (2009)	3	3	3	1	2	3	2	3	20
Chew-Graham et al. (2010)	2	3	3	1	2	3	3	2	19
Hannon et al. (2012)	2	2	3	1	1	3	3	3	18
Hellstrom et al. (1998)	3	3	3	2	1	2	2	2	18
Horton et al (2010)	3	2	3	1	1	3	2	3	18
Raine et al. (2004)	3	3	3	1	1	3	3	3	20
Stenhoff et al. (2015)	3	2	3	1	1	3	3	3	19

Table 2. CASP quality appraisal table

Appendix E

Translation of the studies

Table 3.

Study	Knowledge	Management	Stigma and stereotyping
			Stereotypes of people Existence of condition
	Groping in the dark Illness beliefs Training	Ideal management Challenges of management Usefulness of diagnosis	
Asbring & Närvänen (2003)	✓	✓	✓
Briones-Vozmediano et al. (2013)	✓	✓	–
Chew-Graham et al. (2009)	✓	✓	✓
Chew-Graham et al. (2010)	✓	✓	✓
Hannon et al. (2012)	✓	✓	✓
Hellstrom et al. (1998)	✓	✓	✓
Horton et al (2010)	✓	✓	✓

Raine et al. (2004)	✓	✓	✓
Stenhoff et al. (2015)	✓	✓	✓

Appendix F

Table 4

Translation of current themes

Theme	Study 1	Study 2	Study 3	Study 4	Study 5	Study 6	Study 7	Study 8	Study 9
Groping in the dark	Feeling incompetent,	Not knowing what is	Limited experience,	Feeling unconfident in	Feeling unsure how to help	Not feeling in control	*Feelings of*	*Feeling*	*Feeling*

	helpless	happening/ what to do	uncertain how condition presented	making diagnosis	patients		*inadequacy*	*hopeless, 'groping in the dark'*	*intimidated by presentation of patient*
Illness beliefs	CFS/ME and FM are illnesses not diseases	-	Incoherent illness beliefs	Somatic presentation of psychological coondition	Unaware of evidence base/ psychological condition/ 'secondary' gain	Reluctant to admit FM is a biomedical anomaly	*CFS/ME is serious condition/ affects quality of life*	Difficult to conceptualise	Not a serious illness/ a frustrating condition
Training	Physicians pointed out gaps in medical training. Lack of supervision	-	Received very little training, some would like more, but doubts over workload	Training does not prepare doctors for diagnosing and managing CFS/ ME in line with current guidelines.	There is a training need in primary care, however many hesitant to prioritise	Trained from a biomedical perspective leading to them separating symptoms from patient	*Other professionals do not understand condition*	-	*Not included in curriculum, knowledge passed on from senior doctors*
Ideal management	Help patients to accept situation	Management should be individualised	Best placed in primary care	Referrals to secondary care could be useful	Printed information and DVDs should be available for patients	Good communication, empathy, listening	Enable patients to adjust to diagnosis, provide holistic and flexible support	Many conflicts with patients over ideal management. Psychological interventions could be useful	Some described psychological interventions could be helpful
Challenges of management	Poor prognosis, unsure whether they	Successof tratments not guaranteed	Not confident of their own expertise	Effort goes unrecognised, difficult to manage as no	Difficulties with referral to secondary care due to	Doctors had difficulty managing clinical	Severe forms and long-term forms of condition	Some physicians saw the condition as the defining	Participants felt overwhelmed

	were best to treat patients			cure	fragmented services	uncertainty	difficult to manage and are frustrating	feature of patient	and struggled to view condition as real
Usefulness of diagnosis	FM diagnosis more useful than CFS/ME diagnosis	Helps patient to feel legitimised	Generally useful for patient and service	Initially helpful but this is short-lived	A positively framed diagnosis maintains hope and thus affects management	A diagnosis gives access to specialist services	May be overwhelming so patient needs support to come to terms with diagnosis	-	Frustrations due to not fitting biomedical model
Stereotypes of individuals	Illness-fixated, troublesome, pessimistic	-	Patients with CFS/ME more difficult than other conditions, lazy	Passive people who have given up	Using the condition to avoid working	Deviant personalities	Depressed, 'all in the mind'	Transgressing work ethic/ lacking stoicism, adversarial	Lazy, 'whiny'
Existence of Condition	Doubts over severity of condition, queries around whether symptoms were being exaggerated.	Acknowledged existence but difficult to diagnose	Doubts over existence	Doubts over existence	Some questioned whether CFS/ME was a legitimate illness, usually due to lack of knowledge.	-	Other practitioners often deny existence	*Deligitimisation of condition*	Doubts over existence

Appendix G

Guidelines for submission to *Health Psychology* Journal

Information About Submissions

The page limit for research manuscripts is 25–30 pages. The page limit is inclusive of **all** parts of the manuscript, including the cover page, abstract, text, references, tables and figures.

Authors may request consideration of longer papers, in advance of submission, when there is clear justification for additional length (e.g., the paper reports on two or more studies or has an unusual or complex methodology). Scholarly reviews and meta-analyses should not exceed 25 pages, but tables and references may be outside this page limit.

Brief reports are encouraged for innovative work that may be premature for publication as a full research report because of small sample size, novel methodologies, etc. Brief reports should be designated as such and should not exceed a total of 12 pages, inclusive of **all** parts of the manuscript, including the cover page, abstract, text, references, tables and figures.

All manuscripts should be double-spaced, with margins of at least 1 inch on all sides and a standard font (e.g., Times New Roman) of 12 points (no smaller).

On the submission portal you will be asked to provide contact information for three individuals who are qualified to serve as unbiased reviewers for your paper. These people must have published peer reviewed work in a relevant field. They must be without any real or perceived conflict of interest with you and your co-authors. They cannot be at the same institution as any author, cannot be a co-author on any publications, and must not be a former or current trainee, advisor or mentor, etc.

Health Psychology considers letters concerning previously published articles. Letters should be no more than 500 words and have a maximum of five references.

Authors also have the option of placing supplemental materials online.

Submissions that exceed the page limits will be returned to the author for shortening prior to the initiation of peer review.

Submission Letter

The cover letter should indicate that the authors have read and followed the *Health Psychology* Instructions for Authors. It should also include a statement indicating that the paper has been seen and approved by all authors. The cover letter should describe how the paper advances research in health psychology, referring to the journal mission to assure that the submission fits with the types of papers published in *Health Psychology*.

The full mailing address, telephone, fax, and email address for the corresponding author should be included in the cover letter and title page, along with the names and affiliations of all co-authors.

The cover letter must confirm that the manuscript has not been published, is not currently submitted elsewhere, and that it does not contain data that is currently submitted or published elsewhere.

When a manuscript contains data that is part of a larger study, authors should describe the larger study and provide references for other study papers. Authors must be prepared to provide copies of related manuscripts when requested as part of the editorial review process. Authors should clarify the relationship between their paper, including detailed specification of the overlap in participants, measures, and analysis, and others from the study. The value-added scientific contribution of their study must be clearly stated in the cover letter.

Authors of brief reports should indicate in the cover letter that the full report is not under consideration for publication elsewhere and similarly address potential overlap with other papers.

Manuscripts

The manuscript title should be accurate, fully explanatory, and no longer than 12 words. The title should reflect the content and population studied. If the paper reports a randomized clinical trial, this should be indicated in the title. The title of brief reports should start with the words "Brief Report".

The title page should include the names of all authors and their affiliations at the time the research was done. This information will be masked to ensure a blind peer review process by the editorial office. Authors should make sure that all other identifying information in the text of the paper is masked/removed prior to submission.

All manuscripts must include a structured abstract containing a maximum of 250 words with the following sections:

- Objective (brief statement of the purpose of the study);
- Methods (summary of the participants, design, measures, procedure);
- Results (primary findings); and
- Conclusions (specific statement of the implications of the data).
  Please supply up to five keywords or brief phrases after the abstract. The Introduction should not exceed 3–4 pages in length. The paper should be referenced appropriately but excessive citations should be avoided.

  All research involving human participants must describe oversight of the research process by the relevant Institutional Review Boards and should describe consent and assent procedures briefly in the Methods section. All statistical tests should include effect size whenever possible.

  First person language ("I", "we") should be avoided. Terminology should be sensitive to the individual who has a disease or disability. The journal endorses the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of people with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

  It is important to highlight the significance and novel contribution of the work. The translation of research into practice must be evidenced in all manuscripts. Authors should incorporate a meaningful discussion of the clinical and/or policy implications of their work throughout the manuscript, rather than simply providing a separate section for this material.

  Health Psychology publishes a broad array of types of papers. Authors of qualitative and measure development papers should read the guidelines for these types of papers, noted below.

Qualitative Research

Research papers that utilize qualitative methods should follow the general instructions to authors for style and format. We ask that authors of qualitative papers review the additional guidance below to assure that papers meet the following criteria utilized by *Health Psychology*.

The introduction should make a compelling case for the significance of the study and clearly identify if the study is a stand-alone study or if it fits into a larger study. For example, qualitative manuscripts may inform the development of a survey, use small-incident samples, or establish feasibility. The specific qualitative paradigm should be specified (e.g., grounded theory, qualitative descriptive approach, interpretive phenomenology) with a rationale as to why it was selected to address the research question.

At the same time, authors are encouraged to avoid methodological tutorials and cite appropriate references for the methodology. Describe your sampling frame clearly and how the sample was selected, justifying the type and size of your sample using appropriate language for qualitative studies.

While many qualitative studies may not use a conceptual model, if you have done so, explain how the model may have shaped the design, data collection, analysis and interpretation. Explain carefully how you strengthened and insured rigor in your study e.g., data analysis protocols (including how coders were trained), audit procedures, and demonstration of data saturation. Describe the data analysis and how it relates to your overall approach or paradigm. Present rich and compelling results with data that have been analyzed and interpreted appropriately for your method (e.g., discourse analytic results would be presented differently than those of a grounded theory). The paper should convey how this research fills an important gap in the science and promises to change the way we approach future studies.

Scale Development

Empirical papers related to the development of new instruments related to health psychology should follow the general guidelines for style and format of this journal. Authors should make a convincing case for the need and rationale for the new instrument, particularly with respect to new and innovative constructs. Included in this rationale should be the theoretical foundation on which their new instrument rests along with presentation of other, related scales currently in use.

It is important that the research have a degree of generalizability across populations and settings. Instruments that are more narrow in scope or of limited clinical utility may be better suited for subspeciality journals.

Authors should clearly articulate the specifics of the study design and of the analytical techniques used. There should be strong consistency among the purpose statements, methods, and the manner in which findings are presented.

An increasing number of studies are incorporating mixed-methods designs in their research. The specifics of these designs should be equally well-detailed without being excessive. Attention should be given to the nature of the items, the basis for their creation, and the rationale for the response options.

The underlying theoretical structure of the approach should be evident, for example, whether one is premising their study on classical or modern theory (IRT, Rasch) techniques. The characteristics of the research will be in

part dictated by the nature of the scale. For instance, large, nationally-normed tests may have a much different make-up than that of small, more narrowly-defined measures. Research involving both types of instruments will be considered.

Finally, all instrument development papers should convey how the literature base will be strengthened with the addition of the particular instrument along with a clear and convincing case for the clinical relevance of the information that it provides.

Letters to the Editor

Health Psychology will, at the discretion of the Editor-in-Chief, publish Letters to the Editor on the journal website. Letters should be prepared in direct response to articles published in the journal, should include reference to the published paper in the letter, and should be sent to the Editorial Manuscript Coordinator, Lindsay MacMurray within 60 days of the date when the relevant article is published in hard copy.

The text of the letter, excluding the title, references and author(s) name, title, affiliation and email, may not exceed 400 words.

In a separate cover letter, the author should indicate that the submission is a Letter to the Editor for consideration of posting on the *Health Psychology* website and provide the full citation of the original article to which the letter refers. The cover letter should also indicate if the letter writer(s) have any conflicts of interest related to the article or correspondence.

Note: Letters will not be a forum for ongoing dialogue.

Masked Review Policy

Masked review is used. **Do not** include author information (addresses, phone numbers, electronic mail addresses, and fax numbers) in the manuscript.

Please ensure that the final version for production includes a byline and full author note for typesetting.

Use of CONSORT Reporting Standards

All randomized controlled trials must include a diagram indicating participant flow into the study and a completed CONSORT checklist. CONSORT diagrams (and adaptations) should be included whenever possible to clarify the flow of participants through a study.

Manuscript Preparation

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th edition). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the *Publication Manual*).

Review APA's Checklist for Manuscript Submission before submitting your article.

Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the *Manual*. Additional guidance on APA Style is available on the APA Style website.

Below are additional instructions regarding the preparation of display equations, computer code, and tables.

Display Equations

We strongly encourage you to use MathType (third-party software) or Equation Editor 3.0 (built into pre-2007 versions of Word) to construct your equations, rather than the equation support that is built into Word 2007 and Word 2010. Equations composed with the built-in Word 2007/Word 2010 equation support are converted to low-resolution graphics when they enter the production process and must be rekeyed by the typesetter, which may introduce errors.

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- Go to the Text section of the Insert tab and select Object.
- Select MathType or Equation Editor 3.0 in the drop-down menu.

If you have an equation that has already been produced using Microsoft Word 2007 or 2010 and you have access to the full version of MathType 6.5 or later, you can convert this equation to MathType by clicking on MathType Insert Equation. Copy the equation from Microsoft Word and paste it into the MathType box. Verify that your equation is correct, click File, and then click Update. Your equation has now been inserted into your Word file as a MathType Equation.

Use Equation Editor 3.0 or MathType only for equations or for formulas that cannot be produced as Word text using the Times or Symbol font.

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Because altering computer code in any way (e.g., indents, line spacing, line breaks, page breaks) during the typesetting process could alter its meaning, we treat computer code differently from the rest of your article in our production process. To that end, we request separate files for computer code.

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Tables

Use Word's Insert Table function when you create tables. Using spaces or tabs in your table will create problems when the table is typeset and may result in errors.

Section Two: Research Paper

Living with Chronic Fatigue Syndrome: a Social Model of Disability Perspective

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Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Word count: 7984 (excluding references and appendices)

Prepared for submission to Psychology and Health

Abstract

Objective: Clinical psychologists and other health professionals working with people with physical impairments are often accused of neglecting issues relating to disability and impairment. The experiences of people living with chronic fatigue syndrome / myalgic encephalomyelitis (CFS/ME)

were explored from a social model of disability perspective (with a focus on psycho-emotional disablism) in order to gain a deeper insight into some of the difficulties and discrimination faced.

Design: Qualitative methodology employing thematic analysis.

Methods: Interviews were conducted with 12 participants living with CFS/ME. Transcripts were analysed using thematic analysis.

Results: Three themes were identified: "Fighting to be heard", Lack of legitimacy", and "Feeling invisible". Negative attitudes towards people living with CFS/ME resulted in significant amounts of psychological distress for the participants interviewed.

Conclusions: Participants described the discrimination and stigma that they had encountered from many areas of society as being as disabling as the condition itself. Recommendations for practice and ideas for future research are proposed.

Keywords: chronic fatigue syndrome/ myalgic encephalomyelitis, psycho-emotional disablism, narrative analysis, social model of disability

Living with Chronic Fatigue Syndrome: a Social Model of Disability Perspective

Clinical psychology has frequently been criticised for neglecting issues relating to disability and people with physical impairments. These criticisms have often originated from those within the field of disability studies (Goodley & Lawthom, 2006; Olkin & Pledger, 2003; Watermeyer, 2013). There appear to be several reasons for these criticisms. Firstly, psychology in general has been accused of being overly concerned with difference between people and the subsequent pathologising of these differences (Goodley & Lawthom, 2006; Hernandez-Saca & Cannon, 2016). For example, "abnormal" psychology, the study of behaviour which is supposedly markedly different from normal behaviour, is still taught in many undergraduate psychology degrees both in the UK and more globally. Similarly, it has been commonplace for clinical psychologists working with people with physical impairments to be concerned primarily with rehabilitation, e.g. in areas such as stroke and brain injury (Olkin & Pledger, 2003). However, the rehabilitation model of disability locates the "problem" of disability in the individual with an impairment and their disability is thus viewed as a deviance from the norm (Mona, Cameron, & Fuentes, 2005; Olkin & Pledger, 2003). Furthermore, when conceptualising

disability and impairment, psychology has traditionally focused on loss and grief models to explain how an individual lives with impairment (Mona et al., 2005; Reeve, 2006). This means that there is often an assumption that psychological distress and depression will occur as a result of living with an impairment (Reeve, 2004) and that grieving this impairment is a certainty.

This viewpoint appears to be perpetuated due to a lack of disability theory in psychology training and a lack of consideration given to contextual issues relating to impairment and disability (Watermeyer, 2013). Clinical psychologists, as well as those in training, are required to consider issues of diversity and context when working with clients and when formulating their difficulties (British Psychological Society, 2011). However it can be argued that other protected characteristics are given more consideration than individuals living with impairments. For example, clinical psychology trainees took part in a survey on diversity in the USA. When respondents were asked to name terms related to diversity, disability ranked fourth from the bottom (being named by 14%) with ethnicity, race and culture being named significantly (and disproportionately) more frequently by respondents (Green, Callands, Radcliffe, Luebbe, & Klonoff, 2009). This suggests that trainees are more focused on other populations when defining diversity and are thus not taking into account contextual issues related to disability when working with this population. This is perhaps due to a combination of lack of coverage in the curriculum as well as the low numbers of people who identify as having a disability working in the profession (Watermeyer, 2013). This means that there are few individuals working within this field who have lived experience of having a physical impairment and thus negative attitudes regarding loss and difference continue through ignorance and lack of exposure to common difficulties experienced by people with impairments.

Psychology and disability studies have therefore occupied very different viewpoints and have had a difficult history (Goodley & Lawthom, 2006). In order to address this difficult relationship, Simpson and Thomas (2015) have suggested that the two fields can share common ground from the viewpoint of psycho-emotional disablism. This term originates from the social model of disability (Oliver, 1990). The social model of disability contends that it is the structural deficiencies as well as disablist attitudes of society, and the consequent exclusion of people with impairments, which actively disables people, rather than the impairment itself. However, critics of the model have argued that it fails to take into account the subjective experience of the individual (Marks, 1999), thus failing to acknowledge the impact that the impairment itself can have on a person (Shakespeare, 2010). In addition, its focus on structural barriers is seen to be a further weakness as this means that those barriers more commonly experienced by women regarding care responsibilities and roles within the home, for example, are neglected (Thomas, 1999).

Because of these criticisms, a social relational definition of disability was proposed by Thomas (1999; 2007). This views disability as a form of social oppression and describes how, in addition to the structural elements of disability, impairment effects such as pain and fatigue are also factors. A further aspect introduced by Thomas within this model is the term psycho-emotional disablism. This refers to both the social barriers which can lead to the individual being hurt by other people's reactions and behaviour, such as staring or making negative comments, known as direct psycho-emotional disablism (Reeve, 2014). Over time, this can be seen as internalised oppression, in which the individual will decide not to apply for a particular job because of a reluctance to deal with potentially negative attitudes to the individual's impairment, or to decline social invitations due to the negative behaviour of others, thus isolating themselves.

In order to explore how psycho-emotional disablism affects people living with impairments, the example of chronic fatigue syndrome/ myalgic encephalomyelitis (CFS/ME) will be used to illustrate this issue. CFS/ ME is a life-disrupting long term condition which is characterised by extreme fatigue that is not alleviated by rest (Bayliss et al., 2014). The condition has continually attracted debate over a suitable name. This difficulty has arisen because its aetiology and pathology remain unknown (Institute of Medicine [IOM], 2015). The name chronic fatigue syndrome has been attacked by campaign groups and many people living with the condition as one that is trivialising and stigmatising. Many campaigners prefer the term ME, which means inflammation of the brain and spinal cord; however, there is inconclusive evidence of this inflammation (Jason & Richman, 2008). People who live with CFS/ME can experience other difficulties such as pain and weakness in the muscles, memory and concentration difficulties (Evengård, Schacterle, & Komaroff, 1999), and sore throats and headaches (Burgess & Chalder, 2005); because of this, in the USA, the IOM has asserted that the name 'chronic fatigue syndrome' perpetuates misunderstanding of the illness. This organisation has therefore proposed that a new name, 'systemic exertion intolerance disease' (SEID), and new diagnostic criteria should be adopted in order to describe more accurately the condition and to be accepted by both those in the medical professions and the general public (IOM, 2015; Jason et al., 2015). However the condition is often more commonly referred to as CFS/ME which is seen as a compromise, and thus will be referred to as such within this paper.

Despite research in many areas such as immunology, exercise, sleep and viral studies, the aetiology of CFS/ME remains unknown (Afari & Buchwald, 2003; Komaroff & Buchwald, 1998) and there is currently no cure; treatment is therefore based on symptom management (Drachler et al., 2009). CFS/ME is diagnosed clinically after all other possible conditions have been excluded (Fukuda et al., 1994). Moreover, the individual often has to endure a series of tests in order to obtain a diagnosis, with the average time taken to obtain a diagnosis estimated at 3.7 years (Wearden et al., 2010).

A further significant factor affecting the understanding of the condition appears to be its legitimacy (Horton-Salway, 2007; Mountstephen & Sharpe, 1997; Thomas & Smith, 2005). Some of the debate can be traced to an event half a century ago when it was hypothesised by physicians at a UK hospital that some patients there had contracted the illness after an epidemic of what was suspected to be poliomyelitis (anon, 1957). In response, psychiatrists McEvedy and Beard suggested in two influential articles that the symptoms experienced by these patients could be due to 'mass hysteria on the part of the patients' (1970b, p11). The explicit suggestion was that one of the factors contributing to the hysteria was the majority of the patients were female (McEvedy & Beard, 1970a). Perhaps surprisingly, this theory was perpetuated decades later by Showalter (1998). Moreover, the condition continued to be dismissed into the 1980s, with it often being referred to as "yuppie 'flu" (Winslow, 1990, p1). It has been controversially viewed by some as having a mainly psychological component (Sharpe, Chalder, Palmer, & Wessely, 1997). Although now recognised as a genuine neurological condition (UK Department of Health, 2002), there is still some disquiet about CFS/ME, with the view that the condition is 'all in the mind' still being reported to be held by some (Couper, 2000; Horton et. al, 2010). In fact, some health professionals still question its legitimacy (Chew-Graham, Dowrick, Wearden, Richardson, & Peters, 2010; Hannon et al., 2012; Horton et al., 2010). It has been hypothesised that this focus away from biological causes is due to a historical tendency to attribute psychological factors to illnesses predominantly affecting women (Hamilton, 1994), as is the case with CFS/ME.

It is thus unsurprising, given the mostly negative discourses relating to the condition, that people living with CFS/ME have reported discrimination and lack of understanding from members of society, in particular health professionals and family members (Åsbring & Närvänen, 2002; Hannon et al., 2012; Lee, Rodin, Devins, & Weiss, 2001; Ong, Evans, & Bartlam, 2005; Whitehead, 2006). According to Anderson and Ferrans (1997), 95% of the 22 people living with CFS/ME whom they interviewed had been hurt by negative comments from friends regarding the condition. Moreover, studies have reported lower quality of life (QOL) in people living with CFS/ME compared to the general population and people experiencing mental health difficulties (Hardt et al., 2001), with reductions in social support and the loss of friendships and relationships contributing to this reduction in QOL (Anderson & Ferrans 1997). Indeed, insufficient social support and negative interactions encountered by people living with CFS/ME have been reported to be further disabling factors (Prins et al., 2004). Furthermore, several factors have been found to be influential on a person's experience of living with a long term condition, some of which result from external interactions and so these negative interactions can have profound and long lasting effects on individuals with CFS/ME. For example, Leventhal's self-regulation model of illness (Leventhal, 1980; Moss-Morris, Petrie, & Weinman, 1996) describes the process by which individuals seek to make sense of their illness including its cause, symptoms and duration. This understanding not only arises from physical experience of symptoms but also extends to social factors including interaction with family, friends and health professionals. Therefore, how an individual is perceived and treated by others affects how positively or negatively they themselves view their condition and this influences the coping strategies they use to manage their illness. For example, seeking emotional support as well as positive reinterpretation of the condition has been found to have a positive effect on the psychological well-being of individuals with CFS/ME (Moss-Morris et al., 1996). In addition, believing that living with CFS/ME has serious consequences also leads to greater distress.

This perspective from which to view the experiences of people living with CFS/ME seems particularly relevant given the discrimination, lack of empathy (Dumit, 2006) and low levels of social support experienced by this population (Prins et al., 2004).

Aims and rationale of the study

Given that CFS/ME remains a controversial illness with its name, cause, legitimacy and diagnostic criteria still being discussed in an attempt to gain appropriate recognition, research into the impact that living with this poorly understood condition is still as relevant now as when it was first debated. Previous qualitative research in this area has focused on issues such as the specific illness experience of living with CFS/ME (Åsbring, 2001; Travers & Lawler, 2008; Whitehead, 2006), couples' and family perspectives (Blazquez & Alegre, 2013; Lingard & Court, 2014) and experiences of healthcare providers (Hannon et al., 2012) with limited attention specifically paid to stigma and discrimination as a result of societal attitudes (Åsbring & Närvänen, 2002).

Clinical psychologists often work with people with long term conditions such as CFS/ME to support them with psychological difficulties such as anxiety, depression or panic however it has been established that psychologists may not be fully aware of the contextual issues that face people living with impairments (Watermeyer, 2013). It is therefore important that clinicians understand the ways in which this group may experience discrimination and psychological distress as a result of others'

actions and attitudes. It is important to understand the extent that society– and psychologists themselves - play in causing and maintaining the distress they may be experiencing. It is also essential that health professionals have an in-depth understanding of how psycho-emotional disablism, whether intentional or unintentional, can have an impact on their clients' wellbeing.

Consequently, the aim of this study was to explore the lived experience of CFS/ME, with a particular focus on the psycho-emotional disablism that participants may experience. A qualitative approach was selected in order to allow participants the opportunity to describe their experiences in their own words. In particular, the data were analysed using thematic analysis (TA). TA is a systematic process of identifying themes or patterns in the data and is best suited to elucidating the specific nature of a given group's conceptualization of the phenomenon under study (Joffe, 2012). This method has been used to investigate young people's beliefs about CFS/ME (Hareide, Finset, & Wyller, 2011) as well as the social support needs of those living with CFS/ME (De Carvalho Leite et al., 2011).

The present research investigated how the attitudes in general of people in contact with the participants (e.g. family members, friends and acquaintances), as well as society (e.g. health services, government, popular culture and media) impact on the self-worth of the participants interviewed. Participants were recruited through support groups and interviewed regarding their experiences. The research question developed to guide the study was: "In what ways have people living with CFS/ME experienced psycho-emotional disablism?"

Method

Design

The study used a qualitative methodology. Individual interviews were considered to be the most appropriate form of data collection compared to other methods such as focus groups. Outspoken members of focus groups can dominate the group discussion (Leung & Savithiri, 2009), thus stopping quieter members from telling their stories. Interviews offer the opportunity for people to tell their story focusing on ideas and events that are important to them.

Participants

Eight women and four men living in the North-West of England were interviewed between October 2015 and January 2016. The inclusion criteria were that participants must be English speaking adults who had lived with a diagnosis of CFS/ME for at least one year. The diagnosis was self-reported. The only exclusion criterion was the presence of an unrelated, acute, significant illness, such as cancer, which would require invasive medical treatment, surgery or multiple hospital stays or appointments meaning that the illness or condition would have a significant impact on the participants' psychological or physical wellbeing and thus their ability to take part. No potential participants were excluded on this basis. Demographic information relating to participants can be found in Table 1.

Insert Table 1

Procedure

Recruitment literature was shown to a member of the university service user network, who suggested some changes to the recruitment poster in order to make it more appealing to prospective participants. Following this change, university ethical approval was obtained (section four), and following this, organisers of regional CFS/ME support groups in the north-west of England were approached by the lead researcher to ask permission to address directly members of these groups to inform them of the current study. In addition, some support groups emailed their members with details of the study, and interested people were sent the participant information sheet. The study was also published in the newsletters of two regional support groups, with contact details supplied. Interested participants then contacted the lead researcher via telephone or email to express their interest. Organisers of the support groups were not told who had participated and were not given any information regarding numbers of people expressing an interest in the research. The participant information sheet was supplied as well as additional information regarding the logistics of the study. At least a week elapsed between sending participant information and booking the interviews, to allow potential participants sufficient time to consider their involvement in the study. The support groups were contacted in two phases, approximately one month apart. A purposive sampling technique was employed.

Interviews were scheduled to take place at a time and place convenient to the participant, and all interviews were conducted during normal working hours. Eleven interviews were conducted in participants' homes and one in a public house, in a suitably private area chosen by the interviewee. The lone worker policies for the lead researcher's employing organisation, as well as that from the lead researcher's host academic institution, were followed.

Participants had the option to cancel or rearrange interviews, and contact was made with them either the night before or on the same day to give them the option to do so. This was done so that participants did not feel obliged to take part even if they were not feeling well or alert enough on the day. Several participants did cancel or rearrange due to feeling unwell or too fatigued on the day of the interview.

The interviews were digitally recorded and lasted between 45 minutes and one and a half hours, with a mean duration of 67 minutes. Participants had the option of conducting the interview over more than one sitting or having a break during the interview if they felt that their fatigue or other physical symptoms were impacting on their ability to concentrate, however all interviews were completed in one sitting and without breaks. They also had the option of terminating the interview at any point. A further opportunity to ask questions was provided before the start of the interview. Written informed consent was then gained.

Interviews commenced with a single, opening paragraph aimed at allowing participants to express themselves freely when describing any ways that they had experienced psycho-emotional disablism:

> I am interested in finding out about your personal experience of being diagnosed with and living with Chronic Fatigue Syndrome / ME, and how this has affected your relationships and role in society. Please include in your story any events and experiences that you think are important. Please start wherever you like and take as much time as you need. I will be listening but will not interrupt you.

This method was particularly important given the lack of already published research on psycho-emotional disablism in this population and was designed to gain as rich a dataset as possible.

Following the participant's narration of their story, questions were asked in order to deepen understanding of particular events such as 'what happened after...?' or 'can you tell me a bit more about that time?'

At the end of the interview, the participants were given a debrief sheet with contact details of relevant support services in case of distress during the interview process. The participants were advised that they had the option to withdraw some or all of their data at any point up until the time of analysis. Each interview was then transcribed verbatim by the researcher to an appropriate level of detail. Names and locations were anonymised.

Analysis

Data from the interviews were analysed using thematic analysis (TA). TA is a qualitative method of analysis which identifies meaningful themes and patterns in data (Fereday & Muir-Cochrane, 2008) while preserving depth of analysis (Braun & Clarke, 2006). TA is one of the most systematic and transparent forms of analysis (Joffe, 2012), while also being flexible due to its theoretical freedom and relative independence from epistemology (Braun & Clarke, 2006). There is no standardised approach to TA (Braun & Clarke, 2006) however the six step process outlined by Braun and Clarke (2006) was used a guide to analysing the data.

It is important to consider the researcher's epistemological position when reporting this research. The researcher believes that there is no objective truth, and that interview narratives 'are co-constructed between the participant and the researcher in a particular social, cultural and historical context' (Hunter, 2009, p.44; Madill, Jordan, & Shirley, 2000). Aspects of the researcher's biases, assumptions and personality are always present in research (Sword, 1999). Because of this, in order to enhance trustworthiness in the interpretation of the data, a reflective diary was kept and used at all stages of the process; recruitment, interviewing, transcription and analysis. This enabled the lead researcher to be transparent regarding her own thoughts, preconceptions and attitudes (Robson 1993). Peer supervision was held via a qualitative analysis group which met regularly during the analysis stage, in which thoughts and challenges were discussed, and alternative interpretations were offered. Discussions with both research supervisors were also conducted with similar aims.

Following transcription, summary stories for each participant were created in order to preserve the integrity of individual accounts (appendix A).

Analysis of the data began after all interviews had taken place and transcription of all data had been conducted. Transcripts were read and re-read (Rice & Ezzy, 1999) with the aim of identifying themes relating to the subject matter in hand, psycho-emotional disablism. Coding began by making annotations in the margins of the transcripts and quotes relating to this subject were highlighted and when all transcripts were read, these quotes were entered into a spreadsheet, and were sorted according to subthemes. The final subthemes were condensed into overarching themes. As subthemes and themes were developed they were periodically checked against the initial codes to ensure they preserved the original meaning (Fereday & Muir-Cochrane, 2008). Three overarching themes were found.

Results

The participants' experiences of psycho-emotional disablism were divided into three overarching themes, each comprising of three to four subthemes (Figure 1).

Insert Figure 1

Theme one: fighting to be heard

Subthemes- friends and family, difficulties with health professionals, ignorance in the workplace.

This first theme relates to the participants' initial experiences of becoming ill and the subsequent difficulties in having their illness acknowledged by those around them, particularly when it became clear that their symptoms were not improving. Many participants described difficult encounters with their family doctor regarding obtaining help with the condition and the search for a diagnosis which would explain their difficulties. In some cases, individuals had difficulty persuading their doctor of the severity of their condition: "It was blamed on things like, 'it's your working hours'. I wasn't actually working at the time. It took about a year to get any doctor to take me seriously" (Jenny). Jenny's lengthy fight to be taken seriously by her GP and the subsequent push for a diagnosis meant she then felt she would be reluctant to seek help, should she develop another illness in the future. Several other participants echoed this reluctance to engage with standard health services, now preferring to stay away and instead seek alternative therapies or home remedies for the majority of ailments.

Some participants found their GP - although sympathetic -to be ignorant of their condition, and thus had to weave tactfully their own suggestions regarding the condition into the consultation, without disrupting this relationship. For example, Liam recalled:

> The diagnosis was led by me as well cos I read a book ... and I said, 'look I know I'm not a doctor ... but it's written by a doctor, and it says about these various symptoms, and I've got these symptoms', so I said, 'I wonder, I just wonder...' and she said, 'I was thinking that' - very tactful! [laughter].

Other participants felt that the poor treatment they had received was specifically due to their condition. Several doctors were dismissive of individuals' difficulties and were quick to prescribe anti-depressants which were often rejected: "no, I don't WANT that!" (James).

The second subtheme 'Friends and family', describes similar lack of understanding from friends and family of some of the participants. For example individuals recalled the simplistic advice they were given regarding alleviating themselves of the symptoms they had been experiencing for months, such as going for bike rides, going back to work (Brian, Margaret and Jenny), or changing lifestyle: "...lots of conversations, 'oh just get enough rest, change your diet'. Don't they think I've tried all that?" (Kate). Other participants recalled how friends ignored requests to stay only a short while

when visiting, instead often staying double the time, and thus causing the participants to have to cancel plans the next day due to increased fatigue. This lack of insight into the participants' difficulties caused some to experience distress: "It wracks me with guilt that people are offended" (Lynn).

'Ignorance in the workplace' captured the lack of understanding that participants experienced when returning to work, or when working part-time. A minority of participants (Jenny and Kate) described having supportive employers who made reasonable adjustments to enable them to remain in employment when they were feeling able to return. Unfortunately, many individuals described negative experiences involving colleagues and unsympathetic employers who put pressure on people to return to work. For example, Brian was able to return on reduced hours, but described how people he had known for years did not know how to act around him, and he was eventually moved to a different department, "because I was no longer the old Brian". Ellie described being teased for working part-time, however the social isolation that she had experienced at college as a result of her condition was so great that she also joked along in order to maintain these friendships: "...kind of rolled with it ... it sounds horrible - I probably made it into a bit of a laugh and a joke and stuff and played down actually my condition".

Others felt pressured into returning to work but were unsuccessful and ceased employment on medical grounds: "I was pressured by work to go back, and I tried, tried really hard" (Margaret). For those who were no longer able to work, the end of their working life signified a loss of identity, particularly where they were far from conventional retirement age: "it was just so difficult psychologically being retired at 35, having no friends and no purpose - everybody else was working, that was hard" (Lesley).

Theme two: Lack of legitimacy

Subthemes: Not being believed by others / comparison with other conditions / media representation / benefits system

This theme relates to the doubts expressed by acquaintances, family, and the wider society regarding both the existence of CFS/ME as well as whether participants were actually unwell. On an interpersonal level (the subtheme 'not being believed by others'), participants described being told by friends about others' scepticism regarding their condition; "suchabody doesn't think you've got it" (Sheila). Sometimes, doubts stemmed from acquaintances seeing the participant in question engaging in a pleasurable activity: "cos I went to a party and was able to run a bit, and sort of be ok at the party, she thought I was OK… they don't see you when you get home, you're zonked out" (Liam). In terms of healthcare provision, some doctors openly admitted to not acknowledging the existence of CFS/ME and in extreme cases refused to treat individuals: "I went in and she basically dismissed me and told me that 'I don't wanna deal with this', she didn't wanna deal with my condition!" (Ellie).

Some participants experienced verbal abuse or discrimination when attempting to use disabled facilities such as mobility scooters, disabled parking bays and disabled toilets. Ellie (aged 23) and Pauline both recalled being verbally abused for using and mobility scooters and disabled parking bays - even with the appropriate disabled badge displayed in the vehicle. These participants all went

on to describe how these occasions had severely impacted their desire to go out for fear of further challenges.

For some, the stigma associated with the diagnosis led to them claiming to have another illness, usually multiple sclerosis (MS): "I sometimes say I've got MS because it's almost like people know more about that, they accept that more and I know that's not just me saying that, it's something we've talked about in the [support] group" (Pauline). Ellie saw how a colleague, who was undergoing treatment for cancer at the same time that she was absent from work, received well wishes, cards and gifts from dozens of other colleagues and friends. This led to Ellie guiltily admitting she wished she too had cancer so that she would receive some acknowledgement of her condition and thus social support and concern.

In a wider context, some participants described the negative way CFS/ME was presented in the media, such as online polls on newspaper websites asking: "is it real or not?" (Kate). Several participants described unhelpful instances of celebrities who had claimed to "recover" from CFS/ME, and they felt that this was very damaging to its reputation and the ongoing struggle to be accepted as a legitimate condition "…and she [celebrity] said oh it's just a silly little thing you get over" (Liam). All participants who talked about the media viewed it in a negative light, with its limited but simplistic reporting of recent CFS/ME related research (i.e. White et. al, 2011, Sharpe et. al, 2015), which recommended cognitive behaviour therapy (CBT) and graded exercise. "Unfortunately they read these and then they'll look at someone like myself and think 'oh no wonder you're like that! You know, you don't go out for jogs!' [incredulous] Going out for a jog? It'll be fine! [laughter]" (Ellie). This exasperated tone was echoed by many of the participants when describing the inaccurate coverage, or the lack of coverage, of the condition.

Some participants recalled lengthy applications processes in order to receive disability benefits. In many cases, the benefits system itself was a structural barrier (Oliver, 1990), rather than a system put in place to support people with impairments. Here, frustration and despair arose from needing to access benefits in order to survive financially while recognising that the stress involved in this process was actually exacerbating their symptoms: "the thing that affected me the most is the benefit system. It's made me feel rubbish ... it's all negative. So by the time you've finished filling out the form it's pulled you right down" (Julia). Some participants' applications were unsuccessful but they chose not to appeal due to negative experiences, such as being accused of "exaggerating" or "lying" on their application forms by staff at the benefits agency. Those who voluntarily rejected the benefits system in order to avoid the stress caused by it then experienced feelings of guilt about not being able to contribute to the household income, instead relying on partners' salaries.

Theme three: feeling invisible

Subthemes: others being dismissive or not interested/ isolation and loneliness/ feeling powerless.

This theme captured the experiences of feeling invisible due to living with CFS/ME. For example, in the subtheme "others being dismissive or not interested", participants described many family and friends showing no interest in their condition, leaving them feeling like they "were talking to a brick wall" (Brian), and feeling as if their experience of living with a long term condition was not acknowledged. Some participants described particular family members who appeared to not take any interest in their condition: "even after all these years, my brother will say, what is it that's wrong

with you?" (Pauline), while others talked about whole family and friendship groups appearing not to be interested. In particular, Ellie recalled how she organised a charity fundraising event to try to raise awareness of CFS/ME however described feeling hurt and rejected when many family and friends who said they would attend did not. This feeling was echoed by Margaret: "if people aren't willing to listen, you can have the best leaflet in the world …" Brian recalled how he no longer admitted to others that he lived with CFS/ME as previous experiences of people showing little or no interest in his condition had left him feeling invalidated and ignored.

For many of the participants, these experiences left them feeling increasingly isolated as they recognised that some friends and acquaintances were not interested in their experience: "I've lost lots of friends as they're not interested. It's very isolating" (Freddy). Several felt that the loneliness they experienced was more difficult to bear than the physical symptoms of the condition they were living with: "I think the worst thing about ME is the isolation" (Lynn). Jenny found that she had to prioritise work over her social life, as she felt that her energy levels did not permit her to have both, particularly given her reports of inconsiderate friends who did not take time to understand her condition.

For some people, this led to them feeling powerless over their situation as important decisions about their lives – especially relating to health and benefits - were made by other people. In particular, difficult application processes for benefits left people feeling powerless and lacking control over their lives: "…having to lay it on thick and jump through hoops… people more ignorant and less educated than you making decisions about your life" (Freddy).

Discussion

The aim of study was to explore the negative experiences of people living with CFS/ME in regards to the attitudes of others. The twelve participants in the current study described their life experiences leading up to become ill with CFS/ME and the subsequent difficulties regarding diagnosis, seeking legitimacy of the condition, management of the condition, and maintaining social connections during this time. Thematic analysis was used to identify key themes from the interviews. Three themes were identified: Fighting to be heard, Lack of legitimacy and Feeling invisible.

The findings of the present research supported previous studies which found that people living with CFS/ME experienced discrimination and stigma from other people (Åsbring & Närvänen, 2002; Lee et al., 2001; Ong et al., 2005; Thomas & Smith, 2005). Participants described hurtful comments, alienation and abandonment as a result of CFS/ME.

This is consistent with the findings presented by Anderson and Ferrans (1997) who found that the majority of participants in their study experienced hurtful comments from other people. In addition, the findings echo research into the attitudes of physicians regarding CFS/ME, with some refusing to accept the legitimacy of the condition and others having negative opinions of those living with the condition (Chew-Graham et al., 2010; Hannon et al., 2012; Horton et al., 2010). Many participants described having to be proactive during healthcare appointments with their suggestions regarding what might be ailing them, because their doctor lacked knowledge regarding the condition and its diagnosis. Fortunately, most medics were open to these suggestions; however previous research has found that some do not feel comfortable with this kind of consultation as they feel they are being undermined (Åsbring & Närvänen, 2003; Raine, Carter, Sensky, & Black, 2004). This situation highlights an unfortunate predicament which appeared to occur due to gaps in the knowledge of many medics (Jason, *P*aavola, Porter, & Morello 2010; Raine et al., 2004; Stenhoff, Sadreddini, Peters, & Wearden, 2015). Several of the participants were initially offered antidepressants instead of medical investigations and their subsequent refusal caused ruptures in the relationship with their doctor.

Considering the experiences of participants from a social model of disability perspective, many people faced structural barriers that impacted on their lives in a profound way. For instance, while Ellie was on sick leave, she was offered "reasonable adjustments" to help her return to work which were actually more restrictive than her current role (she was offered a role with fewer hours but which was far more physical). This led to her contract being terminated when she declined these adjustments. It was, however, the psycho-emotional disablism that participants on the whole found more distressing than these societal barriers. Many participants recalled being teased for being 'lazy', for working part-time, or for being unable to do activities that others found simple to complete. Others described ignorant comments from family and friends regarding their condition, with some being told that their problem was psychological and that they were not trying hard enough to get better, leaving them feeling frustrated and hurt. Given that seeking emotional support has been found to be beneficial for the psychological wellbeing of people living with CFS/ME (Moss-Morris et al., 1996), it is worrying that some participants experienced social isolation and negative encounters with friends and family. This means that emotional support was not always easily available for some participants.

In many cases, internalised oppression as a result of stressful encounters with others led to many participants withdrawing from certain situations in an effort to protect them psychologically from further distress. For example, many ceased making medical appointments due to the negative experiences with doctors, instead seeking alternative remedies. Others withdrew from the benefits system due to accusations of exaggerating their condition; however this often led to further isolation as financial pressures meant they were often severely limited in the social and recreational activities they could pursue. Brian found that the way he was treated by others on his return to work, as well as the reactions he encountered when explaining his condition to other people, to be so hurtful that he withdrew from other social engagements for fear of similar outcomes.

Because of previous negative responses encountered from other people, several participants concealed the extent of their condition in an effort to fit in with their peers. Others did not tell friends when they were feeling unwell or particularly fatigued, instead cancelling plans giving reasons unrelated to the condition. These were also attempts to disassociate themselves from the 'undesired difference' (Goffman, 1963) they felt came from having an impairment. Unfortunately, these strategies designed to fit in appeared instead to perpetuate the misunderstanding of the condition as other people then had difficulty understanding the illness trajectory of CFS/ME because they were never aware when individuals were feeling particularly unwell, and thus only saw them when they were feeling well, for example in social situations.

Many participants described difficulties adjusting to changes in identity as a result of living with CFS/ME. Individuals described the powerlessness – a form of social oppression described by Young (1990) - that they faced in the many instances where they felt significant areas of their lives were controlled by others, such as members of the medical profession as well as employees at job centres and the Department of Work and Pensions. This was

particularly difficult for individuals where they had held positions of power and authority in

previous careers. Due to the invisible nature of CFS/ME, other individuals often had

difficulty with others understanding or even acknowledging that they had an impairment.

Morris (1991) has discussed how people with impairments face prejudice due to myths and

stereotypes that are perpetuated within society, and this was something that was experienced

by participants in the study in relation to the negative image of CFS/ME. Many individuals

expressed frustration regarding either a lack of coverage of the condition in the press and on

television, or unhelpful articles describing people with the condition as "lazy", negative

people who needed to get more exercise. Many referred to the "yuppie flu" label of the

1980s, which despite not being a commonly used phrase for many years demonstrated the

lasting power that negative stereotypes can hold.

The present study extends findings on this area with the suggestion that social

isolation was more distressing than living with CFS/ME itself for many participants.

Individuals took part in the study because they felt that this was an area that was much

neglected. For many of them, their participation served two purposes. Firstly, it enabled them

to contribute to what they felt was much needed research on the psychological impact of

attitudes toward CFS/ME. Secondly, it gave them a rare opportunity to discuss the many

negative experiences that had impacted on their psychological well-being, indicating how

important it is for individuals' stories to be heard (Riessman, 2008). Their desire to take part

in the study, as well as the many instances in which they described feeling unheard and

unvalued as members of society, indicates the isolation that many regularly experienced.

Limitations of the study

Only English speaking participants were interviewed due to financial constraints meaning that
interpreters could not be offered. In addition, all participants were White British, apart from one
participant from the Republic of Ireland, and thus individuals from black and minority ethnic
communities (BME) were not represented. This is a limitation particularly considering previous
research has indicated a higher instance of CFS/ME in other ethnic groups despite being poorly
represented in research (Bhui et al., 2011; Dinos et al., 2009; Horton et al., 2010). While a small

number of people taking part identified themselves as living with a severe form of CFS/ME, no individuals who were considered bedbound or housebound were interviewed. Unfortunately, this is a much neglected area of research to which this study could not contribute.

Recommendations for Practice

It is clear from the findings above that all participants interviewed experienced significant amounts of psycho-emotional disablism at various points over the course of their lives with CFS/ME. Moreover, some of this disablism arose from interactions with healthcare professionals, highlighting the urgent need for greater awareness of the distress that can be caused by a lack of consideration of the societal factors that contribute to said distress.

As psychologists, working on an individual level with people with impairments who are experiencing emotional distress can often bring about positive improvements in their wellbeing (Perlman et al., 2010; Radnitz, 2000; Rice, Zitzelsberger, Porch, & Ignagni, 2005) and thus this method should not be discounted. Additionally, due to health service configurations and financial and logistical limitations, this method of working is often the only one available to the practitioner. Practitioners need to be aware of the aforementioned criticisms of working on an individual level, especially as it is clear from the findings of this study that the behaviour and attitudes of other members of society (including health professionals) contributed to a significant amount of this distress in the participants of the current study. At the very least, psychologists should attempt to work systemically where possible and involve a person's wider system – including more than immediate families or partners. Participants' illness representations (Leventhal, 1980) were influenced by negative social interactions with friends and family as well as encounters with medical professionals, thus affecting the amount of distress they experienced and the coping strategies they employed. Clinical psychologists should therefore attempt to share with other healthcare professionals the formulations of their clients' distress from a psycho-emotional disablist standpoint in order to educate and enlighten those who display unhelpful attitudes to people living with CFS/ME.

The limitations of individual work with clients could be tempered by therapists working within more socio-political therapeutic methods, such as narrative therapy, in which issues of power are prominently addressed (Swain, Griffiths & French, 2006). Finally, on an individual level, Reeve (2012) acknowledges that while health and social care practitioners may not have control over service limitations, they do have control over how they interact with a person with an impairment. Therefore it is important that practitioners should be aware of their prejudices and assumptions and be alert to the possibility of inadvertent psycho-emotional disablism on their part.

Simpson and Thomas (2015) suggest that psychologists should seek to create change on a wider scale, which can be done in many ways. For instance Goodley and Lawthom (2006) recommend that psychologists should consider the impact of community psychology, in which there is less emphasis on individual difference and more of an emphasis on working with marginalised people and their communities to increase wellbeing in the wider society. This proactive approach is particularly important given some of the participants' reluctance to engage in further healthcare consultations

as a result of the discrimination they had encountered. Similarly, in the UK, Psychologists against Austerity (PAA) is a group of psychologists who aim to challenge the negative effects that the austerity measures implemented by the current UK government have had on the wellbeing of those who use the benefits system. By supporting this movement and by being aware of these issues that are regularly faced by those accessing these systems, psychologists can campaign against these austerity measures which affect clients and their systems on a daily basis. This echoes recommendations by Simpson and Thomas (2015) who recommend that psychologists should seek to be an advocate for their clients. In addition, when developing services, psychologists should endeavour to make them as accessible as possible.

Participants spoke of unhelpful media representation of CFS/ME. Psychologists working with this group could challenge this output via open letters to producers or editors of said media output, or take part in related programming to offer positive perspectives and also to highlight the damage that psycho-emotional disablism can do to the wellbeing of individuals. Participants also described ways in which employers appeared not to understand how best to support them in the workplace; practitioners could therefore contribute to guidance for employers of people with long term conditions and impairments etc.

In line with BPS guidance from the UK (2011), when working with people with physical impairments, psychologists should spend time during the assessment and formulation stages of psychological intervention to ensure that they understand how contextual factors have had an influence on the psychological distress that they are experiencing. Training courses should ensure that trainees have access to disability equality training in order to ensure that trainees have a better understanding of the experiences of people with impairments (Reeve, 2000). Training courses should also continue to attempt to address the disproportionately low levels of recruitment of people with impairments in order to ensure that this population is better represented in this field of work.

Future research

It seems important given the limitations of this study that future research should also consider the experiences of people from BME communities, as well as people who live with more severe forms of the illness. Furthermore, the experiences of men have been neglected in this field, and while this study sought to redress this with the inclusion of four male participants, it would be useful to conduct research which focuses explicitly on their experiences. Many negative encounters with friends and family were described by participants. Therefore, explorations into family and friends' experiences and attitudes relating to the condition and its impact on their relationships would enable a deeper understanding of these difficulties.

Conclusion

This study highlights the impact that the wider attitudes of society can have on the self-identity, psychological well-being and QOL of people living with CFS/ME. The findings of this study suggest that the negative attitudes of family, professionals, friends and other people have a profound impact on how easily people diagnosed with CFS/ME successfully incorporate living with a long term condition into their lives. Although the many instances of psycho-emotional disablism described by participants in this research study suggest that it is unfortunately deeply rooted in society's attitudes and behaviour, nevertheless there are still many ways that clinical psychologists and other

practitioners can attempt to change these negative interactions. Recommendations for future practice have also been recommended.

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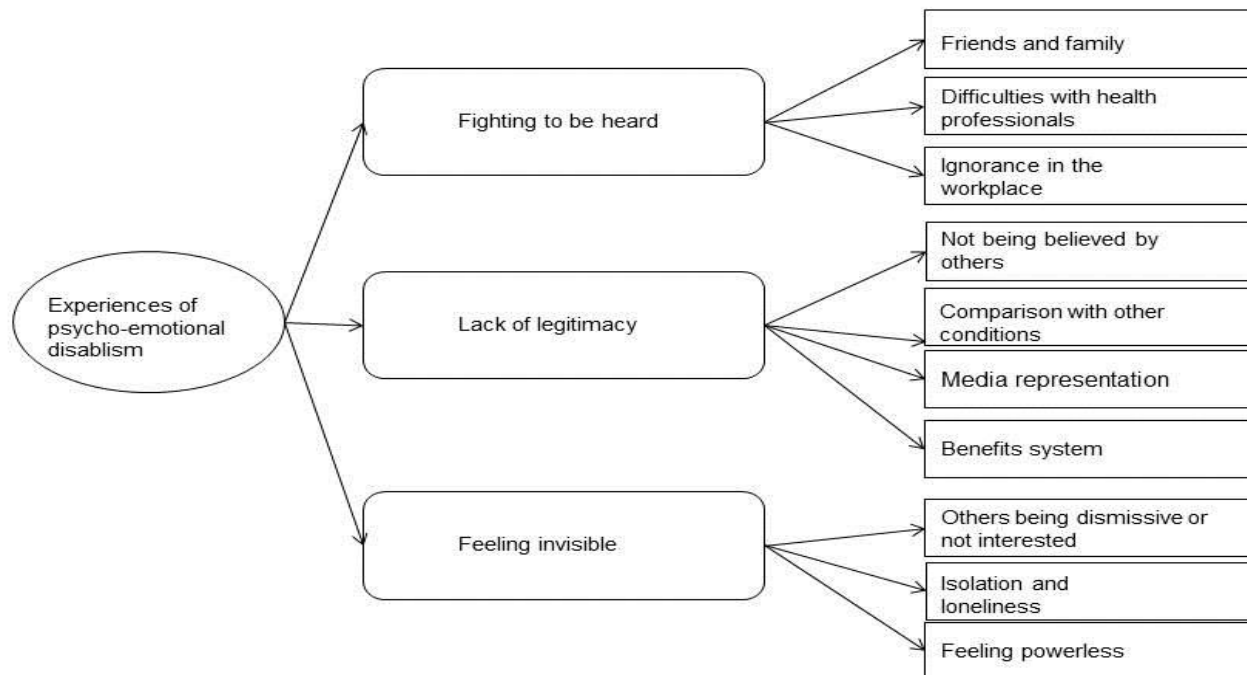
Table 1

Participant Characteristics

Name	Gender	Age	Time since onset of illness	Time to get diagnosed	Illness severity	Employment status	Marital Status
Brian	Male	65	10 years	Participant unsure	Moderate	*Retired*	*Married*
Ellie	Female	23	6 years	1 year	Severe	*Disability benefits*	In a relationship
Freddy	Male	36	8 years	Unknown	Moderate	*Disability benefits*	*Single*
James	Male	51	20 years	Participant unsure	Variable	*Part-time*	*Married*
Jenny	Female	48	7 years	3.5 years	Mild	*Part-time*	Married
Julia	Female	61	5 years	6 months	Severe	*Disability benefits*	Married
Kate	Female	30	2 years 3 months	1 year 2 months	Moderate	*Part-time*	Married
Liam	Male	53	13 years	6 months	Moderate	*Disability benefits*	Married
Lesley	Female	64	29 years	Participant unsure	Severe	*Disability benefits*	Divorced
Margaret	Female	55	21 years	6 months	Severe	*Disability benefits*	Married

Pauline	Female	65	13 years	7 years	Severe	Retired	Married
							Married
Sheila	Female	68	12 years	Participant unsure	Severe	Retired	

Figure 1.

Thematic map

Appendix A

Summary Stories

Brian

In April 2005, at the age of 55, Brian woke up one morning and felt ill, with what he thought was the flu. He took two weeks off work, however when he returned, he realised he was not able to continue working. He then remained off work for a year and a half.

When he went to the doctors, he underwent a battery of tests. By a process of eliminating other conditions, he was eventually diagnosed with CFS/ME. When he was first ill, he describes this period as "like a collapse of the nervous system"; he had to crawl upstairs due to the lack of energy and he was extremely sensitive to noise and lights. He wanted to live somewhere tranquil and peaceful, to escape the sensory overload he experienced.

He describes the first two or three years of the illness as being "the worst part"; a very confusing time in which he tried to make sense of the condition, and to find a cure. He tried many things to find a "miracle cure", such as the Perrin technique, which did not work. He also spent time reading up on the illness, to learn more. In 2009, he did the "Lightning Process", which involved positive affirmations and for twelve months he found it very helpful as the information presented within was new to Brian. His wife told him that during this period "you were the best you've ever been". After some time however the positive effects lessened and he felt it was "another false dawn".

By the middle of 2010, Brian had managed to go back to work part-time, in a desk job doing three hours a day. He felt he had to return to work because he had been conditioned to do so, having worked for 39 years from the age of 16. He feels differently about this now. When he went back to work everybody assumed he was well again, and he felt unable to correct them. People he used to call his friends did not know how to act around him, or would avoid him, and he found this very difficult.

He was then moved to an area where people did not know him, and he felt this was because he was no longer "the old Brian" and he no longer fit in. He recalled how he now worked afternoons, and one afternoon as he was arriving at work, he saw his friends finishing early to play pitch and putt, as they would do every Friday. He found it very difficult to accept that he no longer fit in with this social circle. He managed to remain in work for three years, at which point his workplace were looking to make 1000 people redundant. As this happened a month before his 60th birthday, it was "a no-brainer" and thus he finished working. He feels that this is the best thing that has happened to him, although he did find the first year of retirement difficult to adjust to.

In 2012, his doctor sent him to a cognitive behaviour therapy course. He feels that this has been the most helpful and "long lasting thing", as it helped him to understand how "negatively you approach things and how negative your attitude is on the days you're not well". He now understands how much his attitude can affect his relationships and the way he treats people.

After some time, he realised that his relationships with friends were "slowly breaking down" due to being unable to do the same things. Before he was ill, he used to do many social things even when he did not really want to. After becoming ill, he realised it was important to say no to things he did not want to do. His social life has therefore diminished over the past ten years. He used to have an active role in his local bowling club,

and follow his local football team, however due to the "lads together" attitude of his friends at the bowling club, they would make jokes about of his illness and dismiss it because they did not understand that he was ill, because "you look alright".

Over time, he has learned not to talk about his condition, as he feels that people do not want to hear about it; this means that he will rarely tell anybody that he is ill. He also feels that he has few things that he can talk about to people, and he thus feels others find him boring. For this reason a lot of his friendships have "withered away". He also lacks the confidence to initiate meetings with people. This is also a protective strategy where if he stays on his own then people cannot hurt him. His one remaining hobby is photography, and he posts pictures online. He has told some of the people he corresponds with about his condition; however some of them did not acknowledge that he had told them he was ill.

When Brian was diagnosed, he was referred to a CFS/ME group where the members of the group were told that they would never be 100% recovered. He was "outraged" at the time, however now realises that the facilitator was right and in the last three or four years has come to accept that he will never be his "old self". Brian has experienced periods of depression and anxiety that stem from living with CFS/ME. He can feel anxious "out of the blue"; similarly, he can have a good day with no warning, and then return to normal the next day. He uses a variety of coping mechanisms to manage his situation; he compares his condition to others who he considers to be worse off than him, such as those living with multiple sclerosis or cerebral palsy.

He described how his wife has been "absolutely fantastic", however he admits that it has been difficult because there is now a lot of things that they cannot do together, such as going for walks. If he over-exerts himself (e.g. by walking too far), the next day he can "be on another planet, emotionally, in every way", and has difficulty communicating with others. His wife can find that difficult to understand and can take it personally. When he is feeling particularly bad, he has admitted that he sometimes resents his wife, because she is fit and healthy and able to do more things. He feels in the past he has treated his wife badly by resenting her and isolating himself. He feels communication has greatly improved between them, partly due to the CBT course, and things are now much better. He now tries to stop reacting to situations as he realises that this worsens their relationship. He now stays calm and tries to see things from her perspective. She works in a stressful job and he recognises when she is stressed; he thus tries to help her when she is feeling this way.

In order to feel that he has a purpose in life, Brian spends some time during the week caring for his grandchildren. He enjoys this greatly, however it uses up a lot of energy and he spends a large portion of each week recovering. This is another reason why Brian feels unable to maintain friendships as he has so little energy remaining to do so.

Brian feels that the passage of time has helped him to adjust to his condition, as well as the stage of life that he is in, where he would be naturally winding down work commitments. He believes that "a normal, active retirement would have been wonderful", however he understands this is unlikely. At one stage about three or four years ago, he longed to be able to talk to somebody who would understand, however he feels that he no longer needs to do this. He considers himself to be lucky to be of the "baby boomer" generation, where it was relatively easy to buy and pay off a house. He wondered how younger people today living with the condition manage financially and get on the property ladder.

Ellie

When Ellie was 16, she became ill with glandular fever when she came back from a holiday in Egypt. She was at college at the time, and over the next twelve months she became increasingly withdrawn and tired, and was having difficulty getting out of bed. She felt that she unintentionally distanced herself from her friends at college, as she could not relate to them, as they were going out and drinking, while she would stay at home but "wake up with their hangover!" When she was 17, a doctor who "was absolutely amazing" knew about CFS/ME and sent Ellie to get her tested for the condition. When she got diagnosed, she had to tell her lecturers as she needed extra support, however, with the exception of one friend, she felt unable to tell the other students at college.

When her health eventually stabilised, she got a part-time job at a nursery, where she worked afternoons. She felt that people did not understand her condition as she appeared well when she came into work. They made remarks such as, "it's the part timer!" and teased her for being lazy. At the beginning Ellie did not mind too much, and in fact joined in with the jokes. She puts this down to fitting in and being grateful that she had friends, unlike at college. However later on the remarks started to hurt her.

On one occasion, Ellie went to see her doctor to ask to be referred to the CFS/ME clinic. The doctor told her "she didn't wanna deal with me" and to go and see another doctor. Months later, when Ellie needed an emergency appointment, she recalled how she saw the same doctor who shouted at her for returning. Now, Ellie ensures that she sees one specific doctor when she needs to attend the surgery. He is "great"; however she feels that she needs to educate him as he does not know much about the condition. When she was

eventually referred to the CFS/ME clinic, she met other people with CFS/ME and she was inspired to set up an awareness group on Facebook, in order to help people with the same condition as herself. She also started doing charity events in order to educate people, however many people who she hoped would attend, such as work colleagues, did not come.

At the start of 2014 she developed an infection in her mouth which led to a major relapse. She was unable to walk and was very sensitive to touch. Her doctor gave her a sick note for two weeks however consequently she was on sick leave far longer than this. At the time she felt that she had a good friend base from the nursery, however when she relapsed she got some text messages enquiring about her health, but nothing more. She was not sent any cards or presents. Ellie found this very hard to accept as she saw on Facebook the get well cards and flowers that another person got when they were ill with cancer. She found the difference in reaction so difficult to take that she wished that she had cancer so her pain would be recognised. This is something she felt very guilty about. For Ellie, it was the lack of concern, rather than the material gifts, that most hurt her. She estimated that at one point, she went about six months without having a visitor, despite her workplace being a five minute walk from her house. This made her very depressed as she felt extremely isolated, which led to her not wanting to leave the house.

She described how her employers at the nursery were "absolutely awful with me"; after she was off work for about five months they wanted to move her into a different role, which was shorter hours but much more physical, so she refused this. Shortly after this, when she was unable to get her sick note to them she was not paid and she felt that they were very unsympathetic towards her. When she had been off sick for exactly six months, she received an email notifying her that her employment was terminated.

Ellie described how difficult the last year had been for her because of the lack of support and the way her employers had treated her. Her family and her partner were very supportive. Her best friend, who had been very supportive, eventually started distancing herself, which Ellie found very hurtful. Ellie invited her and her children to one of her charity events; however she decided not to attend. Ellie felt that it was a combination of her not understanding the condition, so that when she saw pictures on Ellie at a meal online, she felt she had been "faking" her illness, to her finding Ellie boring because she could not do the social things that other friends could do. Ellie has not spoken to this friend for months.

Last year, Ellie arranged a race night at a pub to raise money, however many of her friends said they could not make it and so friends of her family had to step in to buy tickets. Ellie was hurt by the lack of support from those who she called her friends. Ellie still has difficulty with how people treat her and she described how she feels people think she is making up being ill. She stated that the social isolation is worse than the condition itself and pointed out that if "I was to make up a blooming condition at the age of 23, it would not be this condition where I don't get to see friends". Her occupational therapist from the CFS/ME clinic came round to explain her condition to her family as some of them did not understand. Ellie believes that a lot of this is due to the condition being invisible.

Ellie feels that media representation of the condition is unhelpful and gives people inaccurate ideas of the condition, such as her going out for a jog will make her better. She feels that in the six years since being diagnosed, some people still do not understand, although some people are now more understanding.

Freddy

In the late 1980s when he was eight or nine, Freddy was knocked down by a car and sustained a brain injury. He was in a coma for eight weeks and had to learn to walk, talk and eat again.

Freddy "had to leave home" when he was 19, because he had "pushed a few boundaries". He lived alone in a flat. One night he was assaulted outside a nightclub. Later on when he was doing community work with youths, he was "robbed by three youths!" For this reason, he does not go to clubs and does not go to pubs, unless it is to have a meal.

He developed ulcerative colitis in 2005 and reflected how all these conditions (including CFS/ME) are invisible. During his undergraduate degree, he "tried to be normal for YEARS", and fit in because he reflected that when people have a weakness, they are exploited. Because of this he pushed the boundaries of his mental and physical health, which resulted in them both declining. He described this society as "the survival of the fittest". He used to go to see the learning support service because he was dyslexic and he felt that he was discriminated against because of this.

He feels that he developed both CFS/ME and ulcerative colitis through not looking after himself properly. He was diagnosed with CFS/ME in 2007, when he was 27 or 28. He went to the doctor because he "wasn't functioning", who referred him to another doctor. The doctor asked him lots of questions then diagnosed him with ME, and sent him on a course for eight weeks at the hospital, with about 13 women and a female facilitator. It consisted of pacing and coping skills.

He described how he has tried to "make a go of it", but "it has been a real struggle". In his thirties, due to a combination of his own expectations and other peoples' attitudes towards him, he experienced depression because he was unable to work. When he was not working, he did an MA in creative writing, which satisfied the benefits system. After he completed the course, they started putting more pressure on him and sent him to a "job club", where he felt the teachers treated people "like animals". This inspired him to want to become a teacher to treat people better, so from 2001 he taught for two years, but because he was living with CFS/ME, it was very exhausting and "not really very realistic". He then offered home tuition, however the business side of this is also very demanding.

He claimed Disability Living Allowance (DLA) for ten years and then this changed to Personal Independence Payment (PIP). Before he went for the assessment for PIP, he put a lot of preparation into the assessment. However, they scored him zero for a lot of things, because of the courses he had done, and therefore he did not qualify for PIP. He appealed this decision, which involved him "having to lay it on really thick", which he

found very stressful. He feels that on paper he looks like he has excelled because of his education. This experience left him feeling belittled, humiliated and angry. He felt that he should be entitled to the benefits because he had tried to do everything that they asked of him, however "just couldn't do it, so go back in the system, there's nothing wrong with you." About a year ago, the DWP finally acknowledged that he was not fit for work. Although his experiences with the benefits system were very stressful, he reflected how he would not have been able to do the courses that he did and have the pleasurable experiences he has had. Freddy described some rich experiences in his life, such as living and working in London, and collaborating with an artist.

Freddy feels that some of the people working in the benefits system resent him because he is better educated than them; in turn, he has difficulty accepting that people less educated than him are responsible for his future. He believes that the government's - and society's - expectations in general have contributed to his ill health in that he has had to push himself more than he considered healthy. This has also contributed to the depression that he has experienced.

Freddy described how there is a great deal of pressure from society for people to achieve, and to fit in etc. This means that he has felt pressure to do his best (e.g. education, etc), however this has meant that he has not always disclosed his health problems. For example, when he was studying for his undergraduate degree he did not tell anyone of his accident and coma etc, as he wanted to fit in. Also, because the writing groups he attends are "terribly pretentious", he does not disclose there either. However, he feels he is now getting to an age where it is ok "not to fit the box". Somebody wants to publish his work on their website, however if this happens, "they will expect more from you; it's a way to launch yourself, but if you're not fit to launch, then what's the point of it?" He is the youngest at the writing group "by a long shot". He reflected that although he enjoys the writing groups, they consist of people he would not normally socialise with; for example elderly women rather than men his own age. He finds going to writing groups pleasurable, however, the process of going there, parking etc. is very tiring. In addition, the socialising and concentrating further exhausts him. Sometimes he is so tired that he slurs his speech, thus potentially appearing drunk "when I haven't touched a drop". Because socialising is so exhausting, attending the writing groups is all he has capacity for. He has had friends outside the writing group, but they have lost contact with him because of his illness. He finds this very isolating.

He has lived in his current house for two years, and found moving very hard work, because of his health. Previously he lived in the neighbouring town, however it was "terribly rough" and he was victimised there, hence he decided to move. He found it "grim", however has used these experiences in his writing. Freddy still experiences depression and has asked his doctor to refer him to a psychiatrist. He feels that asking for help "doesn't do wonders for my ego", and he finds the process very difficult as he has "been trying to pretend there's nothing wrong with me for most of my adult life". Recently, he went to the GP and asked to be referred to the CFS/ME clinic; the GP told him they had to ensure that he has got CFS/ME, despite being told in 2007 that he did have CFS/ME, he found this very frustrating.

James

James moved to his current hometown in 1991 to do teacher training, however he did not finish this because he decided to increase his part-time job at the time to full-time hours. He became ill in 1995, and thinking he had caught glandular fever from his then girlfriend, he went to the doctor who took a sample and said he had an unspecified virus. He remained ill for some time, and when he reported his concern about still being unwell to his doctor, they interpreted that as James being depressed and prescribed anti-depressants. James refused these and instead went to an herbalist, which improved his health significantly, however it has never returned to its previous state. She also advised him to become dairy free, which he found challenging. He was also told that he had an intolerance to spicy food and alcohol. He has since cut back on spicy food, and eliminated alcohol and wheat. After several months, he went back to the doctor who informed him he had post viral fatigue, however it has never got better. He felt that his treatment at the practice where he refused the anti-depressants had not been "great treatment".

 Since 1997, he has worn a copper band on the recommendation of an acquaintance and has found it to be very successful for reducing "aches and pains". Initially, his mother was doubtful of the condition: "nah, can't be! You're a big strong healthy fella!", however, he feels that her attitude has improved, mainly because she has seen him at his worse, for example, when he has dozed off in her armchair, and still been exhausted after several hours sleep. Other family members do not accept his condition. Some friends have joked about it and referred to the condition as "yuppie flu", however he also makes similar jokes so does not find this a problem. He feels that the people in the town where he lives have been more sympathetic than those in Ireland.

He now divides his time between his home and his mother's house in Ireland, where he spends time caring for her. He has found this to be a positive thing that has enabled them to be reacquainted and become closer, as he left home in his early twenties. Two years ago he went to his mother's doctor in Ireland who told him that CFS/ME does not exist. He was told by another Irish doctor that "we don't accept ME in Ireland". He feels that his treatment in this practice has been poor since he mentioned to them that he has CFS/ME, and now when he goes to the doctor he does not mention his condition, in a bid to be taken seriously. Because it costs money to receive treatment in Ireland, he is able to complain that he is not getting the service that he is paying for. He has also found other health professionals, such as his physiotherapist, to be sceptical of his condition; however he ignores this negativity; if people are not willing to accept him and CFS/ME, "there's nothing that I can do".

He has found that there is a "class dimension" to people's attitudes to his condition, with middle class people being more accepting of CFS/ME than working class people. He has found that people are more understanding if they have experienced a serious or chronic illness themselves, for example, one of his friends did not really understand until he himself had a heart attack which left him weaker. It was only then that he understood James's difficulties and was thus more sympathetic. Similarly, a friend had a daughter who became ill with CFS/ME, and then his attitude changed towards James. Other people with CFS/ME are very understanding.

He now realises he has a certain amount of energy which he must use wisely. He finds himself become tired in the afternoon and often needs to sleep for two hours. One of James's main symptoms is "brain fog". He also finds that getting wet makes him very tired.

Jenny

Jenny has lived with CFS/ME for about five or six years. She had a viral infection when she was on holiday but after four weeks her energy levels had not returned. She went to her doctor and although she was not working at the time, she felt he was dismissive and he blamed it on long working hours and her "lifestyle". She found this very insulting. It took about a year to get him to take her seriously and she eventually had blood tests to investigate. Because of the attitudes of doctors, Jenny has been put off from going to see the doctor and thus worries that if she develops a serious illness in the future, she would delay going to see a doctor, hence endangering her life.

It took her about three and a half years to be seen by the ME clinic as they had lost her referral. When she was waiting for a diagnosis, the Job Centre put pressure on her to apply for full-time jobs, however she did not feel able to tell them that she would have difficulty with this type of job due to her energy levels, and did not have any diagnosis to be able to help her explain. At the time, she suspected that she had CFS/ME and she feels the stigma relating to this condition prevented her from being able to say anything.

Jenny got diagnosed about one and a half years ago. While she was waiting to be diagnosed she joined the local ME group and learned some useful coping skills there. When she was eventually diagnosed, she was sent for about eight sessions with somebody to learn about pacing and other coping skills. She found this very helpful as she realised that she had not been using her energy wisely. She has also attended a CBT course, which she also found useful, although sometimes too much information was presented. She also feels that it would have been useful earlier, although because of her lost referral this did not happen. When she was diagnosed, her employer at the time was "absolutely brilliant", and allowed her to be more flexible in her working hours, which enabled her to remain in employment. Unfortunately this experience has been the exception, and current colleagues are very ignorant to her condition.

Jenny finds that if she socialises with people with CFS/ME, "we just end up talking about ME!", however friends who do not have the condition do not understand. For example, somebody asked her to go on a cycling holiday, and another person told her "if you want to get better, you will get better!" Jenny found this very insulting as she felt that this would not be said to somebody with diabetes or another serious illness. This makes her reluctant to socialise with some of her friends. Other friends use up a lot of her energy and she thus has to plan when she can communicate with them, because she will be tired for some time afterwards. One of her friends has mental health problems, and even though they do not understand each other's difficulties, they empathise and thus have a mutual respect for each other.

Jenny does not always tell people of her condition, and sometimes if she is not feeling well she will blame it on other things instead of CFS/ME. This is because of the stigma attached to the condition, and she is thus concerned that people will think she is lazy, or has a mental illness. She sometimes tries to appear healthy and fit as she feels being the opposite is often harshly judged in our society. She feels that because her

condition is invisible, people do not understand that she is ill because she looks well. She has not told several employers because she does not want to admit that she is not well, also she does not want to make a fuss. This means that she has difficulty with long days and travelling, because she is unable to tell people that she needs to eat regularly and rest.

Jenny finds that it is very difficult to work and have a decent social life as well, because of the demands that both make on her energy levels. She has had to sacrifice many hobbies and has to plan carefully the things she does, so that she can manage to remain in employment as well as visit her parents. She used to have an active life and finds it difficult to accept that there are many things she cannot do. She is also sometimes envious of those at the support group who do not work, as she feels that they can spend more energy on hobbies and thus have a greater quality of life.

At the beginning of the illness, Jenny feels that she was at a moderate stage of CFS/ME, however it is now mild. Jenny believes that if there were a test for CFS/ME that would help people to understand that it is a real condition.

Julia

Julia used to work for a government department, and travelled a lot in this job. Her husband, who also lives with a long term condition, became ill soon after they got married, and had to give up work. She used to be very active before being diagnosed with CFS/ME and had a number of hobbies in the arts. In October 2010, Julia felt extremely fatigued so decided to take a week off work, however never returned as she did not get better. At first her doctor, with whom she has a very good relationship, thought there may be a problem with her heart, however after a series of tests she was diagnosed with CFS/ME in February 2011. When she was diagnosed, she read up on the condition, and understood she would probably never fully recover, however hoped her condition would improve enough to work again. She took a redundancy package out at work, which left her with enough money to take two years to recover, before hopefully going back to another job. Unfortunately Julia was unable to return to work as her condition has not improved sufficiently. In 2003 Julia developed Crohn's disease, and she also lives with fibromyalgia.

Julia stated that she had a good relationship with her GP; however felt that she had to be proactive with her suggestions regarding treatment. Her GP attributed her condition to being her husband's carer as well as working full time. She spent the first 12 months after being diagnosed working out how to manage the condition. She tried a variety of alternative therapies, such as the Perrin technique, she also saw a reflexologist and an acupuncturist, an osteopath.

She has two daughters and she feels that one is more sympathetic than the other, who is a medical professional and who Julia believes "should know better". She described her younger daughter having grown up with illness, as her father became ill when she was very young. Her youngest daughter does many errands for her, and she has a cleaner that comes to the house. The rest of her family sometimes do not understand.

She has lost some friends along the way, who were not understanding of her condition, however the ones she still sees have been very supportive, and she is able to tell them when she is not feeling able to communicate or socialise. They have also adjusted the times of day when they socialise in order to accommodate Julia's energy levels. They also know to invite her to social activities and let her decide whether she feels able to go without being excluded from things.

Managing finances successfully has always been important to Julia, and being short of money is something that causes Julia a great deal of stress. Julia has been rejected twice for DLA and feels that the benefits system has caused her the most stress. This is in part due to having to describe the most negative aspects of the condition and the way it affects her life, thus leaving her feeling very down about her situation. Also, when she received the transcript from one of the meetings it said that Julia had lied about her condition, which she found very stressful. When PIP was introduced, Julia decided to apply for this however did not hear back for over a year so she contacted her MP who communicated with senior ministers to speed up her application. She received a small amount of benefits and although she felt that they had ignored the information she had provided she did not appeal the decision as this would have been too stressful. She also applied to charities for help around the house, and while this also required filling an application listing her

difficulties, the process was less stressful with better outcomes. In addition to her own health needs, Julia has to apply for help for her husband, which she also finds stressful.

Before she stopped working, she was able to access private counselling through her employer and had some CBT. This helped her to "embrace the change", and she wrote a list of things that she could do when feeling better. Her acupuncturist recommended that she keep a journal to record her activity and moods and she found this very useful. It enabled her to see that when she had exerted herself, she would feel the effects two days later, rather than the day after, and this knowledge helped her to plan better. She was also able to see how negative her journals were, so she started to record one positive thing a day, which improved her overall mood.

Because she likes to make an effort with her appearance, and tries to remain positive, she has found that people do not think that she is ill. This means that she has difficulty having people realise that she needs help, and thus her needs often go unmet. She stated that "you only get help when you ask for it" when you live with an invisible condition. She also feels that sometimes her husband does not understand how she feels and often competes to be "the illest", and in this way he also ignores her needs.

Her illness has fluctuated over the years since developing CFS/ME. In the first year, she "was really ill", then "had a couple of good years". At the start of the year, she went "downhill" again. She described how she tries very hard to manage her condition, and when it deteriorates for no perceivable reason, she finds this very soul destroying. She feels that she has experienced a grieving process for the life she used to live and the hobbies and lifestyle she has had to give up. This process is ongoing. She believes the condition has become the "new bad back syndrome", and that media reporting of the condition makes its reputation worse.

Kate

Kate had glandular fever in 2003 when she had just turned 17. She was told it would take several months to recover, but when she did not, she was told, "it's depression" by her doctor. Because her situation was not taken seriously for around six months, a relative paid for her to be seen privately by a doctor, who diagnosed her immediately.

Kate had just started a new job when she became ill. She had a large friendship group, because as she stated at that time of people's lives, "you've got friends coming out of your ears!" Unfortunately they found it very hard to accept that she could not do what she did previously. Because of the age of her friends, many of them did not know how to deal with it.

Kate has had two occurrences of the condition for over 13 years, and finds that people should understand it better given how long she has lived with the condition. When she was diagnosed with the condition the first time, she found people's attitudes the illness to be upsetting as many people gave her unsolicited and simplistic advice, and implied that she was not trying to get better. She described how people find it difficult to understand the unpredictability of the illness, as well as the fact that she can look well with attractive makeup and hair etc. They find it hard to understand that she is unwell. Kate relapsed a second time at the beginning of the year and reflected that this time it was easier because friendships were more established.

The first time she became unwell, Kate had taken a year out of education and had moved to another town to work at a camp for children. She worked as an activities instructor which involved rock climbing, hiking and many other outdoor activities. Her parents were separated, and when she became ill, she had to move back home to live with her mother. Fortunately, the company that she worked for were very supportive and six months later, when she "started gaining strength again" they allowed her to go back part time, so that she could return to the family home to recover for the remainder of each week.

Kate experienced significant anxiety and depression when she first became ill, because of the social isolation as well as the lack of information available to her at the time. Her family were very supportive; her mother and father were separated and her mother did a great deal to assist her when she was ill.

She had originally hoped to go to university to be a nurse but was not well enough so she chose to attend college one day a week to help address her depression and anxiety, because by that point she "used to get so worked up with going out". Because the college was out of the area, she did not know anybody and thus felt "she was back to square one" in terms of establishing friendships. When she started to learn to drive this enabled her to be less isolated. When she went to the doctor about her psychological difficulties she felt that her age meant that she was dismissed with anti-depressants and was told "you'll bounce back". Kate tried anti-depressants however she experienced hallucinations which she found very distressing.

After slowly increasing her hours at college, after four years Kate had obtained a qualification in jewellery making. She moved to another city to work for a jewellers, and by this point she felt that she was "totally better ...physically and mentally". This took her a long time to realise as the improvement in her health was so gradual. Because of the lack of information available to her however, she did not realise that the condition could return.

By 2010, Kate believed that she was fully recovered, and "had loads of really good years." During this period of her life, she "travelled the world, met my husband, got a fantastic job... LOVING life". Unfortunately she got made redundant and following this took two part time jobs in shops in the city where she lives. In 2013, she started getting "ME pain again" in her arms and legs, which she tried to deny was happening for around six months. However, she was eventually was unable to fight it any longer and she became ill again. When Kate went to her doctor with her concerns, the doctor told her she was "just depressed" and wanted to give

her medication, which she refused on several occasions. After writing a letter of complaint, Kate went to another surgery where her GP was much more empathic and helpful, although "he admitted he didn't know anything about ME". He referred her to the CFS/ME clinic and recommended that she join an ME support group. She found the help from the ME clinic to be helpful, with sleep hygiene techniques and CBT being particularly useful.

She stopped working for the shop which she felt was the least understanding of her condition. The remaining retailer allowed her to take three months unpaid to recover, and without any pressure from them. After three months, Kate went back to work however felt the situation too overwhelming and decided not to continue.

When comparing the first time being ill with the present time, Kate described how she has received much more emotional support from friends the second time. She attributed this in part to friends having had their own setbacks in life by that point and thus being able to empathise more than the friends she had when she was younger.

Her partner can work away for long periods of time, and so she is especially grateful of the practical support from friends and her local church community. She described how those close to her understand her condition much more compared to people who have never met anyone with a chronic illness, who are thus more susceptible to picking up on the negative way that the condition is often portrayed in the press.

Kate believes that society is not patient with people with chronic illnesses, and that because of the negative reputation of people who are on benefits, people appear to think that she could get better and return to work by doing something simple such as 'just cut dairy out of your diet', which she finds very frustrating. She feels that people did not understand that she was not working because she was unable to, rather than because she was lazy.

Kate described society's expectations of somebody of her age: "by the time you're thirty, you should have a house, be married, have children" as being very unrealistic. Kate has learned to put her health before owning material possessions and although she believes that some of her friends and family disapprove of her not being in a full time job and having a mortgage, she believes that on some level they are envious of her not conforming to society's expectations. The unpredictability of the illness and her future does not scare her as much as it once did, and reflected that "you know you'll just muddle through!"

Kate reflected on her poor experience with the medical community and felt that the condition was under-researched because medical companies could not find a way to make money from the condition, as there is currently no cure. She also stated that doctors need much more training on CFS/ME and other invisible illnesses, in order to reduce the stigma that she and others have experienced.

Liam

Liam worked in the South-East of England as a train driver for 19 years. He described himself as a full-on person who enjoyed boxing, rugby, football, and was active in the union. He believes that this contributed to the CFS/ME developing. Liam "nearly cracked up" driving trains due to the boredom he experienced. He was then moved to checking people's tickets, however he did not enjoy this job because he "likes to help people, not get them into trouble".

Liam had a virus in 2003, from which he did not fully recover. When Liam became ill, his whole identity, as well as his social life, was based on what he did for a living therefore when he was on sick leave he felt he had no value. He described experiencing depression when he was diagnosed with CFS/ME and was offered anti-depressants however he did not wish to take medication, as it is "just a money making scheme". Liam believes that Western medicine needs to adopt a more holistic approach when dealing with the human body and any illnesses.

Liam described having many tests to obtain a diagnosis. He was diagnosed six months later in March 2004.The diagnosis was led by Liam suggesting to his doctor that he may have CFS/ME. When Liam was diagnosed he was referred to a top hospital in the South-East of England. He described how they believed that CFS/ME was a psychosomatic condition. Some of the people in the CFS/ME group that he attended were very upset by that statement; however he understands the body-mind connection and was not offended in the same way. Liam believes that there is a psychological component to every illness, which is very individual and is dependent on a number of factors such as coping strategies. Following this, he went back to work and was "OK for a while", however went on sick leave again in May 2004. During this time he followed a programme of cognitive behaviour therapy and graded exercise. Liam liked the structure of CBT and "took to it like a fish to water". He went back to work on a graded return, however reached a plateau and "couldn't cope". In 2005 he was medically retired.

After some time, he joined the local CFS/ME support group- he delayed this because "if you wanna get well don't hang around with unwell people!" He described how the majority of people in the group were middle class women with large houses, and as a working man he was not accustomed to socialising in such circles.

Despite this, he found that people at the CFS/ME group were "really nice people" and he enjoyed socialising with them. Liam described other positive experiences, such as being able to relocate to a seaside town in the north-west of England as an indirect consequence of being medically retired. In addition he has had religious experiences, and appreciates nature more than he used to.

Since being medically retired he has had to accept a new reality, and adjust to that reality, which involves taking things on a day by day basis. He is aware how easy it is to become "too anal" about some aspects of the management of the condition, such as pacing, as this can lead to a "stress reaction". Liam described how increased stress can feed into the symptoms of the condition, leading to a negative cycle. Liam described the many ways he had tried to reduce the symptoms of his condition, and to increase his energy levels. This included diets such as a vegetarian diet which also eliminated wheat and dairy, however this "didn't work". He also visited an osteopath as well as taking some "smelly" Chinese medicine; neither of which had an effect. Liam also described using "the Lightening Process", a technique which includes positive affirmations and which is intended to break patterns of negative thought. He found that this worked "up to a point"; however it then became stressful as he would have to find time to carry out the techniques at inconvenient times, such as at parties, and this itself would be a stressor that would worsen his symptoms. He also recalled trying neuro-linguistic programming, which also had a temporarily positive effect, as well as a naturopath. He recognised that the methods he tried involving positive thought would only have a limited effect as the condition is a physical one. He felt that the only supplement to have some effect was magnesium, which reduced the burning sensation often present in his thighs.

Liam's attitude towards CFS/ME has changed a lot since living with the condition. When it was commonly referred to as "yuppie flu" in the 1980s, he "used to take the mickey out of yuppies", who would work very long hours in order to make significant amounts of money and then become ill. He recalled having little sympathy for them. His attitude changed when he became ill with CFS/ME, which he found "quite interesting and quite good". He believes the experience of living with CFS/ME has been a positive one in the way that it has made him less judgemental towards other people. When he worked in public transport, he believed that when people who were moved from train driving roles they were "swinging the lead". He believes some people thought that about him when he had similar difficulties.

He described how he had encountered negative attitudes from some family members. For example, his step-sister did not think that he was really ill, because she saw that he had been to a party and was also sometimes able to run short distances. He described how people had difficulty understanding the extent of his condition, because they did not see him when he was "zonked out". Liam has had to explain to a neighbour that he has to break activity into chunks and rest in-between, as he did not understand how he could garden if he was living with CFS/ME. Sometimes Liam feels he has to justify his condition to other people as he feels they think he is lazy. He stated that he does not expect people to understand the condition, as he himself does not. Liam uses an analogy to describe his energy levels to those who do not understand. Liam likens energy to a mobile phone battery where full battery is ten bars; however his is usually five. He thus he needs to be careful about the energy that he uses to avoid getting a flat battery.

Liam discussed media coverage of the condition which appeared to imply that people living with CFS/ME do not "push themselves" enough. He disputed this allegation as he felt that people living with CFS/ME were doing so because they had pushed themselves too much. He described people living with CFS/ME as "Type A personalities", who did not look after themselves because they preferred to care for everybody else. He was also annoyed about a celebrity who stated that she had CFS/ME but it was "just a little thing". The lack of a

specific diagnostic test meant that he wondered whether she may have been mis-diagnosed hence her being able to recover so easily.

In addition to meeting people through the CFS/ME support group, Liam has also volunteered for "caring organisations", where he feels in general people are less judgmental and therefore he experiences less negativity from other people. Despite this, he recalled an instance in which a manager at an organisation was pressuring him to do full working days, however he resisted in order to conserve his energy levels. Liam described how he "gets brain fog", leading to a difficulty in absorbing information which is "like thinking through treacle", and this gets worse at the day progresses. On one occasion, he did do a full working day of his own volition as he felt that the tasks to be completed on that day would not be too strenuous and he felt his energy levels were sufficient. However, when the manager heard of this she felt that this meant that Liam would be able to do more full days, and was unable to understand why he was politely refusing to do so. He explained how attempting to explain to the manager so that she understood was a necessity, however because it was a stressful experience it used a lot of energy. In general, Liam tries to stay as calm as possible in order to conserve energy.

Liam describes himself as a "glass half full person" who believes that people can recover from CFS/ME, however he does not know anybody personally who has done so. He enjoys volunteering in the charity sector, as he enjoys meeting people and "hearing their stories". He also finds worth in "empowering people" particularly because he feels he has been disempowered himself. He has managed his CFS/ME himself for several years, because there is nothing else that the NHS can offer him.

Lesley

Lesley is 64 years old and has lived with CFS/ME since the age of 35. She believes it developed as a result of a "dreadful marriage and a very bitter separation". Her first husband had been "very cruel" to her and had abused her "in every way possible". They had two children together and Lesley was reluctant to take them away from their father, however eventually realised that the situation was too bad to remain in and she left him and took the children. At this point she realised she had been living on adrenaline for the last 15 years, because of the stress of the home environment. About six months after the separation she came down with a virus and took a fortnight off work, after which she felt much better.

She met another man and moved to the city where she now lives to be with him, and got a new job in that area. Several months later she felt herself becoming more and more exhausted, which she attributed to needing more exercise, so she started walking on her lunch breaks however this exacerbated her tiredness and she "gradually started to go downhill". Her fatigue increased to the point where she was sleeping for large parts of the day. She was worried that her new partner was thinking "what the hell" he had become involved in. One morning she started her journey to work however became very tearful and was unable to go in.

Her doctor told her she was in a "severe depressive stage" which she contested. She changed doctors' surgery shortly after this, and was sent to the hospital for many tests. One of the scans revealed an aneurysm

on her brain which had to be operated on, and this surgery carried a high risk of dying. Because of this, Lesley believes herself to be very fortunate that she has CFS/ME because without it they would not have discovered the aneurysm in time. Regarding her diagnosis, her new doctor was very empathic and told her that she most probably had multiple sclerosis; CFS/ME "was not thought of in those days". She therefore believed it was MS until she met somebody with MS who had completely different symptoms. By this point Lesley had become more aware of CFS/ME and held the belief that she might have been mis-diagnosed. When she asked her doctor about it he admitted that he also thought she probably had CFS/ME however regarding benefits and her retirement etc., it was easier to label her condition as being MS. She believes he was being kind to protect her although she felt uncomfortable being dishonest so would tell people that she did have CFS/ME despite still having the diagnosis of MS. Eventually, around ten years later when people had become more aware of CFS/ME, she went back again and asked her doctor if she could officially say that she had CFS/ME and at this point he agreed.

Lesley found it very difficult being medically retired at the age of 35. The social isolation was very difficult because all her friends were working, however her partner was "wonderful", during this stage. She cannot really remember how she got through this stage of her life however it involved bringing up her children and being a "hausfrau". During that time she started writing classes, writing poetry which she described as her "personal therapy". She also completed an MA in creative writing, which she found very rewarding.

After being married to her second husband for around ten years, they unfortunately separated, at which point she moved to her present house. She described how although her health was quite stable by this point, one day she heard an interview on the radio with a doctor who claimed to cure CFS/ME "100%". Because Lesley was expecting to become a grandmother at some point in the foreseeable future, and therefore very keen to be at optimum health again, she decided to invest all of her life savings on the treatment, with the hope of improving her energy levels even more. Unfortunately by the end of the year, her condition had worsened and she was "far worse" than before the treatment and was housebound for a long time. It took several years for her health to build back up again.

She recalled how her daughter got married and asked Lesley to give her away as well as give a speech at the wedding. Because her social life is so restricted due to her low energy levels, she described this as "a massive thing to do". She described the wedding as "beautiful" and the day, including her speech, went well, however it took her some months to recover from the event. For this reason she is usually understandably anxious that she will experience a similar deterioration in energy levels when she attends other major social events.

When she tells people that she is living with CFS/ME, they often do not understand and wonder why she is at home all the time. She explains to people that she gets very tired, very quickly. She finds it difficult to talk on the phone. She has to explain to people before they come round to her house that she can only talk for an hour, but frequently people will lose track of time and stay two hours or more. Lesley finds it very difficult to ask people to leave, and thus will be exhausted when they have gone. Some of her friends do not understand her condition. Her Pilates teacher does not understand how she is able to do some of the exercises, however opts not to do so if they are too strenuous. She described how it is difficult for people to see that you have to prepare for that window that they see you in. Some people understand her condition, for example her children, because they had lived with it, and some people accept that they will never understand. One health professional told her that "95% of the population are tired" when she described her fatigue. This angered her greatly and she wrote a letter to complain about her treatment.

Regarding her acceptance, she says that she still struggles with this and describes that she still has "almost a denial" as she used to be a naturally energetic person. She states that she has forgotten what it is like to be a

"normal person" and do spontaneous things such as pick people up to go out somewhere. Before she recognised her limitations she would push herself too far as she was still in denial about her condition.

Her health has gradually improved over the years and she describes herself as "quite well now", and "quite happy", and attends several groups e.g. creative writing. Despite this, she cannot go out at night which she finds very restrictive, as she loves other peoples' company. She does not enjoy being on her own and would love to share a life with a partner, however because she does not go out at nights she feels she would not be able to date anyone. Her friends sometimes find it difficult when she has to cancel plans, because she "looks normal; there's nothing wrong with her!" Despite having extremely supportive children, she still feels guilty when she cannot attend family events as she feels she is not able to support them in the way that they would like.

Margaret

Margaret was diagnosed 21 years ago, while working for the local council in a very demanding job with good prospects. Margaret caught a number of bugs before developing CFS/ME, and believes that the cause of her condition was catching "a bug too far". She was off sick for about six months, and tried to work from home during this time, but was unable to do so. She was pressured by work to return, however managed a day and a half before being unable to continue and then left on medical grounds with a small pension. She was "only 34", and hoped to return to work at some point in the future, however "I've never been in a fit state". Margaret and her husband tried to have children but unfortunately she had a miscarriage around fifteen years ago. Margaret felt that because she did not work, and had no children, many people thought she was "not particularly interesting", because "what you do defines you". She recalled occasions where she felt other people struggled to converse with her because they could not find a common ground. One of Margaret's hobbies is wildlife photography and she regularly posts her pictures online. This helps her to feel that she has a purpose as well as something interesting to talk about, however because this is traditionally a male-dominated hobby, she sometimes experiences negative reactions from people who are surprised at her involvement in this area.

Her late mother was very sympathetic of her situation and would try to read about her condition to educate herself. Unfortunately, other people in her family, such as her father and her husband's family have "never shown a lot of interest" or tried to understand her condition and the difficulties associated with it.

Margaret felt very fortunate that her GP at the time of becoming ill was "almost a specialist in ME" and he suspected immediately that she may have CFS/ME, however did not diagnose her immediately. Amongst other things during his involvement in her care, he recommended that she eliminate gluten from her diet and after six months she reported feeling a "bit brighter". She also tried a number of methods to improve her health, including an electric pendant, and a prescription drug.

About four years ago, the government started to reform the benefit system, and Margaret was very concerned that she would be classed as suitable for work because of these changes. Margaret was sent to the CFS/ME clinic as part of her benefit application, where she saw a counsellor. The health professionals at the clinic also wanted her to try graded exercise therapy however she explained that there are several things that she already does (such as walking the dog and helping her elderly father) and that she knew from experience when she increased these activities she felt physically significantly worse and so was reluctant to try this. After one of the professionals also suggested to her that she thought they could help Margaret to completely recover, which she was very doubtful of, she "put the ME clinic on hold".

Unfortunately around this time, her GP left the practice and so she had to see other doctors. After her original GP left the practice, she encountered negative attitudes from the doctors that she subsequently saw, including being told that "believing in ME was like believing in the tooth fairy". Following these negative encounters she started to research the condition herself online, as she felt that she had no other alternative regarding its management.

 Margaret was eventually assessed for employment and support allowance and was put in the work support group with a view to returning to employment within a year, however the money stopped after a year and she is still waiting to be reassessed. Margaret felt judged by employees at the job centre who she felt thought she was "a scrounger" who was "fit for work". The whole process of having to go to the job centre was

exhausting and stressful for Margaret, and she "was in tears before going each time". She does not expect to receive this benefit should she reapply.

Margaret had some counselling around two years ago because of difficulties with her in-laws, her miscarriage, and her self-esteem, which has helped her to understand that she was internalising some of the unreasonable criticism from close relatives.

Margaret sometimes feels guilty because the financial responsibility for the house and the bills lies with her husband she wishes that she could do more to contribute. Her husband will have to work longer to ensure that the house is paid off, and this sometimes upsets her, although he is very supportive and does not complain.

Margaret has difficulty concentrating for long periods of time so finds reading difficult, however she tries to keep herself updated on the recent research related to CFS/ME. Margaret gets frustrated with reports that CFS/ME is a psychological condition, because she feels that there is now enough evidence stating that it is a physical condition, and these reports only serve to misdirect funding away from the correct avenue of research.

Pauline

In 2003, Pauline was working full-time with children and adolescents, "loving the job I had". Her background was in social work, specifically child protection. She admitted that before she became ill she "was probably over-working", as she was also doing private work as well as supervising other practitioners. She was married, had two children and often looked after the grandchildren. "She had a really busy but fulfilling life". Then, she and her husband returned home from holiday when he had a brain haemorrhage and "it was touch and go whether he would survive". He was operated on and it was a very stressful time. Pauline believes that her immune system was depleted due to the prolonged and extreme stress. Just after Christmas, Pauline had a very bad chest infection which she "never really recovered from".

When she went back to work in 2004, she was always exhausted, however "plodded on" believing it was the stress of her husband's illness. She and her husband went away for two days when he was well enough to do so, however when they went for a walk, she could barely move her legs and had pins and needles. She was taken to hospital. Over a period of 12 months, she had numerous tests: e.g. for Guillain-Barre, motor neuron disease, multiple sclerosis, muscle biopsies, lumbar punctures, MRI scans and saw lots of consultants however they "never got to the bottom it". She was mostly housebound and bedbound for two years and then started to improve slightly. During this period she was sent all over the country to be tested.

In 2010/2011 medical professionals thought it might be fibromyalgia. Eventually, she was told that they thought it was CFS/ME. She was initially happy to receive a diagnosis as this meant she could research the condition. Pauline believes that she is a "Type A personality", and thus was motivated "to get to the bottom of it", however she has found that some professionals and journalists "turn that into a negative". As she researched the condition and met people from the support group, she realised that there was not enough research conducted in the area, there were lots of negative responses, and a consultant was very pessimistic when he was explaining it to her. She thus concluded that it was "a mostly negative label".

Pauline described many changes in her life since living with the condition, for example it had a financial impact as she was previously the main breadwinner. She discussed the loss and grief that she has experienced. She also described a change of roles within her family as well as a lack of confidence. She was "the matriarch of the family" and traditionally made and hosted the family Christmas dinner, however now her daughter does this, and she finds relinquishing this role difficult. Pauline estimated that it took her about three or four years to realise that her condition was not going away. It is a grieving process, she acknowledges that it is a chronic condition but still has difficulty accepting it. She has had counselling over the past 12 years to help her with this.

She has been with her husband for 46 years, and she feels that her marriage is more secure now due to both their illnesses, as they have supported each other throughout. She has a son aged 46 and a daughter aged 43. She believes her daughter was sad and angry about the loss of the mother she knew; her son was more accepting. She understands why professionals do not understand, because she does not understand either. She sometimes has difficulty understanding the unpredictability of the condition.

At the beginning of the year, she had a very bad relapse for five months, and was referred to a consultant as they thought it might be multiple sclerosis. She uses a mobility scooter when she goes out and has a blue badge. She sometimes says she has MS as that provokes a very different attitude; people are more understanding. She has experienced negative responses using the blue badge, as people do not accept that there is "anything wrong" with her. She was relatively young when she started using the scooter (in her fifties) so would attract looks from strangers, similarly, because she wears make-up and takes pride in her appearance, people remark to her that she cannot be ill. She used to reply but now says that she just gives people "a look", as she does not feel she owes them an explanation.

When she gets angry about people not understanding, she has to temper that emotion as she realises that stress is unhelpful for her symptoms. She therefore practices mindfulness and meditation. She also paces to make sure she has enough energy for the day. She has lost some of her friends "along the way"; however others have stuck by her and have tried to understand her condition. Sometimes her husband gets upset when she has to cancel plans at the last minute due to being unwell. They are both disappointed when that happens, and she gets frustrated at the unpredictability of the condition and the difficulty she has in being able to plan ahead. Her sister has fibromyalgia and compares Pauline to her own symptoms, and tells Pauline that she does not push herself enough. She has found that doctors and consultants have been very negative and she believes that they have thought her to be a time waster or a hypochondriac, which makes her angry.

Despite the grief and loss of identity that Pauline has experienced, she described the positives that have arisen from her living with CFS/ME. For example, she was able to spend more time with a seriously ill relative, and she is more appreciative of the "smaller things in life". She also chooses how she spends her day much more wisely, to ensure that she gets the best out of each day.

Regarding her future, she envisaged a very active retirement and has had to accept that this is not the reality. She feels envious of friends and those around her doing active things and travelling a lot. Her life "has shrunk now". She admitted that she worries that her ME will become worse because of the ageing process, and thus worries about the future a lot. She also worries what will happen if something happens to her husband as the stress reaction could have a major effect on her body, leading to a further deterioration in her health. When her mother died, the stress caused her to relapse and she described being "clinically depressed".

Sheila

Sheila is 68 years old and lives with her husband. She has not worked since the age of 38 years old due to spinal problems; at this point she was sent for counselling, and did voluntary work. She currently volunteers for the NHS. Twelve years ago, Sheila had a double chest infection over Christmas and following this was "sleeping the clock around", for 18-20 hours a day. She went to her doctor, who sent her to the hospital for "shed loads of tests"- the results came back three months later and they were all normal. She recalled how her GP then diagnosed her with CFS/ME on the same day that it became recognised as a disease in the UK. He referred her to the CFS/ME clinic, where she did CBT with other people who she felt were worse off than her.

Sheila considered herself very fortunate that her GP was "very clued up" when she was diagnosed, however due to restructuring at the medical practice she attends it is common not to get the same GP so currently when she attends she often sees doctors she does not know.

Her CFS/ME does not involve any pain, and she considers herself fortunate in this way, however she was diagnosed with irritable bowel syndrome (IBS) shortly after the CFS/ME, which her doctor advised her was linked. Living with IBS means that she has difficulty planning things, because she needs to know where the toilets are; she needs to be close to a toilet 20-30 minutes after she has eaten. For this reason travelling is

very hard as she and her husband rely on public transport. She followed an exclusion diet for some time however this did not reduce her symptoms. She also has to turn down a lot of social invitations, especially where there is only one toilet, which she finds very frustrating and very distressing. Insomnia is also often a problem.

Sheila currently manages her symptoms without input from NHS services, as there "is no cure" so there is nothing they can offer her. Her only support relating to her condition is a monthly newsletter from the ME Association. She lives with many other physical health problems, but feels that CFS/ME is the worse one, with the fatigue and the restrictions from the associated IBS being the worst features of the condition.

Sheila does not see many people now; she used to do a lot of socialising but had to reduce this as the activity was making her ill. She and her husband have no family- they now have fewer friends due to having to reduce their social activities and being unable to plan things. She described how nobody asks her what it is like to live with CFS/ME. Some people do not believe her and think that she is "putting it on". She used to take part in many physical activities, such as aqua aerobics however now does not have the energy to even change into her swimsuit. As a consequence of her sedentary lifestyle through living with CFS/ME, she is concerned that she has put on weight.

Her husband has to help her with some aspects of personal care and does most things around the house due to her low energy levels; this is something that upsets her. She finds pacing very difficult. Stressful situations, such as anti-social neighbours, exacerbate her symptoms.

Sheila does not feel that attitudes have changed over the last 12 years since she was diagnosed. Sheila believes that the lack of recognition and understanding around the condition is due in part to the lack of a suitable name i.e. one that is not an acronym, as well as the fact that its name has changed several times. There is also a lack of celebrity support which would raise awareness.

Appendix B

Journal submission guidelines

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read them and follow the instructions as closely as possible.

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Manuscript preparation

1. General guidelines

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A typical manuscript will not exceed 30 pages including tables, references, captions and endnotes. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.

Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgements; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

Structured <u>abstracts</u> of 200 words are required for all manuscripts submitted. Primary headings should be: Objective, Design, Main Outcome Measures, Results, Conclusion.

Each manuscript should have 3 to 6 <u>keywords</u>.

Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance <u>here</u>.

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Description of the Journal's reference style.

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References in the text

In the text	
Placement	References are cited in the text by the author's surname, the publication date of the work cited, and a page number if necessary. Full details are given in the reference list. Place them at the appropriate point in the text. If they appear within parenthetical material, put the year within commas: (see Table 3 of National Institute of Mental Health, 2012, for more details)
Within the same parentheses	Order alphabetically and then by year for repeated authors, with in-press citations last. Separate references by different authors with a semi-

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	colon.
Repeat mentions in the same paragraph	If name and year are in parentheses, include the year in subsequent citations.
With a quotation	This is the text, and Smith (2012) says "quoted text" (p. 1), which supports my argument. This is the text, and this is supported by "quoted text"

	(Smith, 2012, p. 1). This is a displayed quotation. (Smith, 2012, p. 1)
Page number	(Smith, 2012, p. 6)
One author	Smith (2012) or (Smith, 2012)
Two authors	Smith and Jones (2012) or (Smith & Jones, 2012)
Three to five authors	At first mention: Smith, Jones, Khan, Patel, and Chen (2012) or (Smith, Jones, Khan, Patel, & Chen, 2012) At subsequent mentions: Smith et al. (2012) or (Smith et al., 2012) In cases where two or more references would shorten to the same form, retain all three names.
Six or more authors	Smith et al. (2012) (Smith et al., 2012)
Authors with same surname	G. Smith (2012) and F. Smith (2008) G. Smith (2012) and F. Smith (2012)
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Organization as author	The name of an organization can be spelled out each time it appears in the text or you can spell it out only the first time and abbreviate it after that. The guiding rule is that

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	the reader should be able to find it in the reference list easily.
	National Institute of Mental Health (NIMH, 2012) or
	(National Institute of Mental Health [NIMH], 2012)
	University of Oxford (2012) or (University of Oxford, 2012)
Author with two works in the same year	Put a, b, c after the year (Chen, 2011a, 2011b, in press-a)
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Classical work	References to classical works such as the Bible and the Qur'an are cited only in the text. Reference list entry is not

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Personal communication	References to personal communications are cited only in the text: A. Colleague (personal communication, April 12, 2011)
Unknown date	(Author, n.d.)
Two dates	(Author, 1959–1963) Author (1890/1983)
Notes	Endnotes should be kept to a minimum. Any references cited in notes should be included in the reference list.
Tables and figures	
Tables and	Put reference in the footnote or legend.

figures	
Reference list	
Reference list	
Order	Alphabetical letter by letter, by surname of first author
	followed by initials. References by the same single author
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	author are ordered after all references by the first author alone, by surname of second author, or if they are the same, the third author, and so on. References by the same author with the same date are arranged alphabetically by title excluding 'A' or 'The', unless they are parts of a series, in which case order them by part number. Put a lower-case letter after the year: Smith, J. (2012a). Smith, J. (2012b). For organizations or groups, alphabetize by the first significant word of their name. If there is no author, put the title in the author position and alphabetize by the first significant word.
Form of author name	Use the authors' surnames and initials unless you have two authors with the same surname and initial, in which case the full name can be given: Smith, J. [Jane]. (2012). Smith, J. [Joel]. (2012).

	If a first name includes a hyphen, add a full stop (period) after each letter: Jones, J.-P.
Book	
Book	
One author	Author, A. A. (2012). This is a book title: And subtitle. Abingdon: Routledge.
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Three authors	Author, A. A., Author, B. B., & Author, C. C. (2012). *This is a book title: And subtitle. Abingdon: Routledge.*
More authors	Include all names up to seven. If there are more than seven authors, list the first six with an ellipsis before the last.

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Organization as author	American Psychological Association. (2003). *Book title: And subtitle.* Abingdon: Routledge.
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Chapter	Author, A. A. (2012). This is a chapter. In J. J. Editor (Ed.), *Book title: And subtitle* (pp. 300–316). Abingdon: Routledge. Author, A. A. (2012). This is a chapter. In J. J. Editor & B. B. Editor (Eds.), *Book title: And subtitle* (pp. 300–316). Abingdon: Routledge. Author, A. A. (2012). This is a chapter. In J. J. Editor, P. P. Editor, & B. B. Editor (Eds.), *Book title: And subtitle* (pp. 300–316). Abingdon: Routledge.
Edited	Editor, J. J. (Ed.). (2012). *Book title: And subtitle.* Abingdon: Routledge. Editor, J. J., Editor, A. A., & Editor, P. P. (Eds.). (2012). Book title: And subtitle. Abingdon: Routledge. Editor, J. J., & Editor, P. P. (Eds.). (2012). *Edited online book: And subtitle*. Retrieved from http://www.xxxxxx

Edition	Author, A. A. (2012). *Book title: And subtitle* (4th ed.). Abingdon: Routledge.
Translated	Author, J. J. (2012). *Book title: And subtitle*. (L. Khan, Trans.). Abingdon: Routledge.
Not in English	Piaget, J., & Inhelder, B. (1951). *La genèse de l'idée de hasard chez l'enfant* [The origin of the idea of chance in the child]. Paris: Presses Universitaires de France.
Online	Author, A. A. (2012). *Title of work: Subtitle* [Adobe Digital Editions version]. Retrieved from http://www.xxxxxx
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Other article types	Editorial: Title of editorial. [Editorial]. (2012). *Title of Journal, 14*, 1–2. Author, A. A. (2010). Title of review. [Review of the book Title of book, by B. Book Author]. Title of Journal, 22, 123–231. doi:xx.xxxxxxxxxx
Article in journal supplement	Author, A. A. (2004). Article title. *Title of Journal, 42*(Suppl. 2), xx–xx. doi:xx.xxxxxxxxxx
Conference	
Conference	
Proceedings	To cite published proceedings from a book, use book format or chapter format. To cite regularly published proceedings, use journal format.
Paper	Presenter, A. A. (2012, February). *Title of paper*. Paper presented at the meeting of Organization Name, Location.

Poster	Presenter, A. A. (2012, February). *Title of poster*. Poster session presented at the meeting of Organization Name, Location.
Thesis	
Thesis	

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Unpublished work	
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Newspaper or magazi	
Newspaper or magazine	
	Author, A. (2012, January 12). Title of article. *The Sunday Times*, p. 1. Author, A. (2012, January 12). Title of article. *The Sunday Times*. Retrieved from http://www.sundaytimes.com

	Title of article. (2012, January 12). *The Sunday Times*. Retrieved from http://www.sundaytimes.com/xxxx.html
Report	
Reports	

Issued 2007; Revised 5 Dec 2014. Changes in this revision: more reference examples added.

Warning - not controlled when printed. Maintained by Head of Quality Management, Taylor & Francis Journals UK.

May or may not be peer-reviewed; may or may not be published. Format as a book reference.	Author, A. A. (2012). *Title of work* (Report No. 123). Location: Publisher. Author, A. A. (2012). *Title of work* (Report No. 123). Retrieved from Name website: http://www.xxxxxxxx.pdf
Working paper	Author, A. A. (2012). *Title of work* (Working Paper No. 123). Location: Publisher. Author, A. A. (2012). *Title of work* (Working Paper No. 123). Retrieved from Name website: http://www.xxxxxxxx.pdf
Discussion paper	Author, A. A. (2012). *Title of work* (Discussion Paper No. 123). Location: Publisher. Author, A. A. (2012). *Title of work* (Discussion Paper No. 123). Retrieved from Name website: http://www.xxxxxxxx.pdf
Personal communicati	
Personal communication	
	Personal communication includes letters, emails, memos, messages from discussion groups and electronic bulletin boards, personal interviews. Cite these only in the text. Include references for archived material only.

Other reference types	
Other reference types	
Patent	Cho, S. T. (2005). U.S. Patent No. 6,980,855. Washington, DC: U.S. Patent and Trademark Office.
Map	London Mapping Co. (Cartographer). (1960). Street map. [Map]. Retrieved from http://www.londonmapping.co.uk/maps/xxxxx.pdf
Act	Mental Health Systems Act, 41 U.S.C. § 9403 (1988).
Audio and visual media	Taupin, B. (1975). Someone saved my life tonight [Recorded by Elton John]. On *Captain fantastic and the* *brown dirt cowboy* [CD]. London: Big Pig Music Limited. Author, A. (Producer). (2009, December 2). *Title of*

Issued 2007; Revised 5 Dec 2014. Changes in this revision: more reference examples added.

Warning - not controlled when printed. Maintained by Head of Quality Management, Taylor & Francis Journals UK.

	podcast [Audio podcast]. Retrieved from http://www.xxxxx.com Producer, P. P. (Producer), & Director, D. D. (Director). (Date of publication). *Title of motion picture* [Motion picture]. Country of origin: Studio or distributor. Smith, A. (Writer), & Miller, R. (Director). (1989). Title of episode [Television series episode]. In A. Green (Executive

	Producer), *Series*. New York, NY: WNET. Miller, R. (Producer). (1989). *The mind* [Television series]. New York, NY: WNET.
Database	Author, A. A., Author, B. B., & Author, A. A. (2002). A study of enjoyment of peas. *Journal Title, 8*(3). Retrieved February 20, 2003, from the PsycARTICLES database.
Dataset	Author. (2011). National Statistics Office monthly means *and other derived variables* [Data set]. Retrieved March 6, 2011, from http://www.xxxxx.com If the dataset is updated regularly, use the year of retrieval in the reference, and using the retrieval date is also recommended.
Computer program	Rightsholder, A. A. (2010). Title of program (Version number) [Description of form]. Location: Name of producer. Name of software (Version Number) [Computer software]. Location: Publisher. If the program can be downloaded or ordered from a website, give this information in place of the publication information.

Issued 2007; Revised 5 Dec 2014. Changes in this revision: more reference examples added.

Section Three: Critical Appraisal

Word Count: 3,438 (excluding references)

Rachel Barcroft

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Critical Appraisal

This critical appraisal will describe my reflections on conducting the research project contained within

this thesis. I will describe the decision making processes which led to the direction and methodology that

this project took. I will reflect on the experience of designing, planning and conducting the research

project. Finally, I will also consider the strengths and limitations of this study as well as ideas for future

research.

Stage One: Choosing a Thesis Topic and Designing the Project

I completed a master's degree in health psychology some years before starting the clinical

psychology doctorate. There, I was particularly interested in the impact of long term conditions as well as

the concept of invisible illnesses; that is, conditions that impair an individual but cannot be seen by those around them. I was particularly interested in how others react to individuals when there is no visible evidence of an illness or impairment. However, I did not conduct any research in this area at this point, and thus this interest was not developed any further at this stage. Also at that time, I had a friend who had lived with chronic fatigue syndrome/ myalgic encephalomyelitis (CFS/ME) for several years. Unfortunately, she was often unable to attend events due to being ill or too fatigued; when this occurred, other friends or acquaintances were sometimes unsympathetic or doubtful of the extent to which she was ill. I observed that this seemed to be mainly due to her condition being invisible, as well as fluctuating, with people often being unable to understand how she was at times unable to perform activities that she had carried out days or weeks previously.

In the second year of my doctorate my interest regarding the relational aspects of long term conditions was reawakened when I worked in a chronic pain centre as part of my clinical health placement. The centre operated from a bio-psychosocial perspective and the psychology team used cognitive behaviour therapy (CBT) to help clients with chronic pain understand how their thoughts, feelings and behaviour had an effect on the pain they experienced, and vice versa. While this form of therapy was often successful in helping clients understand their chronic pain and improve their psychological wellbeing and quality of life, I was aware that many of them still expressed dissatisfaction and frustration with social and relational aspects of their lives. For many of my clients, it appeared that a significant proportion of the psychological distress that they were experiencing could be attributed to the attitudes of those around them rather than due to the pain or their having to adjust to life with a chronic pain condition. For example, some had friends who ceased inviting them out, believing them to be unable to take part in social activities because of their pain. For others, colleagues or acquaintances would joke about them being unable to take part in some activities. Unfortunately, this often meant that the person with chronic pain would feel excluded from activities or would report feeling 'a burden'.

By this point in my training, I had been introduced to the concept of psycho-emotional disablism (Thomas, 1999; Thomas, 2007) and I started to view these clients' difficulties from this perspective. It

seemed apparent to me that many of the problems that my clients described stemmed from the psycho-emotional disablism that they had experienced as a result of encounters with other people, in addition to the pain that they experienced. I wanted to explore the phenomenon in more depth and so this led me to design a research project as part of my thesis that would incorporate both ideas; psycho-emotional disablism and an invisible illness. I was particularly drawn to CFS/ME for two reasons; firstly, due to my friend's experiences and secondly, as an illness it has traditionally attracted controversy and stigma. I was aware that it was frequently negatively reported in the press and could remember reading headlines regarding 'yuppie flu' when I was growing up.

For logistical reasons, I decided to recruit through support groups; this would mean that I would not need to seek ethical approval from NHS ethics boards which can often be a lengthy process. Also, I was aware that there is a lack of funding relating to CFS/ME, and thus there is a lack of specialist services nationally, which would mean that I might have had difficulty accessing potential participants. I also knew that there were several CFS/ME organisations through which support groups ran, and thus decided that I would have a greater access to potential participants via this method. Furthermore, if people had negative experiences regarding accessing appropriate healthcare, they may be deterred from participating if the project was affiliated with the NHS or any other medical organisation, perhaps through a fear of losing whatever healthcare provision they currently had.

Stage Two: Recruitment and Research Interviews

Fortunately, the process of gaining ethical approval was straightforward and fairly short, and following this, I started to contact various associations with a view to contacting their members to advertise the project. Although the recruitment literature clearly stated the aim of the project and the perspective from which the research would be conducted, i.e. focusing on the psycho-emotional disablism experienced by individuals as a result of interactions with other members of society, I wondered whether participants would be suspicious or wary of a study conducted by a psychologist. As discussed in the research paper, there is an ongoing debate regarding whether CFS/ME has a mainly biological or psychological basis (Sharpe, Chalder, Palmer, & Wessely, 1997), with the majority of people living with

the condition as well as the CFS/ME associations and charities rejecting the idea that there is a largely psychological basis for the condition. Such is the strength by which some of the more extreme campaigners hold this conviction that researchers in this field have been the subjects of abuse and threats to cease this research. While I understood that this was an extreme outcome, I was nevertheless curious as to how people living with CFS/ME would receive a study being conducted by a psychologist.

Indeed, during the recruitment process I contacted many CFS/ME support groups in North West England in order to ask them to circulate the details of the study to their members; however one administrator of a support group advised me that he would not do so because he did not believe that CFS/ME had psychological causes and did not want to endorse my project by passing it on to his group. He also felt that CBT was completely ineffective in the management of the condition. My recruitment literature did not have any mention of psychological causes or CBT, however it was clear from this communication that the individual in question felt extremely strongly about the impact of this school of thought that it seemed that he had automatically interpreted an email from a psychologist to hold this position. In addition to this resistance, a small number of potential participants contacted me to find out more about my motives for conducting the research, and some of them wanted assurances that I would not be portraying them as having a condition with psychological causes. Some felt that this stance implied that their difficulties were 'all in the mind or head', meaning that they were somehow subconsciously responsible for their own difficulties. Others were keen to point out that there had been an established neurological/ biological cause to the condition and thus it did not have a psychological cause. It is interesting to consider the meaning behind this, as I felt that in holding the opinion that any psychological aspect to the condition was extremely negative, this actually stigmatised those who do live with psychological difficulties, in the same way that some members of society have stigmatised CFS/ME. I felt it was important when questioned on my own stance that I did acknowledge my belief that those living with CFS/ME may indeed experience psychological difficulties, however they were likely to be due to the nature of the condition, rather than the cause of the condition. I did want to acknowledge that there is often a psychological component, as I did not want to be complicit in reinforcing the attitude that psychological difficulties were shameful, and I was careful how I described this. Everyone who spoke to

me about this concern they held appeared satisfied with this answer and indeed many participants acknowledged their own psychological difficulties that had arisen from living with the condition.

When I started to interview the final twelve participants, some people were curious about my conducting the research for different reasons, mainly because they perceived CFS/ME to be an under-researched condition and one that is often neglected by the scientific community. They acknowledged that it was not considered a 'glamorous' area, nor one in which many people were interested. This actually appeared to be a significant factor in the number of people expressing an interest in participating in the study as many more potential participants than I needed offered to take part. I reflected that while this was advantageous for me personally, it only highlighted the societal and relational difficulties that people were experiencing as a result of living with CFS/ME. When some participants described how taking part in the process would use their energy - both physical and mental - in such a way that would require them to rest in bed for the remainder of the day or the day after, I interpreted this determination to participate to be another indicator of how neglected people living with CFS/ME felt in terms of research.

StageThree: The Interview Process

I chose to use unstructured interviews to allow participants to speak freely on the subject of psycho-emotional disablism and this meant that that they could direct the conversation toward any theme they wanted. Every participant described many instances of psycho-emotional disablism spanning all areas of their life; however the focus varied for each individual. For example, some participants spent more time discussing the healthcare system while others focussed on friends and family, and others still on the difficulties regarding media representation and the impact of celebrities discussing the condition. I was curious how the interview process would work. I expected that people's initial narratives would finish far sooner than they actually did; some people talked for half an hour uninterrupted, before expanding on their narratives through the follow up questions I posed. I reflected that this was possibly as a result of feeling unheard regarding the difficulties they had experienced regarding other people's attitudes towards their illness. It also seemed that having additional space in which to reflect on the

experiences that were particularly important to them meant that they gave more detailed, meaningful responses in this approach.

As discussed in the research paper, some participants had been offered CBT, sometimes in the form of individual therapy, or in groups organised through the specialist clinic to which they had been referred. Many of the participants described how useful they found CBT to be, which is in contrast to the opinions voiced extremely loudly by some. This aspect of the interview process was surprising to me as I expected my participants to hold similarly strong views on psychological methods as those I had read about, however those who discussed it found that learning about the impact of different thought processes on behaviour, as well as CBT coping skills such as relaxation and mindfulness, to be a positive experience. In fact, one participant described the huge improvement that understanding the thoughts, feelings, behaviour cycle had had on his relationship with his wife. These positive experiences from the participants led to me wondering whether the CFS/ME campaigners who were vociferous in denouncing any psychological intervention actually had any experience of these techniques. Alternatively, I also considered that individuals who had had a positive experience with psychological techniques would be more likely to put themselves forward for a research project conducted through a clinical psychology establishment.

I was aware throughout the whole process that the project was guided by many pre-conceived ideas I held regarding how people living with CFS/ME might be treated or perceived by society and so the use of a reflective journal throughout was invaluable in noticing how my opinions may be influencing the data. For example, I erroneously thought that most participants would have negative perceptions of psychological therapy, especially CBT as this was used in the controversial 'pacing, graded activity, and cognitive behaviour therapy: a randomised evaluation trial' (PACE trial, Sharpe et al., 2015; White et al., 2011), and so I was careful that my questions or body language when discussing this subject were as neutral as possible. Another element of the interviews that I reflected on was the use of support groups as a way through which I recruited, as well as an outlet for people living with the condition. Many participants stated that they had reservations regarding attending said groups, or socialising with people

from the groups, as they did not want to talk about CFS/ME all the time. Also, many of them believed that in order to be 'healthy' (i.e. recovered from CFS/ME) an individual should associate with healthy people. Two things struck me about these comments. Firstly, it appeared that perhaps some had internalised the negative messages from society about CFS/ME which then led them to feel they were deficient in some way while they still experienced the symptoms associated with CFS/ME. Indeed, many participants used words such as 'healthy' and 'normal' to describe a life without CFS/ME. This in turn led them to view others with the condition in a similarly negative way. Secondly, as participants discussed becoming 'healthy' or 'well again' as if living without CFS/ME was something that they could control, it appeared that messages from friends and family around them telling them they needed to start 'getting better' and 'think yourself well' influenced this reluctance to associate with other people living with CFS/ME. To me, these repeated messages suggesting that the participants living with CFS/ME were not doing enough for themselves to improve their wellbeing led to them feeling pressured to do something that they had limited control over, thus increasing their levels of distress. Nevertheless, the negative connotations regarding attending support groups left me questioning how useful the current support group model was to people. I also wondered how many others living with CFS/ME do not receive any of the emotional support provided by groups because they have similar views and thus stay away from this type of group. Many participants spoke of connecting with others through the use of online forums and social media instead.

Stage Four: Analysis and Writing up of the Data

So far, the process of recruitment and interviewing had been very interesting and relatively straightforward, however as I had not conducted any qualitative research before I was unsure exactly how to go about analysing the data. Even though I researched how to conduct thematic analysis (TA), particularly following the method as outlined by Braun and Clarke (2006), I still found it difficult to know where to start and how to handle what to me was a large amount of data. I understood that researchers used many methods to code and keep track of the themes and subthemes including post-it notes or other forms of paper records. Personally, I found that using an electronic spreadsheet to enter the codes that I

had initially marked on the transcripts to be useful to begin to separate quotes and ideas into themes. This enabled me to move coded data from one subtheme to another where necessary to find the best fit, and also to check how each subtheme may become part of a wider theme. This system led to me developing three themes that incorporated the many ways in which participants experienced psycho-emotional disablism. I also found it very helpful to continue to check subthemes and themes against the initial coding as analysis progressed as this helped to ensure that the original meaning was preserved. As I had not done any qualitative research before, this helped me remain confident that I was remaining as faithful as possible to the original coding.

Following the development of the themes, the next step involved writing up the results. Here, it felt it was necessary to represent each participant in order to ensure that each voice was heard, while still making sure that the quotes chosen were relevant to the theme being discussed.

My Reflections on the Project

Strengths and limitations of the study

CFS/ME is vastly under researched and underfunded. For example, in the USA, the National Institutes of Health (NIH) have published league tables showing the amount of funds provided for research for 265 diseases and conditions. In 2015, CFS/ME was ranked 249th out of 265 conditions and diseases, with only $6 million spent on research (NIH, 2016). This study therefore provides a much needed opportunity for people living with CFS/ME to participate in research and increase awareness of the difficulties they often experience. In particular, as some of these difficulties arise from the lack of research, such as the absence of a diagnostic test or effective treatment pathways, the study emphasises the effects that this lack of funding and therefore understanding has on the lives of those interviewed. The narrative framework provided an opportunity for in-depth description of living with CFS/ME and the summary stories enabled each participant's story to be heard.

A further strength of this research is that it attempts to integrate concepts from disability studies into the field of clinical psychology. One of the criticisms of clinical psychology is that it has been

accused of not engaging with critical disability studies (Goodley & Lawthom, 2006), instead focusing on viewing people with impairments from a rehabilitation perspective (Olkin & Pledger, 2003). When psychologists work with people with impairments, the focus of interventions has traditionally been on adjusting to life with the impairment, as well normalising experiences. However, this locates the difficulty within the individual, rather than acknowledging that society in many ways excludes and discriminates against people with impairments (Goodley & Lawthom, 2006; Simpson & Thomas, 2015). One of the aims of this research has been to consider how psychological distress experienced by participants has been as a result of a society that often excludes and discriminates against people with impairments, rather than focussing on internal processes to reduce this distress. A limitation of the study is that as qualitative research is not generaliseable to the general population, it should therefore not be assumed that all people have experienced similar difficulties in relation to psycho-emotional disablism.

I was aware that by highlighting the difficulties experienced by the participants in the research study, while emphasizing the strength and coping strategies that they demonstrated, I ran the risk of reinforcing the victim or tragedy model of disability, in particular the stereotype of the 'brave victim' (Morris, 2015). Also, the political climate in which the study was conducted was one of austerity, in which cuts to disability services, benefits and provisions were being discussed nationally in parliament as well as in the media. As Oliver (2013) states, campaigning against these cuts has often been carried out by people on behalf of those with impairments, undertaking 'special pleading', and thus situating disabled people as victims. However, in using a narrative interview approach and ensuring individuals were given a platform to describe their own opinions and difficulties, I hoped to avoid this stereotype by empowering participants to describe their strengths and difficulties in their own way.

Future Research.

As well as the ideas for future research presented in the research paper, there should also be an emphasis on methods to increase the awareness of CFS/ME. This should be targeted at organisations such as workplaces and governmental organisations that are routinely involved in CFS/ME in order to educate on this complex condition, as well as to reduce the stigma that still prevails in society.

Dissemination.

Given the considerable support I received from the majority of the support groups I contacted in the North West of England, I will produce a short summary of the findings for dissemination via their websites and newsletters. I intend to submit the research paper to *Psychology and Health* and the literature review to *Health Psychology*. Many of the participants expressed an interest in reading the study when it was published, and one individual, who also helped put together the local support group newsletter, offered to print a summary of the results within this at a later date. This was, I felt, especially pertinent given the considerable effort that many of the participants went to in participating.

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Section Four: Ethics Application Process

4-101

Rachel Barcroft

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

**Application for Ethical Approval for Research involving
direct contact with human participants**

Instructions *[for additional advice on completing this form, hover PC mouse over 'guidance']*

1. Apply to the committee by submitting:

   a. **The University's Stage 1 Self Assessment (part A only) and the Project Questionnaire. These are available on the Research Support Office website:** LU Ethics

   b. **The completed application FHMREC form**

   c. **Your full research proposal (background, literature review, methodology/methods, ethical considerations)**

   d. **All accompanying research materials** such as, but not limited to,

      1) Advertising materials (posters, e-mails)
      2) Letters/emails of invitation to participate
      3) Participant information sheets
      4) Consent forms
      5) Questionnaires, surveys, demographic sheets
      6) Interview schedules, interview question guides, focus group scripts
      7) Debriefing sheets, resource lists

   Please note that you DO NOT need to submit pre-existing handbooks or measures, which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. **Submit all the materials electronically** as a **SINGLE email attachment in PDF format** by the deadline date. **Before converting to PDF ensure all comments are hidden by going into 'Review' in the menu above then choosing** *show markup>balloons>show all revisions in line.*

3. **Submit one collated and signed paper copy** of the full application materials in time for the FHMREC meeting. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.

4. Committee meeting dates and application submission dates are listed on the FHMREC website. Applications must be submitted by the deadline date, to:

   Dr Diane Hopkins
   B14, Furness College
   Lancaster University,
   LA1 4YG
   d.hopkins@lancaster.ac.uk

5. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application.

6. Attend the committee meeting on the day that the application is considered, if required to do so.

---

1. **Title of Project**: Narratives of living with chronic fatigue syndrome: a social model of disability perspective

2. **Name of applicant/researcher**: Rachel Barcroft

> [empty box]

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3. **Type of study**

✓ Includes *direct* involvement by human subjects.

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. Please complete the University Stage 1 Self Assessment part B. This is available on the Research Support Office website: LU Ethics**. Submit this, along with all project documentation, to Diane Hopkins.**

---

4. If this is a student project, please indicate what type of project by marking the relevant box: (please note that UG and taught PG projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐   Masters dissertation ☐   DClinPsy SRP ☐   PhD Thesis ☐   PhD Pall. Care ☐

PhD Pub. Health ☐   PhD Org. Health & Well Being ☐   PhD Mental Health ☐   MD ☐

DClinPsy Thesis ✓

Applicant Information

5**. Appointment/position held by applicant and Division within FHM**   Trainee Clinical Psychologist

6**. Contact information for applicant**:

E-mail: r.barcroft@lancaster.ac.uk   **Telephone**: 07830013259 (please give a number on which you can be contacted at short notice)

Address: Lancaster University

7. **Project supervisor(s), if different from applicant**:   Dr Jane Simpson

Prof Carol Thomas

8. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**:

Dr Jane Simpson - Research Director and Senior Lecturer, Division of Health Research, Lancaster University

Prof Carol Thomas – Professor of Sociology, Centre for Disability Research, Lancaster University

9. **Names and appointments of all members of the research team (including degree where applicable)**

Rachel Barcroft, Trainee Clinical Psychologist

Dr Jane Simpson

Prof Carol Thomas

The Project

NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. **Summary of research protocol in lay terms (indicative maximum length 150 words**):

The aim of the study is to explore what it is like to live with Chronic Fatigue Syndrome (CFS), with a particular focus on any discrimination, stigma or other negative social encounters that the participants have experienced. The study will look at these issues from the perspective of the social model of disability and as such these negative experiences will be framed as psycho-emotional disablism where appropriate.

11. **Anticipated project dates (month and year only**)

Start date: August 2015   End date: May 2016

12. **Please describe the sample of participants to be studied (including maximum & minimum number, age, gender**):

Participants will be adults living in the UK who have received a diagnosis of CFS or ME and have been living with the condition for at least one year. I aim to recruit between six and twelve participants. Exclusion criteria would be the presence of unrelated, acute, significant illness. For example, a serious illness such as cancer which would require invasive medical treatment, surgery or multiple hospital stays or appointments meaning that the illness or condition would have a significant impact on the participants' psychological or physical wellbeing and thus their ability to take part**.**

13. **How will participants be recruited and from where? Be as specific as possible**.

I plan to recruit by initially accessing regional support groups in the north-west of England to inform them of my study. There are a number of groups in the North-West, including in Bury/Bolton, Stockport, Ashton/Leigh/Wigan, East Lancashire, and Central Manchester/Salford. I will contact them via email or letter (Appendix 2, 5), to ask permission to recruit at their meetings. I will hand out information sheets and consent forms (if permitted) to potential participants during these meetings.

Should I not gain enough participants from recruiting via support groups, I will then recruit by advertising online, contacting potential participants using social networking methods. There are many organisations dedicated to people living with ME/CFS, such as 25% ME group, Action for ME, Association of Young people with ME, Forward ME, Action 4 ME, ME Action UK and the ME Association, and I intend to contact them via Facebook and Twitter to advertise my study. I will also email organisations giving my university email address and will use a university research mobile phone to make calls and texts.

14. **What procedure is proposed for obtaining consent**?

I will briefly outline the aim of the study to potential participants in the recruitment posters, information sheets and in direct contact with them. I will also give them the participant information sheet which explains in more detail what will happen if they wish to take part. I will also give them the consent form which outlines anonymity, confidentiality and data storage procedures so that they have enough information to make an informed decision.

I will ensure that participants have time to fully consider taking part in the study by giving them a minimum of five days from initial contact and handing out of the information sheet / consent form to them giving consent to take part.

15. **What discomfort (including psychological e.g. distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks**.

Any potential discomfort will be minor and will be related to the time burden of taking part in a detailed interview. This will be addressed by given full information regarding the procedures of the study, so that participants can make fully informed consent. It will be made clear in the consent form, information sheet and before commencement of the interview that the participants have the right to withdraw at any stage and with no consequences. Interviews will be scheduled at a time and place convenient to the participant. It is expected that most of the interviews will take place during working hours. Arrangements can be made to interview participants outside of this environment if required, for example at their home. In the event of this occurring Lancaster University's lone worker policy will be followed (see Appendix). In the event of participants experiencing any distress in the course of the interview, they will have the option to postpone the interview or to withdraw entirely from the study. They will be given a debrief sheet with relevant contact details of organisations that can provide information or support. I will also make it clear during the recruitment and information process that participants are free to stop the interview at any time, should they be experiencing fatigue or any other physical difficulty that would impact on their ability to take part in the interview. Participants may rearrange or cancel interviews if they are not feeling able to take part in order to eliminate any pressure to take part when not feeling able to. If participants wish, they will also be able to continue the interview on another day, so that they do not become too fatigued.

16. **What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take**).

The researcher will be carrying out one to one interviews, and these are likely to be held in participants' homes. The relevant lone worker policy will be followed (see Appendix 6). This will entail using a buddy system, as well as the academic and/or field supervisor being aware of the whereabouts of the chief investigator, with plans made to check in by phone at the start and end of each interview. Should I fail to check in at the end of the interview, the buddy will call my phone to check my whereabouts (I will ask them to set an alarm on their phone for when the interview should be ending). If I do not answer the phone, the buddy will contact the course to advise that they cannot contact me.
Details of my whereabouts will be provided in such a way as to ensure the confidentiality of the participant, as appropriate (e.g. in a sealed envelope to be opened in the event that I am not contactable).

17. **Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study**.
There are no direct benefits to participation and this is made clear in the participant information sheet (Appendix 1).

18. **Details of any incentives/payments (including out-of-pocket expenses) made to participants**:

Up to £10 travel expenses can be claimed by the participant.

19. **Briefly describe your data collection and analysis methods, and the rationale for their use. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality**.

The study will qualitative, using interviews which will be analysed using narrative analysis (NA). Chronic illness has been described as a disruption in a person's life, and as part of an attempt to make sense of this disruption, the person will seek to integrate this event into their life story. As NA involves asking participants to tell their story in their own words regarding a particular event in, or aspect of their life, it is an ideal method of collecting and analysing the data. This also means that because the interviewee is asked to provide an account of their experiences in their own words, rather than participating in a question-answer format as used in other types of analysis, the story is told in the order that they choose, using their own words. Each interview will be audio-recorded and transcribed verbatim by the researcher to an appropriate level of detail. Confidentiality- participant information will be kept confidential throughout the study, in line with Lancaster University guidelines. Exceptions to this would be if I am concerned for the participant's safety, or another person's safety, in which case I would

have to break confidentiality by contacting the appropriate parties (e.g. safeguarding teams, or the university), after discussion with my supervisor. If participants are recruited through support groups, the organisers of these groups will not be told who has participated or be given any information regarding numbers of people expressing an interest in the research. The academic supervisor of the study will have access to these details, and will listen to some of the audio recording to ensure accuracy of transcription and quality of interview style. Anonymity- the personal details of participants will not be published. Pseudonyms will be used when using direct quotes in the final write up, and the service and any identifying features including geographical location and participant information will be disguised.

20. **If relevant, describe the involvement of your target participant group in the *design and conduct* of your research**.

I have shown the recruitment documents to a member of LUPIN who lives with CFS. On the basis of their feedback, I have redesigned the poster to make it more eye catching. I have also made it clear on the PIS that interviews can be conducted over more than one meeting.

21. **What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998**.

All electronic data will be anonymised and encrypted. Electronic data will be stored on the secure Lancaster University network, which is accessible both on and off university premises through the Virtual Private Network (VPN). Hard copies of completed transcripts will be anonymised and stored in a locked cabinet during the coding process, these will then be transferred to Lancaster University at the earliest possible time. Hard copies of the consent form will be kept separately from the transcripts and will be transferred to Lancaster University at the earliest possible time. This data will be securely stored within the Division of Health Research in line with Lancaster University policy and the Data Protection Act 1998. Data will be stored at the university for ten years; if the decision is taken to publish this work, data will be stored for a further five years from the date of publication.

22. Will audio or video recording take place?　　　　　**X**　audio

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

The audio recordings of the interviews will be downloaded and stored electronically and encrypted on a USB pen drive. The original recordings on the digital audio recorder will then be erased.

Data on portable devices will be deleted as quickly as possible (after being transferred to a password protected PC). In the meantime, the recorder will be stored securely.

The data will be transferred securely to the Research Coordinator. The data will be destroyed ten years after submission of the thesis.

23. **What are the plans for dissemination of findings from the research? If you are a student, include here your thesis**.

It is expected that the final study will be submitted in partial fulfilment of the Doctorate in Clinical Psychology in May 2016, with a viva examination in summer 2016. It will also be submitted to a relevant journal (yet to be identified) for publication.

24. **What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC**?

It may be that participants become distressed during the interview when discussing difficult experiences. Should this happen, they can stop the interview at any time, and have a break, or withdraw completely. They will be provided with a list of organisations that will be able to provide support.

Signatures: Applicant: …………………….…………………….................................

Date: ………………………………………….................................

*Project Supervisor (if applicable): ……………………………………........................

Date: ………………………………………….................................

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

Experiences of living with chronic fatigue syndrome: a social model of disability perspective

Research Protocol, Version 3. July 2015. Principal Investigator- Rachel Barcroft

Academic supervisor – Dr Jane Simpson, Lancaster University.

Field supervisor – Professor Carol Thomas, Lancaster University.

Introduction

Some types of illness are often referred to as invisible or hidden disabilities, as they are not immediately obvious to other people. These include asthma, juvenile rheumatoid arthritis, epilepsy, fibromyalgia, chronic pain, congenital heart disease, muscular dystrophy and celiac disease (Valeras, 2010). Chronic fatigue syndrome (CFS) - sometimes known as myalgic encephalomyelitis (ME) or post-viral fatigue syndrome (PVFS; Burgess & Chalder, 2005) - is also one such condition. People who live with CFS can experience difficulties such as extreme fatigue, pain and weakness in the muscles, memory and concentration difficulties (Evengard, Schacterler & Komaroff, 1999), and sore throats and headaches (Burgess & Chalder, 2005). The severity of the condition varies in each individual, and affects people's lives in different ways. In some cases, people may cease employment or studying and may reduce social activities and family engagements (Burgess & Chalder, 2005).

As well as the physical effects of the condition and the sometimes profound effects on an individual's lifestyle, CFS has also always attracted controversy and debate (Smith & Wessely, 2014), which can cause additional distress to the individual. For instance, CFS has not always been recognised in the medical community as a genuine condition (Horton-Salway, 1998; Mountstephen & Sharpe, 1997). For example, when it was hypothesised that patients at the Royal Free Hospital in the UK had contracted the illness after an epidemic of a

virus, McEvedy and Beard (1970, p11) suggested that the symptoms experienced by these patients could be due to 'mass hysteria on the part of the patients'. CFS has also been referred to as a 'fad' illness (Horton-Salway, 2007) and moreover, for decades, it has been seen by some psychiatrists as 'all in the mind' (Couper, 2000, p764). The fact that there is no specific test to identify CFS, meaning that other conditions have to be ruled out before a diagnosis can be made (NICE, 2007), also appears to be a factor in its lack of recognition as being a serious condition. Over time the impact of these opinions and publications have had a damaging effect on the reputations of those who live with the condition. This lack of acknowledgement led to a number of support groups being formed, notably the ME Association, which has campaigned for CFS to be recognised as a genuine condition (Shepherd, 1995).

People living with CFS can have difficulties receiving appropriate levels of support from health professionals (Davidson, 2005) or employers (Moss & Dyck, 1999); however it is not only people living with CFS who may experience discrimination or difficulties being accepted in society as a result of their impairment or long term condition. Over the years, sociologists and other academics have studied how people who live with physical impairments live in society, as well as any difficulties that they may face. The most influential model of disability is arguably the social model of disability (Oliver, 1983). This contended that it is the structural deficiencies as well as disablist attitudes of society, and the consequent exclusion of people with impairments which actively disables people, rather than the impairment itself. This definition of disablism has been extended by Thomas (2007, p73) using the phrase 'psycho-emotional dimensions of disability' to refer to how negative interactions (such as ignoring or verbal abuse) can impact on a person's psychological wellbeing. People who live with 'hidden' long-term illnesses or disabilities often experience discrimination from friends, family, employers and colleagues due to others being unaware of the nature of the impairment, or not fully understanding or believing the extent of the individual's impairment (Åsbring & Närvänen, 2012). As in other invisible illnesses such as chronic headaches, people living with CFS face a dilemma regarding disclosing their condition, which can lead to stigma and discrimination, or concealment, which means a lack of social support (Lonardi, 2007).

Over the years, progress has been made in building a convincing argument that there is a biological basis for CFS, with recent research adding to this argument (Hornig et al., 2015). Despite this, however, it continues to be a controversial illness, with people living with CFS still encountering a lack of acceptance from some areas of society about the authenticity of the condition. One aspect of the condition that has been argued as contributing to this lack of acceptance is its name. In the USA, the Institute of Medicine (IOM) asserts that the name 'Chronic Fatigue Syndrome' perpetuates misunderstanding of the illness and therefore has recently proposed that a new name, 'systemic exertion intolerance disease' (SEID) should be adopted in order to more accurately describe the condition and to be accepted by both those in the medical professions and the general public (IOM, 2015).

Given that CFS remains a controversial illness with its name and diagnostic criteria still being discussed in an attempt to gain appropriate recognition, research into the impact that living with this poorly understood condition is still as relevant now as when it was first debated.

The aim of this study will therefore be to explore what it is like to live with CFS, with a particular focus on any psycho-emotional disablism that participants may experience. Participants will be recruited through support groups and interviewed regarding their experiences.

The present research will investigate how the attitudes in general of people in contact with the participants (e.g. family members, friends and acquaintances), as well as society (e.g. health services, government, popular culture and media) impact on the self-worth of the participants interviewed.

Method

Participants

This will be a qualitative study using purposive sampling to obtain a sample size of between six and twelve participants. Participants will be adults living in the UK who have received a diagnosis of CFS or ME and have been living with the condition for at least one year. Exclusion criteria would be the presence of unrelated, acute, significant illness. For example, a serious illness such as cancer which would require invasive medical treatment, surgery or multiple hospital stays or appointments meaning that the illness or condition would have a significant impact on the participants' psychological or physical wellbeing and thus their ability to take part**.**

Materials

Equipment used for the recording and transcription of the interviews will be used by Lancaster University (e.g. digital recorder, pedal for transcription). Participant information sheets, consent forms, debrief sheets, and recruitment posters will also be used (see appendix).

Procedure

I intend to approach organisers of local CFS/ME support groups to ask permission to directly address members of these groups to inform them of my study, and to leave recruitment literature with them, should they wish to contact me to find out more information (Appendix 2, 5). I will hand out information sheets and consent forms (if permitted) to potential participants during these meetings. There are a number of groups in the North-West, including in Bury/Bolton, Stockport, Ashton/Leigh/Wigan, East Lancashire, and Central Manchester/Salford. I will apply the Lone Worker Policy for Lancashire Care Foundation Trust as well as the Lancaster University guidance on lone working (see appendix) when I visit any of these establishments.

Should I not gain enough participants from recruiting via support groups, I will then recruit by advertising online, contacting potential participants using social networking methods. There are many organisations dedicated to people living with ME/CFS, such as 25% ME group, Action for ME, Association of Young people with ME, Forward ME, Action 4 ME, ME Action UK and the ME Association, and I intend to contact them via Facebook and Twitter to advertise my study. I will also email organisations giving my university email address and will use a university research mobile phone to make calls and texts. I will use email and phone to make initial contact and to

informally discuss participation, and then will send information sheets to potential participants for them to make an informed decision regarding participation.

Interviews will be scheduled to take place at a time and place convenient to the participant. It is expected that most of the interviews will take place during working hours. If possible, I will interview participants at the venue where they hold the support meetings, if this is available. I will also offer to interview people at their home. At all times the lone worker policy will be followed (appendix). The academic and/or field supervisor will be made aware of the whereabouts of the principal investigator.

The interviews themselves are expected to last for approximately one hour, although this is flexible and may vary. I will make it clear during the recruitment and information process that participants are free to stop the interview at any time, should they be experiencing fatigue or any other physical difficulty that would impact on their ability to take part in the interview. Participants may rearrange or cancel interviews if they are not feeling able to take part in order to eliminate any pressure to take part when not feeling able to. If participants wish, they will also be able to continue the interview on another day, so that they do not become too fatigued.

Proposed analysis

Data from the interviews to be conducted will be analysed using narrative analysis (NA). This method will be used for several reasons. Firstly, NA is concerned with the analysis of the stories that people construct in order to organise and create meaning to events in their lives (Clandinin & Connelly, 2000). Chronic illness has been described as a disruption in a person's life, and as part of an attempt to make sense of this disruption, the person will seek to integrate this event into their life story (Bury, 1982). As NA involves asking participants to tell their story in their own words regarding a particular event in, or aspect of their life, it is an ideal method of collecting and analysing the data. This also means that because the interviewee is asked to provide an account of their experiences in their own words, rather than participating in a question-answer format as used in other types of analysis, the story is told in the order that they choose, using their own words and may thus be a more authentic account of their experience (Bauer, 1996). Thirdly, many proponents of NA value its ability to be subjective (Smith, 2000), and given that this project will involve analysing pre-identified themes (e.g. stigma, discrimination etc), it is better suited for this project than other qualitative methods of analysis, such as grounded theory and interpretative phenomenological analysis.

Each interview will be audio-recorded and transcribed verbatim by the researcher to an appropriate level of detail. Also, a reflective diary will be kept throughout the data collection phase, which will enable me to be transparent regarding my own thoughts, preconceptions and attitudes (Robson 1993).

Practical issues (e.g., costs/logistics)

Travel costs for the principal investigator to travel to interviews will be incurred. Participants will be reimbursed up to £10 for their travel expenses where costs have been incurred. There will also be printing and photocopying costs. This will be covered by Lancaster University.

Data storage

The audio recordings of the interviews will be downloaded and stored electronically and encrypted on a USB pen drive. The original recordings will then be erased. All electronic data will be anonymised and encrypted. Data on portable devices will be deleted as quickly as possible (after being transferred securely to the Research Coordinator. The data will be destroyed ten years after submission of the thesis. Electronic data will be stored on the secure Lancaster University network, which is accessible both on and off university premises through the Virtual Private Network (VPN). Hard copies of completed transcripts will be anonymised and stored in a locked cabinet during the coding process, these will then be transferred to Lancaster University at the earliest possible time. Hard copies of the consent form will be kept separately from the transcripts and will be scanned and stored electronically at the university. This data will be securely stored within the Division of Health Research in line with Lancaster University policy and the Data Protection Act 1998. Data will be stored at the university for ten years and will be destroyed ten years after the submission of the thesis.

Ethical concerns

Talking about any difficulties that the participants may have experienced since living with CFS is an emotive subject and it may be that participants become distressed or angry during the interview process. The debrief sheet will therefore provide contact details for support services available, e.g. Samaritans, ME Association, Disability Rights UK, Association of young people with ME.

Potential participants may become fatigued or have other physical difficulties either before or during the interview and so it will be made clear to them that they can re-arrange the interview if they do not feel able to take part on that day, or they can stop for a break if they so choose.

Confidentiality- participant information will be kept confidential throughout the study, in line with Lancaster University guidelines. If participants are recruited through support groups, the organisers of these groups will not be told who has participated or be given any information regarding numbers of people expressing an interest in the research. The principal investigator will have access to personal details including contact details. The academic supervisor of the study will have access to these details, and will listen to some of the audio recording to ensure accuracy of transcription and quality of interview style.

 If home visits are conducted then contact details will be provided to the individual who agrees to be the buddy in line with lone worker policy, however they will agree beforehand to delete all contact details on completion of the relevant interview, and will be reminded of this to ensure that the participants' data are protected.

The researcher will inform participants that if he or she discloses information that is considered to place themselves or others at immediate harm, the researcher will have to share this information with the relevant individuals and/or authorities, including the academic supervisor of the study.

Anonymity- the personal details of participants will not be published. Pseudonyms will be used when using direct quotes in the final write up, and the service and any identifying features including geographical location and participant information will be disguised.

Risk management-it is possible that the participants may become upset or distressed during the interview process. Participants will be reminded at the start of the interview that they can decline to answer any question that they do not feel comfortable with, and can withdraw from the study up to two weeks after the interview. Should a participant become distressed during the interview process, they will be given the option to stop and take a break. They can terminate the interview at any time.

Dissemination

It is expected that the final study will be submitted in partial fulfilment of the Doctorate in Clinical Psychology in May 2016, with a viva examination in summer 2016. It will also be submitted to a relevant journal (yet to be identified) for publication.

 Timescale

April / Aug- write ethics proposal and submit amendments by end of Aug.

Sep- Dec 2015 conduct data collection for study. Transcribe and code data.

November 2015 – first draft of research paper

December 2015 – first draft of research paper (intro and method)

Jan- March 2016- Analyse data. Hand in draft introduction and method by end of Jan. Write draft references. Hand in first draft of complete research paper by end of March.

Apr/ May- Complete final version of research paper.

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Appendix A

Participant Information Sheet

Narratives of living with chronic fatigue syndrome: a social model of disability perspective

My name is Rachel Barcroft and I am conducting this research as part of my Doctoral qualification in Clinical Psychology at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore the experiences of people living with Chronic Fatigue Syndrome, with particular emphasis on psychological distress encountered as a result of interactions with others, e.g. family members, strangers, employers etc.

I will explore how the attitudes in general of people in contact with the participants (e.g. family members, friends, employers and acquaintances), as well as society (e.g. health services, government, popular culture and media) impact on the self-worth of the participants interviewed.

Why have I been approached?

You have been approached because the study requires information from people who have a diagnosis of CFS, and who have encountered discrimination, stigma or psychological distress as a result of others' attitudes regarding your condition.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. Your participation will not be shared with anyone and the research is not related to any medical service, so will not affect any medical/ health related treatment that you are receiving now or in the future.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to take part in an interview with the researcher, which would last between approximately 45 minutes and 1 hour 15 minutes (with as many breaks as needed). The interview can be conducted over more than one meeting if preferred.

The interview would be arranged at a mutually convenient place and time, and travel expenses of up to £10 will be paid if you have to pay to get there. An interview in your home can be arranged.

Will my data be Identifiable?

The information you provide is anonymous. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

o   Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
o   The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
o   At the end of the study, hard copies of any data will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
o   The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
o   All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in my thesis and may be submitted for publication in an academic or professional journal.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher: Rachel Barcroft; r.barcroft@lancaster.ac.uk.

Trainee Clinical Psychologist
Division of Health Research
Lancaster University
Lancaster
LA1 4YD
Tel: TBC

Telephone: XXXXX

Supervisors:

Dr Jane Simpson
Address: Division of Health Research, Faculty of Health & Medicine, Furness Building, Lancaster University, Bailrigg, Lancaster, LA1 4YT.
Phone: 01524 592858
Email: j.simpson2@lancaster.ac.uk

Professor Carol Thomas
Division of Health Research, Furness Building, Lancaster University, Bailrigg, Lancaster
LA1 4YG
Phone: 01524 594092
Email: c.thomas@lancaster.ac.uk

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance. .....

Samaritans

Provides 24 hr confidential support for people in distress and despair.

Tel: 08457 90 90 90. Email: jo@samaritans.org

ME Association

Informing and supporting those affected by ME / CFS

ME Connect helpline: 0844 576 5326 - **open every day of the year between these times: 10am-12, 2-4pm, 7-9pm.** Email: meconnect@measociation.org.uk

Disability Rights UK

Provides information, products and services developed by and for disabled people.

http://www.disabilityrightsuk.org/how-we-can-help/helplines-0

Association of young people with ME

Helpline & Information Service

Tel: 08451 232 389

Email: helpline@ayme.org.uk

Appendix B

Letter/ email request to advertise the study to support groups

Date:
Address:

Dear Sir/Madam,

My name is Rachel Barcroft and I am a Trainee Clinical Psychologist from Lancaster University. I am currently undertaking a research project as part of my Doctorate in Clinical Psychology. I am seeking to invite between 6-12 participants to interview so that I can listen to their stories about living with Chronic Fatigue Syndrome, with a particular emphasis on the attitudes in general of people in contact with the participants (e.g. family members, friends and acquaintances), as well as society (e.g. health services, government, popular culture and media).

I am writing to ask if it would be possible to attend one of your meetings to inform the members of your support group about my study. I am also asking if it would be possible for you to put a recruitment poster up to inform people of my study.

In conducting this research I hope to provide people living with CFS the opportunity to tell their stories so that the psychological implications can be more clearly understood.

This research has been reviewed and approved by the Faculty of Health and Medicine Ethics Committee at Lancaster University. If you would be prepared to assist me with these requests, or if you would like further information, please do not hesitate to contact me on [TEL XXXX] or email r.barcroft@lancaster.ac.uk.

I would like to thank you for taking the time to consider this request.

Yours sincerely

Rachel Barcroft
Trainee Clinical Psychologist
Lancaster University

Appendix C

Consent Form

Study Title: Narratives of living with chronic fatigue syndrome: a social model of disability perspective

We are asking if you would like to take part in a research project exploring the experiences of people living with Chronic Fatigue Syndrome.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Rachel Barcroft.

Please initial each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study.

2. I confirm that I have had the opportunity to ask any questions and to have them answered.

3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.

4. I understand that audio recordings will be kept until the research project has been examined.

5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.

7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.

8. I consent to information and quotations from my interview being used in reports, conferences and training events.

9. I understand that information I give will remain strictly anonymous unless it is thought that there is a risk of harm to myself or others, in which case this information will be shared with the research supervisor.

10. Data will be shared and discussed with the research supervisor.

11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.

12. I consent to take part in the above study.

Appendix D

Debrief Sheet for Participants

Narratives of living with chronic fatigue syndrome: a social model of disability perspective

Thank you for taking part in this study; your time and contribution are greatly appreciated.

Your participation in this study will remain anonymous and if quotes are used in my study, I will remove any identifying information. If you decide that you have changed your mind and wish to have what you have told me removed from the study, you can withdraw from the study without giving a reason. Any information that you have given will be withdrawn from the study if it has not already been included in the analysis. The analysis will begin approximately two weeks after the interview has taken place. Once analysis of the data has begun, it will not be possible to withdraw your data, however this data will of course be anonymised and all identifying features removed.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance. .....

Samaritans

Provides 24 hr confidential support for people in distress and despair.

Tel: 08457 90 90 90. Email: jo@samaritans.org

ME Association

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Association of young people with ME

Helpline & Information Service

Tel: 08451 232 389

Email: helpline@ayme.org.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
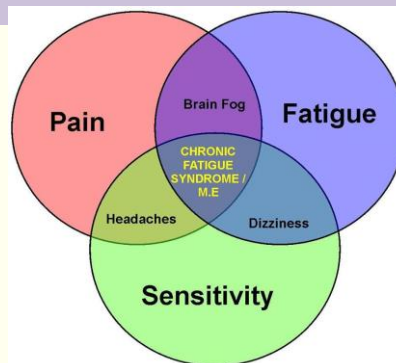Lancaster University
Lancaster
LA1 4YG

Appendix E

Recruitment Poster

Are you affected by Chronic Fatigue Syndrome/ ME?
Are you willing to share your story?

I'm Rachel, a Clinical Psychology trainee, and I'm researching how Chronic Fatigue Syndrome and ME affects people.

I would like to hear about your experiences of the attitudes of other people and society in general to your condition .

If you are interested in taking part, I would interview you at a time and location that is suitable to you. This can be done over more than one meeting.

For more information please contact Rachel Barcroft
[TEL XXXXXX]
r.barcroft@lancaster.ac.uk

Health & Medicine | Lancaster University

Appendix F

Narrative interview

The question to be asked to participants to share their stories:

"I am interested in finding out about your personal experience of being diagnosed with and living with Chronic Fatigue Syndrome, and how this has affected your relationships and role in society. Please include in your story any events and experiences that you think are important. Please start wherever you like and take as much time as you need. I will be listening but will not interrupt you."

Appendix G

Ethics Approval Letter

Research and Enterprise
Services Division | **Lancaster University**

Applicant: Rachel Barcroft
Supervisor: Dr Jane Simpson
Department: DHR
UREC Reference: RS2014/46

30 September 2015

Dear Rachel,

Re: Narratives of living with chronic fatigue syndrome: a social model of disability perspective

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);

- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

S.C. Taylor

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, Professor Roger Pickup (Chair, FHMREC); Prof Stephen Decent (Chair, UREC).

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