

**From legislative intent to current practice:
a relational constructionist perspective on
The Mental Capacity Act 2005
and legal consciousness in hospice decision-making.**

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy. The candidate has already achieved 180 credits for assessment of taught modules within the blended learning PhD programme.

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

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Abstract

Hospice care encompasses physical treatment and emotional, social and spiritual support which recognises what is important to each patient and supports decision-making where patients cannot make decisions for themselves. The Mental Capacity Act 2005 (MCA) regulates decision-making for people without capacity. Post-legislative scrutiny of the Act (in 2014) concluded that it is neither well understood nor working well in practice. The research aim is to describe how the Act's principles are understood and interpreted in hospice practice, specifically considering the patient's role in the decision-making process.

A relational constructionist approach is adopted, situating hospice care within an ethic-of-care understanding of decision-making, adopting a socio-legal perspective and understanding compassion as a concept relevant to the legal process. An innovative genealogical analysis of policy and legislative documents (n=24) influencing the 'coming to be' of the Act and a systematic review of Court of Protection judgments (n=63) 'historicise' the empirical research. Two group interviews and six individual interviews (13 participants from 2 hospices) provide empirical data. Legal consciousness theory influences analysis of the interview data.

In the findings, the hospice is characterised as expert, the guardian of a proper process, 'holding' both patient and family members and recognising the patient's wishes and feelings as fundamental to a good decision. The availability of time to understand a patient's narrative and the collegiate, supportive nature of the multi-disciplinary team are important factors in hospice decision-making.

In conclusion, hospice staff benefit from having time to understand a patient's narrative and to make decisions within a reciprocal hospice-patient relationship, informed by an ethic-of-care approach. The understanding of hospice as a 'movement' (being distinctly and self-consciously different from other settings) influences the legal consciousness of hospice staff such that compliant decision-making is considered to be part of good quality care rather than simply reflecting a legally acceptable approach.

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CHAPTER 1

Introduction: the architecture of the thesis

1.1 Introduction

This is a study concerned with law and with people, specifically hospice staff caring for patients approaching the end of their lives. Within that particular context, it is concerned with the process of making care and treatment decisions for patients whose ability to make decisions for themselves may be compromised by the progression of their disease. Its specific focus is the decision-making framework set out in the Mental Capacity Act 2005 (MCA), which describes what constitutes capacity to make a decision in England, how to assess whether someone has it, and how a decision can legally be made for individuals who lack the capacity to make it for themselves.

The study is cross-disciplinary. I am a student within the Division of Health Research and also a practising lawyer. The evidence-based approach required for social science studies has informed the design of this study, but I have included some elements which do not reflect the social science tradition. For this reason, I have described the architecture of the thesis in this brief introductory chapter in order to assist and orient the reader.

1.2 Overview: the study from a distance

The study is an interpretation of the ‘life story’ of the MCA from conception to practice in the hospice context. In exploring the MCA’s story, I have drawn on narrative materials recording the views, thoughts and priorities of individuals engaging with the MCA at all stages of its development including legislators,

members of the judiciary and hospice staff members. The phases of the study are represented in Figure 1 below.

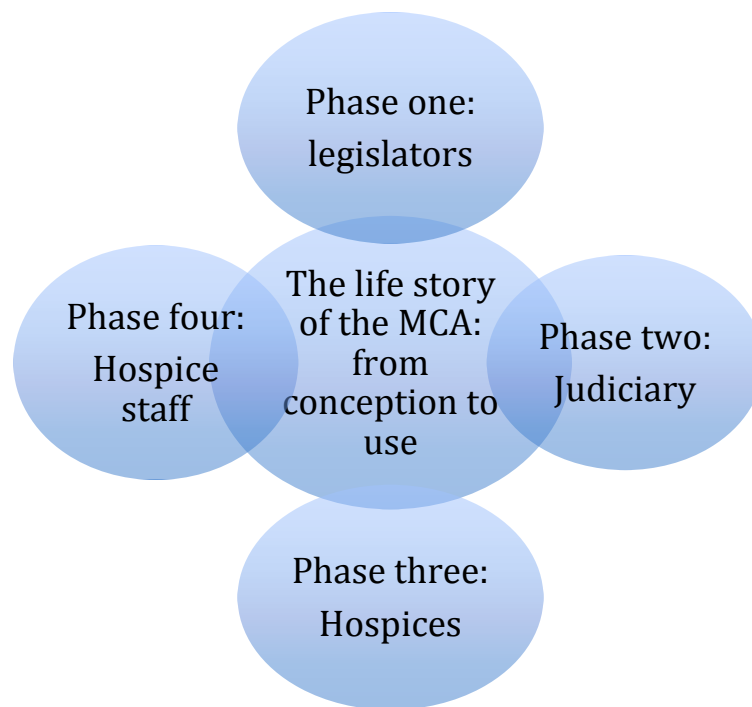


Figure 1: The four phases of the thesis

I have considered the research questions (see Chapter 2.6 below) using four phases of enquiry. The focus of phase one was on documentary sources that illuminated the social and policy context within which the MCA was drafted and debated, allowing me to explore the moral and ethical context from which the MCA emerged by reference to contemporary discourse. In phase two, I designed and carried out a systematic review of judicial decisions to underpin an analysis of the way in which the MCA has been interpreted by the courts since its entry into effect. Phase three considered the way in which the MCA is interpreted in current hospice organisational practice. I explored how present ways of understanding the MCA link to the findings which emerged from the historical analyses, particularly as regards the patient's role in the decision-making process. Phase four moved from the organisational level to

explore staff members' individual experiences of decision-making with patients lacking capacity or losing it as their disease progresses.

1.3 Thesis structure and approach: looking ahead – and back

The thesis starts with a broad consideration of how the MCA emerged from the social policy of the 1980s and 1990s and finishes with a detailed look at how hospice staff members currently use it to guide decision-making. It is an inductive study but, as the study moves from phase to phase, the key findings from each phase are mapped against each other. As the study progresses, a picture emerges of the way in which the key ideas of the policy-makers and legislators have been diffracted through judicial decisions into policy and practice in contemporary hospices. The study constructs a genealogy of the MCA from legislative intent to current practice. Whilst each phase can be seen as a mini-study in itself, taken together the phases chart the dynamic relationship between law and practice. At the end of phase four, the decision-making approach of current hospice staff can be compared to the intentions of the original legislators. A brief route-map of the thesis is set out below.

Chapter 2 sets the scene. I start to explore the contours of the decision-making landscape by describing the MCA framework, introducing the underpinning principles and two key concepts (capacity and best interests) which both guide and constrain decision-makers. These are considered by reference to the statutory definitions and more widely by reference to legal and philosophical literature. I then introduce the concept and reality of hospice in the UK, positioning the 'hospice movement' and 'hospice care' within the landscape of palliative care. Finally, I consider what is known about decision-making for hospice patients, identify a gap in

what is known about the MCA in hospice practice and set out the research questions which guided this thesis.

In Chapter 3, the philosophical, theoretical and methodological positioning of the study is described. The importance of a relational perspective is posited and discussed in the context of relational constructionism. I introduce my view that ‘the law’ is inextricably enmeshed in the society to which it relates (a ‘socio-legal’ approach) and explain that the ideas behind therapeutic jurisprudence infuse the MCA and my findings relating to its implementation in the hospice context. I re-view the concepts of care and compassion from a socio-legal perspective and introduce legal consciousness theory.

In Chapter 4, phase one of the study, my Foucauldian genealogical analysis of the coming-to-be of the MCA is presented. I explore the conditions of possibility for the emergence of the MCA by reference to historical policy and legislative documents. I engage constructively with the past and ‘historicise’ the present (Jackson and Tinkler, 2014). In looking to the birth of the MCA to support an understanding of how it was intended to work in practice, I introduce my archive of materials and present my method for analysing it to explore the emergence of the MCA and the way it has become embedded into practice.

In Chapter 5, phase two of the study, my systematic review of selected Court of Protection judgments is presented. I describe the included judgments as a lens through which to consider the embedding and interpretation of the MCA. Analysis of the included judgments is mapped against the key ideas introduced in Chapter 4 and I

identify additional themes that have emerged as the MCA has been embedded in social and legal practices.

Chapters 6 and 7 discuss my empirical research. In Chapter 6, I introduce my organisational study, which explores how the MCA is working in hospices by reference to group interview data (phase three of the study). I present my analysis of the data and consider how notions of capacity and best interests are interpreted and implemented into hospice practice. In Chapter 7, I look at individual interviews with hospice staff members who routinely work with patients to make decisions under the MCA (phase four of the study). Staff members' individual perspectives of decision-making for patients are considered by reference not specifically to the MCA but to what participants considered most important in the decision-making process.

In Chapter 8, I draw together the phases of my study and discuss the findings from the genealogical analysis, the systematic review and the primary research. In the final chapter, Chapter 9, my thesis concludes and I propose answers to my research questions, evaluating my findings, and reflecting on my research journey as a whole.

1.4 The Thesis

My thesis is that hospice staff are interpreting and applying the MCA as the policy-makers and legislators intended. Hospice leaders set an organisational context which supports 'patient-centred' decision-making, and individual staff members are unconsciously competent in their understanding and application of the principles and key concepts set out in the MCA. Patients' wishes and feelings guide decision-making

as staff members work with them and their families to make decisions about care and treatment.

I will argue that a compassionate, relational approach, grounded in an ethic of care where time is made to hear a patient's story, is key. Further, I will suggest that hospice staff demonstrate a particular legal consciousness of the MCA, influenced by their perception of 'hospice' as something different from other palliative care settings.

CHAPTER 2

The research in context

2.1 Introduction

The MCA, enacted in 2005, was a law intended to catalyse and lead societal change. It has been described as a ‘visionary piece of legislation’ which ‘marked a turning point in the statutory rights of people who may lack capacity’, because it ‘place[d] the individual at the heart of decision-making’ (House of Lords (HoL) 2014 p.6). Yet, post-legislative scrutiny by the House of Lords Select Committee on the MCA (MCA Committee) in 2014 concluded that the Act was not working well in practice, that in its implementation it had not delivered the empowerment it promised, and that cultures of paternalism (in health) and risk aversion (in social care) continued to prevail. The MCA Committee concluded that, in the context of health and social care, the MCA was not widely understood and embedded (HoL, 2014). In this study, I explore whether these conclusions are accurate for the understanding and implementation of the MCA in hospices. My reasons for conducting the research were rooted in my experience (as a hospice trustee) of hospice culture as particularly supportive and thoughtful. I was curious to see whether paternalism and risk aversion were preventing the empowerment of hospice patients in decision-making under the MCA, or whether there was a different story to tell in that context.

In this Chapter I describe the MCA’s framing of the notion of capacity and introduce its codified test for assessing someone’s ‘best interests’ where they have lost the capacity to make a particular decision for themselves at a specific time. I consider the MCA concept of capacity by reference to the requirements of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006) and

discuss individual and relational ideas of autonomy. I briefly introduce theories and frameworks of healthcare decision-making and distinguish MCA decision-making. I then introduce the hospice as the setting for the empirical work, considering both the emergence of the hospice ‘movement’ and the nature of palliative care. ‘Hospice care’ is described and I explain how hospices are assessed in their provision of it. I introduce the research questions guiding my study and the aims and objectives which underpin it. A brief literature review identifies a knowledge gap in my area of interest, and I explain how my study contributes to what is known about MCA decision-making.

2.2 The concept of capacity in the Mental Capacity Act 2005

The MCA provides the legal framework for decision-making on behalf of individuals who lack capacity to make decisions for themselves. The MCA was intended to be enabling and supportive of people who lack capacity, not restricting or controlling of their lives. It aimed to protect people who lacked capacity to make a decision whilst empowering them by maximising their ability to decide or to participate in the decision-making as far as they were able to do so (DCA, 2007). The MCA is underpinned by five key principles (Table 1).

Table 1: The five underpinning principles of the MCA

1. A person must be assumed to have capacity unless it is established that they lack it (s1(2)).
2. A person must not be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success (s1(3)).
3. A person must not be treated as unable to make a decision merely because they make an unwise decision (s1(4)).
4. An act done, or decision made, under the MCA for or on behalf of a person who lacks capacity must be done, or made, in their best interests (s1(5)).
5. Before the act is done, or the decision is made, regard must be had to whether the outcome can be as effectively achieved in a way that is less restrictive of the person’s rights and freedoms of action (s1(6)).

The MCA provides that to have capacity to make a decision (the ‘functional test’), an individual must be capable of:

- understanding what is proposed,
- retaining, using and weighing information in the process of making the decision, and
- communicating the decision in some way (MCA s3).

The MCA accepts that capacity may fluctuate and that an individual may have capacity to make some decisions but not others. The key is that ‘at the material time’ (MCA s2(1)) the individual can both make *and* communicate the decision, whether by talking, using sign language or any other means (MCA s3(1)). If an individual cannot make (or communicate) a decision because of an impairment of, or a disturbance in the functioning of, the mind or brain (the ‘diagnostic threshold’), capacity will not be established (MCA, s2(1)). The MCA permits a decision to be made on someone’s behalf, in their best interests, in the event that they are considered not to have capacity to make it for themselves (MCA s1(5)).

A range of factors must be considered in establishing someone’s best interests (MCA s4(6)). These include their past and present wishes and feelings, their beliefs and values likely to influence their decision and any other factors they would consider if they were able. The MCA does not accord priority to a person’s wishes and feelings; they need not be determinative or even necessarily accorded greater weight than any other factors. Where it is practicable and appropriate to consult them, the MCA (s4(7)) requires that the views of certain others are sought as to what someone’s best interests might be, by reference to what they know of the person’s wishes, beliefs and

values. This would include someone's family or carers and anyone they have nominated to be consulted on the matter in question or matters of that kind.

The provisions of the MCA describing in detail the concepts of capacity and best interests are set out in full in Appendix 1.

2.3 Situating the MCA concept of capacity within wider discussions of capacity, autonomy and decision-making

The MCA Code of Practice (Code) describes the MCA's starting point as confirming an individual's 'right to autonomy'. There is an assumption that an adult 'has full legal capacity to make decisions for themselves unless it can be shown that they lack capacity to make a decision for themselves at the time the decision needs to be made' (DCA, 2007 p.15). In the brief discussion which follows, I consider the relationship between capacity, autonomy and best interests and introduce the concepts of legal capacity and mental capacity. I situate my discussion in the context of decision-making for hospice patients to illuminate the analysis, discussions and conclusions that will be introduced and explored as the thesis proceeds.

The concept of autonomy (from the Greek, meaning 'self' and 'rule' or 'law': 'having the capacity to be self-governing') was a notion which originally related to the government of city states but has since been developed to apply to individuals. Kant's (1785) concept of autonomy required an individual to be capable of rational self-governance and able to direct their actions by reference to a moral code (Randall and Downie, 2006; Campbell, 2017). An inability so to self-direct, or the existence of a controlling authority preventing self-direction, would reduce or remove autonomy.

Beauchamp and Childress (2009), in their development of the principles of biomedical ethics, regarded these two conditions of agency (capacity for intentional action) and liberty (independence from controlling influences) as essential for autonomy.

In the context of patient decision-making, Campbell (2017) has linked the concept of autonomy to the establishment of the principle of respect for persons, which is a key aspect of Beauchamp and Childress' (2009) principle of respect for autonomy. Referring back to the two essential conditions for autonomy, they characterised the principle of autonomy as incorporating both a negative obligation not to subject a patient to controlling constraints and a positive obligation to respect the patient by acting in a way which fosters autonomous decision-making, including disclosing information to ensure understanding and 'voluntariness' (p. 107). Their principle of respect for autonomy was grounded in an acceptance of the idea that people have intrinsic worth, a right to determine the narrative of their own lives and, accordingly, the right to make their own choices and decide for themselves how to act (Beauchamp and Childress, 2009).

Jackson (2018) has argued that respecting someone's autonomy includes respecting the particularity of their point of view and paying attention to the way they choose to regulate and organise their life, whether or not they have capacity to consent to a particular medical procedure. Her account of autonomy requires treating the patient as 'someone', recognising their humanity and their conception of self. Jackson has warned against linking a patient's inability to demonstrate capacity for a particular treatment decision with a reduction or removal of their involvement in the process. She has argued that a patient's inability to consent should not result in the removal of

their interest in having their views attended to and accorded respect. This is an approach which finds support in the concept of capacity that underpins the CRPD.

The CRPD aims to ensure that all persons are equal before the law and have a right, regardless of mental functioning, to have their capacity to make legally binding decisions respected (Article 12). It requires someone's rights, will and preferences to be respected and decisions to be free of undue influences (Article 12(4)). Beauchamp and Childress' (2009) two key conditions for autonomy (agency and liberty) are clearly reflected here but the CRPD accepts that someone's agency may be shaped (or even constituted) by their environment and their relationships with others (Series, 2015, Gooding, 2015). Mental incapacity is not considered to be an individual 'deficit' but, rather, a situation which requires the bringing to bear of such support as may be necessary for an individual to exercise their full legal capacity in accordance with their will and preferences (UN, 2014).

The CRPD distinguishes legal capacity and mental capacity. The Committee on the Rights of Persons with Disabilities (CRPD Committee) describes *legal capacity* as having two strands: the ability to hold rights and duties (legal standing) and the ability to exercise those rights and duties (legal agency) (UN, 2014). Everyone has legal capacity by virtue of being human (UN, 2014). *Mental capacity* refers to someone's decision-making skills, which vary from one person to another and may be affected by many things, including environmental and social factors. The CRPD Committee disapproves of any assessment which uses perceived or actual deficits in mental capacity as the justification for denying legal capacity (UN, 2014). The MCA, by its diagnostic threshold, links legal capacity to mental capacity. Someone will lack legal capacity (to make a particular decision for themselves at that time) if an 'impairment

of, or...disturbance in the functioning of, the mind or brain' (MCA s2(1)) means that they lack the functional ability to understand and consider the information relevant to the decision and communicate their response. Consequently, Martin et al (2014) have asserted, the MCA is not compliant with the CRPD.

Under the MCA capacity is binary: someone either has it or they do not. CRPD capacity, by contrast, is envisaged as a sliding scale. A decrease in functional ability can be balanced with an increase in decision-making support so that, in theory, one never loses *legal* decision-making authority (Bartlett, 2014). The CRPD Committee describes support broadly, as encompassing both formal and informal arrangements of varying types and intensity. The support must be sufficient to enable someone to make decisions that have legal effect and must respect their rights, will and preferences (UN, 2014). The CRPD Committee does accept that it is not always possible to determine the will and preferences of an individual and requires, in these circumstances, that the 'best interpretation' of someone's will and preferences must be sought (UN 2014, p.5). Series (2015) has contended that this 'support-paradigm' offers a more 'cosmopolitan' approach to legal capacity, based on the idea of 'shared personhood' (2015, p.85), noting that even individuals with full legal capacity rely on support in living their daily lives (see also Herring, 2013).

A key principle of the support paradigm is that no one should be appointed to make a decision on behalf of another person if, with assistance and support, that person could make the decision themselves (Davidson, et al., 2015). Underlying the CRPD's approach to capacity is an acceptance of relational theories of autonomy, which differ fundamentally from the notion of autonomy grounded in individual rationality, responsibility and ownership of decisions, that underpins the MCA (Series, 2015). If

someone's legal capacity can be linked to, or even constituted by, others' support and advice, it follows that their autonomy must also be linked to their relationships and their social existence (Herring, 2013; Series, 2015). Martin et al (2014) have noted the existence of a spectrum of ideas regarding relational autonomy. A moderate relational theory would accept someone's capacity to act autonomously if they were able to deliberate and make decisions in the context of supportive relationships (Martin et al, 2014) so long as liberty and agency are not compromised (Beauchamp and Childress, 2009). The MCA is consistent with a relational approach: the presumption of capacity is not displaced if someone is able to make a particular decision with appropriate support (s1(3); Martin et al, 2014). Ideas of relational autonomy in the context of hospice decision-making will be developed later in the thesis.

A patient's ability to actively engage in the decision-making process is relevant to an assessment of their capacity under the MCA and, where they have been found not to have capacity, to the assessment of what is in their best interests. Whilst the MCA best interests assessment process is not a supported decision-making approach, in that the individual's will and preferences are not necessarily determinative of the outcome, the individual's wishes and feelings must be considered to the extent that they are ascertainable (MCA s4(6)). Jackson (2018) has argued that by maximising the weight given to the wishes and feelings of the patient and ensuring that the decisions which flow from a finding of incapacity respect the patient's known preferences, the 'capacity cliff edge' (p.248) can be softened. Where a patient previously had capacity, discussions with their family and friends (as well as with the patient themselves) can allow decision-makers to understand the patient's preferences by reference to the relationships within which the patient is (or was) held. This approach acknowledges that the patient is *interdependent* rather than independent.

Thus some important differences can be identified between the MCA concept of capacity and that which underpins the CRPD. They are, specifically, that the MCA diagnostic threshold creates a link between legal capacity and mental capacity and that the MCA's best-interests decision-making procedures do not prioritise the patient's values, wishes and feelings (Martin et al, 2014). In the light of this, the Essex Autonomy Project (EAP), in its detailed consideration of this question, concluded that the MCA in its present form does not comply with the CRPD requirements (Martin, et al., 2014 and see also Martin, 2015; Law Commission, 2015; House of Lords, 2014).

These conclusions of the EAP were recognised in the recommendations of a recent Law Commission consultation on reform of the MCA (Law Commission, 2015). The recommendations were that someone's wishes and feelings should, where possible, be ascertained as part of a best interests determination, that particular weight should be given to them in making the decision and that a supported decision-making scheme should be established to assist people with decision-making. Whilst these recommendations were accepted by the Government, the Mental Capacity (Amendment) Act 2019 (which amends the MCA and came into force in May 2019) does not reflect them. My study, in considering hospice decision-making by reference to the MCA, will pay particular attention to exploring the way in which patients are supported to make decisions and the extent to which their wishes and feelings are reflected in decision-making.

I have discussed above best-interests decision-making and supported decision-making, a rights-based approach to decision-making for people whose mental

capacity is impaired. These models of decision-making for people with impaired decision-making capacity underpin the focus in my thesis of how the MCA is understood and interpreted in the hospice context. However, for completeness, and to offer a basis for comparison where necessary, a summary of theoretical models of care and treatment decision-making is presented in Appendix 2.

2.4 The ‘hospice movement’ in the UK and the hospice as a provider of ‘hospice care’

The work of Cicely Saunders, particularly her wish to avoid both neglect of the dying and the medicalisation of death, is credited with giving rise to what has become known as ‘the hospice movement’ (Clark, 2018). Saunders has described the emergence of the hospice movement as a kaleidoscope: the ‘putting together of a number of demands which were not previously related, giving a shake and finding that they come down in a new pattern or synthesis’ (Saunders, 2000 p.7). In energising the emergence of the hospice movement, Saunders has been described as creating a rupture in the established social order (Floriani and Schramm, 2012), despite the fact that the practice of palliative care which she developed has its roots in an ancient Greek medical tradition (Randall and Downie, 2006).

Randall and Downie (2006) trace the origins of palliative care to the Greek Asklepiian tradition, which prioritised attending to each patient as an individual and providing holistic, patient-focused care and relief from suffering in the context of an acceptance of mortality. The hospice movement was created to prioritise such care for patients with a terminal diagnosis (Saunders, 2000). Key to the holistic approach which Saunders promoted was the concept of ‘total pain’. This concept emerged from a

conversation Saunders had with a patient who, in describing her pain, said, ‘it seems that all of me is wrong’ (Saunders, 2000, p.9). Saunders developed this into an understanding that hospices, as providers of palliative care, must acknowledge and address patients’ physical, emotional and social pain, as well as the spiritual need for security, meaning and self-worth. This is now reflected in the World Health Organisation (2019) definition of palliative care as:

an approach that improves the quality of life of patients and their families facing ... life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

The language of this definition has been the subject of criticism (in that it promises what is often unachievable) (Randall and Downie, 2006), but in describing the all encompassing nature of palliative care, it reflects what hospices aim to offer in their provision of ‘hospice care’.

Hospices are providers of palliative care in a specific context: hospice care and palliative care are not synonymous. In England, using the Hospice UK (2017) definition of ‘hospice care’, palliative care sits within ‘hospice care’:

Hospice care aims to affirm life and death. It means working with and within local communities to tailor palliative care around the needs of each adult and child with a terminal or life-shortening condition, whatever that may be, and extends to supporting their carers, friends and family before and after bereavement. Hospice care is provided by multi-disciplinary teams of staff and

volunteers who offer expert support that places equal emphasis on someone's clinical, physical, emotional, social and spiritual needs with the understanding that everyone will be different (see 'Our Vision and Mission').

Floriani and Schramm (2012) have contended that the ideal of 'hospice care' has been eroded by increased regulation of the hospice sector, and the fact that hospices are working increasingly closely with the acute sector. They have suggested that hospice care has been institutionalised and that the charismatic character with which Cecily Saunders imbued it has been displaced. Similarly, Randall and Downie (2006, p.9) have described an 'invasion' of the distinctive concepts of palliative care (characteristic of the Asklepiian tradition) by the rational, scientific and evidence-based practices of the Hippocratic tradition which underpins modern medicine. This suggests that the person-centred Asklepiian approach has been displaced in hospices by the paternalistic approach described by the MCA Committee (2014). My findings do not support this in the specific context of decision-making.

2.5 The 'hospice context' for my study

Hospices in England, the context for my study, typically offer care to in-patients, provide day services and offer specialist community palliative care services. They are generally constituted as charities and receive only around a third of their funding from the National Health Service (NHS) (Hospice UK, 2019). Their independence allows them to design their services to be responsive to local need, and most receive both financial support and volunteers' time and energy from their local communities. Hospices in England are regulated as independent healthcare services by the Care Quality Commission (CQC), which assesses hospices for quality and compliance.

Compliance with the requirements of the MCA is a specific focus of the inspection framework. The lines of enquiry which underpin the inspection process (Table 2) align with the aims of the hospice movement to offer personalised care not only to the patient but also to the patient's family, friends and other carers (CQC, 2018).

Table 2: CQC lines of enquiry for inspection of hospices

Focus	Examples relevant to study:
Safe	Do records contain details of the person's emotional, social and spiritual needs alongside their physical health needs Do staff have access to patient-specific information?
Effective	Do staff understand the consent and decision making requirements of the MCA? How do staff ensure that decisions are made in the best interests of a person without capacity? How do staff ensure that decisions made by a person who has capacity are supported and associated risks managed?
Caring	Does the service understand the importance of patient stories? When a person is in the last days/hours of life, are they and those important to them, involved in decisions about treatment and care to the extent that the dying person wants?
Responsive	Do key staff ensure involvement with families and carers? How are people who may be approaching the end of their life supported to make informed choices about their care?
Well-led	Is the culture centred on the needs and experience of people who use services?

Source: CQC (2019) *Sector-specific guidance: hospices for adults v1*

The CQC's (2017) report, suggesting that (on the CQC measures) hospices offer more outstanding care than other services regulated by the CQC, invites further investigation of *how* that care is provided and *what* makes it 'better'. My study will look at the specific context of decision-making under the MCA and explore how hospice staff use and understand the MCA when making decisions for patients.

2.6

Aim, objectives and the research questions

The aim of my study was to explore the MCA decision-making framework from its inception through to its translation into practice by hospice staff. Against the background of the areas in which the MCA has been judged not to meet the standards of the CRPD, I was interested in looking at how (and to what extent) patients' values, wishes and feelings are reflected in decisions made in their best interests and to what extent supported decision-making takes place in hospices.

The objectives of the study, were to:

- a) understand the discourse around capacity and best interests which underpinned the MCA and has informed its development since enactment;
- b) explore how historical constructions of capacity and best interests are interpreted in the hospice organisational context, particularly the role of the patient in the decision-making process and the importance of the patient's values, wishes and feelings; and
- c) explore how key concepts underpinning the MCA are interpreted by hospice staff in the practice of decision-making with hospice patients, with a particular focus on the patient's role in the process.

The following research questions informed my study:

1. How are the legislative principles concerning decision-making for patients who lack or, as their condition progresses, are losing capacity, interpreted and

expressed within hospice organisational policy and practice, particularly as regards patients' values, wishes and feelings in the decision-making process?

2. How do hospice staff perceive the hospice patient's role in making decisions about their care and treatment?

2.7 Literature review

At the beginning of the project, I carried out a brief scoping review, which identified limited literature specific to the MCA in the hospice context. I subsequently carried out a comprehensive and systematic supportive literature review (Aveyard et al, 2016) to identify what was already known about MCA decision-making in the hospice setting. This review was carried out following completion of phases three and four of my study, so that my analysis of the hospice-specific primary data would not be influenced by discussions in the literature from other settings in which decisions are also made under the MCA.

The literature review considered:

1. how the concepts of 'capacity' and 'best interests' are interpreted in hospices where care and treatment decisions are being made under the MCA for patients who lack or are losing capacity; and
2. whether supported decision-making takes place.

The review strategy and process is documented in Appendix 3. Four studies were included and, of these, none made specific reference to hospices. They were included because the descriptions of the participating settings suggested that hospices might

have been involved. I have described the settings in more detail and listed my reasons for including these studies in Tables (i) and (ii) in Appendix 3.

The included studies all consider the fundamental question of *how* to achieve a balance between empowering and protecting a patient. Williams et al. (2012) suggested that a decision-maker seeking to achieve this balance has a weighty duty to discharge and that a team-based approach spreads that load. Reference is made to a relational communication process to support decision-making, involving both members of the care setting's multi-disciplinary team and, where possible, the patient's family and other carers (Williams et al., 2012; Harris and Fineberg (2011). Williams et al. (2012) also considered that collective decision-making led to more reflective and successful best interests decisions. The importance of getting to know a patient and their carers, and gathering relational knowledge to inform decision-making, was emphasised (Williams et al, 2012; Hinscliff-Smith, 2017; Wilson et al., 2010).

2.8 Locating the knowledge gap

My literature review suggests that there is little empirical research specific to the way in which the MCA is understood and implemented in the hospice sector, despite the MCA Committee's (2014) overall finding that it is not working well in practice. My study will add to the body of knowledge about how the MCA is working in practice by investigating the way the legislative principles are interpreted and expressed in the hospice sector. In the next chapter, Chapter 3, I will develop the broader philosophical and theoretical context within which I have situated my research and introduce the socio-legal ideas that have influenced it.

CHAPTER 3

Introducing the ideas influencing my research and setting the methodological scene

3.1 Introduction

In Chapter 2, I described the legal and organisational context of the study. In this chapter, I will introduce the philosophical, theoretical and methodological ideas that have influenced my research. My approach has been inductive and iterative; each phase of the study has developed my thinking. The ideas generated by each phase have then directed my further exploration of relevant philosophical and theoretical literature. As my study progressed and my awareness of existing ideas and theories increased, I reflected further on interpreting what my findings might mean and how they might contribute to what is known about the way the MCA is working in practice.

In this chapter, I will question and explore the nature of care and the nature of compassion in a legal context. I will consider whether, in the context of hospice care, decision-making capacity is interpreted as a relational concept, where increased support balances a patient's inability to understand, and whether the process of identifying someone's best interests is rooted in their narrative and their relationships, including in some cases, a patient's relationship with their former self. I will contend that a relational constructionist approach provides a consistently appropriate context to explore the key concepts of the MCA in hospice organisational practice and in the caring relationships between individual staff members and their patients. I will link a relational approach to a discussion of compassion and Gilligan's (1977) ethic of care.

I will contend that law does not sit outside the social world in a separate, distinct, rational and objective reality. Rather, law is experienced as part of society, woven through individuals' private and professional relationships (Ewick and Silbey, 1998). My analysis and discussion of the empirical data will draw on legal consciousness theory: I will consider legal consciousness as it relates to the cultural context of the hospice and staff members' decision-making processes. In order to set the scene for my discussion later (Chapter 8), the theory of legal consciousness will be introduced in this chapter, together with the concept of therapeutic jurisprudence as a legal approach that situates the MCA and my findings about how it is working in practice in a larger socio-legal discourse.

3.2 Relational constructionism

The central premise of social constructionism is that the social world does not exist separately from the individuals living in it and is not able to be investigated simply by observation (Hosking, 2011). Further, the social world is continuously in the making, constructed by individuals as they live it (Mezey, 2001; Holstein and Gubrium, 2008). Cultural context is important; an individual's experiences and the societal context within which they take place shape that individual's understanding of the world and what is culturally warranted will direct their actions and interactions.

Relational constructionism focuses on the relational process between an individual and something 'other'. Rather than considering the individual as a separately existing, bounded, knowing individual who independently constructs knowledge about 'other' and represents it in language (Burr, 2002), a relational constructionist approach views individuals as constituted in the relational processes which go on in language-based

interactions (Hosking, 2011; Livholts and Tamboukou, 2015). Barad (2007) describes individuals' 'entanglement' in human relations as follows:

Existence is not an individual affair. Individuals do not pre-exist their interactions; rather individuals emerge through and as part of their tangled intra-relating. Which is not to say that emergence happens once and for all, as an event or as a process that takes place according to some external measure of space and time, but rather that space and time, like matter and meaning, come into existence, are iteratively reconfigured through each intra-action, thereby making it impossible to differentiate between creation and renewal, beginning and returning, continuity and discontinuity, here and there, past and future (p ix).

Barad characterises relational processes between individuals and 'other' not as interactions, which take place between already-established and separate entities, but as 'intra-actions' which take place between components. Relational processes, 'intra-actions', construct local relational realities which open up certain possibilities whilst making others less likely. Some local relational realities become warranted and accepted and others are less successful, but relational processes are always powerful; intra-actions always have the potential to effect change. Cicely Saunders' relationships with her patients catalysed the concept of 'total pain', for example (Saunders, 2000 p.9), and her wider network of physicians with similar ideas together energised the development of the hospice movement, illustrating the potential of local relational processes to effect change. Local, in this sense, includes reference to the cultural and the historical, where the historical is not seen as a linear process from an origin to a future destination but something which is linked to what has gone before

and has implications for what might come next (Hosking, 2011). For Barad (2007), the past is never finished, we never leave it and it never leaves us behind. This non-linear view of history, and the idea of ‘historicising the present’ (Tinkler and Jackson, 2014) is expanded and further explored in Chapter 4 as I construct and discuss the life story of the MCA.

Conversations and other intra-actions, whether verbal or non-verbal, are key to relational constructionism. Conversations link ‘self’ and ‘other’, and each relational process of social interaction and dialogue constructs a relational reality. This has the effect that individuals construct multiple ‘selves’ as a part of the process of social interaction: ‘relational selves’ are produced in particular relationships with particular others (Hosking, 2011). Relational processes are not limited to conversations but can include hearing and listening, gestures, seeing, physical interactions, such as dance, and interactions between people and objects, facts or events. Barad’s (2007) observations about relational ‘entanglements’ link the social world and the world of natural science so that, for example, even scientific apparatuses are not characterised as instruments for passive observation. Hosking (2011 p.53) describes interaction as ‘a performance that involves the coming together of ‘whomever and whatever’ thereby constructing ‘person-world’ relations as relational realities.’ Thus, a hospice patient living with the fact of a physical disease can be understood to experience a ‘person-disease’ relational reality and to construct a self which is rooted in that ‘person-disease’ reality.

The focus of this study is the relational processes of decision-making within the MCA framework. The relationships between hospice staff, patients, and the local relational

realities they create, are the unit of analysis - the lens through which the study explores how the MCA is interpreted as decisions are made about care and treatment.

3.3 Legal consciousness theory

My interest in legal consciousness is in the way in which the MCA is experienced by hospice staff members as they make decisions in the context of caring for patients. I have drawn my ideas on legal consciousness theory from the work of Ewick and Silbey (1998), considered by Mezey (2001), Halliday and Morgan (2013), Halliday et al. (2015) and Hertogh (2018). Ewick and Silbey were interested in the way in which the power of the law was experienced by ordinary individuals in their everyday lives. Their research focus was the ‘gap’ between ‘the law in books’ and ‘the law in action’ (Herzogh, 2018). The central premise of their work (1998) was that law both constitutes and is constituted by social relations and cultural practices. They conceived of law as powerful and were influenced by the Foucauldian idea that power cannot be disentangled from social relationships (Mezey, 2001). Key to their analysis was Foucault’s (1975) conception of power not as a ‘thing’ to be possessed by some and lacked by others but as a part of *all* social relations and intra-actions. Foucault (1975) theorised that power is always present and that it is productive (of, for example, relational realities and the knowledge which can be gained from them) rather than repressive or otherwise necessarily negative. Resistance to power is perceived as an attempt to deflect the products of power in a particular relationship, rather than as a confrontation with a single source of power.

Ewick and Silbey (1998) concluded that law, like power, is everywhere in society. ‘Legality’ is thus attributed to any social practices and processes which have a link to

law and exists in all the institutions, rules, and conventions that people defer to or try to deflect or defy. Legal consciousness is described as ‘participation in the process of constructing legality’ (Ewick and Silbey, 1998 p.45). Insofar as the relational processes in which individuals engage are in any way linked to legal concepts, each individual has a role in reproducing (and potentially minutely remaking) law. Ewick and Silbey’s (1998) work considered situations where individuals experience the law as authoritative and unfair in the context of legal proceedings or conflict. They concluded that in enacting legal consciousness, individuals are ‘before the law’ (accepting the appropriateness of justice being delivered by formal legal procedures, 1998 p.47), ‘with the law’ (engaging with the law as if it were a game, manipulating it, looking to use it for one’s own advantage, p.48) or ‘against the law’ (deciding to resist, avoid or ignore the law, p.749). They theorised that each of these orientations towards the law acts both at an individual level and at a cultural level that makes sense of the law as a societal structure (Ewick and Silbey, 1998).

Halliday et al. (2015) have offered an empirical analysis of the legal consciousness of the family members of patients with chronic disorders of consciousness. The law for their purposes was the MCA and the way that it impacted family members’ involvement in clinical best interests decisions. Their analysis identified relatives’ construction of the law as a sword (potentially double edged), with which the power of the medical world in a decision-making process might be resisted, and as a shield, guaranteeing the legality of a certain course of action. Where the Court of Protection was involved, law was also a way of allocating responsibility for a difficult decision to the Court. Finally, the law was experienced as a barrier, standing in the way of a decision to withdraw treatment and facilitate a patient’s peaceful death (because the Court would not sanction withdrawal of life-sustaining treatment). Halliday et al.

characterised both the ‘law as sword’ and ‘law as shield’ themes as standing ‘before the law’ in Ewick and Silbey’s (1998) typology, and the ‘law as a barrier’ theme as standing ‘against the law’. I will develop these ideas in discussing my findings (Chapter 8).

Halliday and Morgan (2013), looking at legal consciousness through the lens of cultural theory, introduced a fourth orientation, ‘collective dissent’, which expresses a collective rejection of the authority of the law by groups considering themselves to be systematically disadvantaged within the larger social system. Their concept of ‘collective dissent’ implied a collective struggle to influence and catalyse societal change. In Chapter 8, I will develop this idea by reference to the ‘hospice movement’ and its action to change the way in which acute hospitals provided medical care to dying people. I will also link it to Tronto’s (1987) development of Gilligan’s (1977) ideas about an ethic of care, and to the relationship identified by Hunter et al (2016) between cultural morality and legal consciousness.

3.4 Caring and the law: an ethic-of-care approach

Gilligan (1977) has suggested that caring is a fundamental aspect of human existence. She characterised human existence as intrinsically relational; not only are humans always dependent on others (although dependency is a sliding scale which changes as people move through life) but individuals can never truly be independent. For Gilligan (2014), an ethic of care is a guide to acting carefully, understanding the costs of not paying attention, not listening, of being absent rather than present and of not responding to another with integrity and respect.

Herring's (2013) thesis is that law is mistakenly arranged around an independent, autonomous adult, working to protect freedom and rights, where rights are understood as tools to keep others out. Herring, developing Gilligan's ideas, seeks to recharacterise law so that it recognises *relationships* as productive of autonomous individuals (and see also Nedelsky, 2008). Herring's focus is not on the community (or the communal) rather than the individual, but on the individual as emerging from, and continually constructed by, a supportive network of ongoing relationships within which care is given and received. Herring has offered a definition of 'care' which he describes as encompassing four key markers of care, summarised in Table 3. The presence or absence of these markers indicates whether or not the activity in question is 'care' for his purposes.

Table 3: The four markers of care

<i>Markers of care</i>	<i>What this means in practice</i>
Meeting needs	Caring is an activity: it usually involves doing something but need not – care might flow from allowing another to do something for you, even if it would be easier for you to do it.
Respect	Respect entails recognition of a fellow human being. Care should attend to the dignity of the other and account for how the other experiences the care.
Responsibility	An assumption of responsibility is part of caring.
Relationality	Caring is relational, reciprocal and not uni-directional. Both parties should be empowered in the relationship

Source: Herring (2013, pp14-15) *Caring and the law*

For Herring, an ethic-of-care approach challenges the traditional legal emphasis on individual autonomy; he suggests that the starting point should be 'the norm of interlocking, mutually dependent relationships' (2013 p.46). Rights and interests, not protective action, are key to underpinning and maintaining networks of relationships

because it is entangled relationships that enrich individuals' lives with value and meaning. Herring contended that, rather than focusing solely on rationality, law should also recognise emotion so that rational thought *and* feeling are both accounted for in the context of the relationships within which individuals live (Herring, 2013). He has suggested that law should be used to encourage and support actions which would promote caring relationships and supports the view that law should promote therapeutic outcomes. The idea of law as a tool for supporting therapeutic outcomes is the central pillar of therapeutic jurisprudence.

3.5 Therapeutic jurisprudence

Therapeutic jurisprudence (TJ) is an approach to law that regards laws, legal processes and lawyers as having both therapeutic and anti-therapeutic effects (McMahon and Wexler, 2003). TJ aims to develop awareness of, and make explicit, the therapeutic contributions of law and legal procedures: TJ's proponents assert that the process of legislative change should be attentive to the *effects* of laws and that legislators should aim to maximise their therapeutic consequences (Birgden and Perlin, 2008). I would suggest that the MCA is an example of a law whose therapeutic consequences *have* been considered, both during the legislative process (see Chapter 4) and in judicial interpretation of its key principles (see Chapter 5).

I also see TJ as a broad concept linking law and healthcare. It can encompass the philosophical and socio-legal ideas I have described above and my methodological interest in stories and narrative knowledge (discussed in the following section). Birgden and Perlin (2008) have suggested that TJ takes a relational approach to the practice of law and Brookbanks (2003, p.75) has contended that the importance of

narrative knowledge in medical practice is reflected in TJ's focus on enhancing 'human connectedness through conciliation and dialogue'. My findings suggest that, in the hospice context, staff interpret the MCA so as to maximise the therapeutic benefits to patients. I will argue that the legal consciousness of hospice staff is a key part of this interpretation of the MCA. This suggests a link between legal consciousness and therapeutic jurisprudence which I will consider further in Chapters 8 and 9.

3.6 Compassion as a relational concept

In exploring how the MCA is interpreted and applied in the hospice context, I will argue that compassion is intrinsically important in differentiating an approach which properly acknowledges the five principles on which the MCA rests and one which characterises the MCA Committee's view that the MCA is poorly understood and is not working well in practice (House of Lords, 2014). I accept and am guided by Del Mar's (2017) description of compassion as a relational process in the context of legal reasoning.

In contending this, Del Mar first distinguishes compassion from empathy and sympathy. He characterises empathy as the ability to, and the process of, understanding what another person might be experiencing and the situation in which they are experiencing it. Empathy in this sense does not involve feeling emotion but, as a cognitive process, simply to being able to understand what another may be experiencing. Sympathy is related, but requires an ability both to understand the situation in which someone finds themselves *and* to evaluate it by reference to one's own experience. It may, but need not, involve an evaluation of the person suffering as

deserving of their suffering. The observer need not feel any emotion to sympathise; sympathy and empathy both imply some element of remaining distanced from the other person.

Compassion is similarly cognitive and evaluative but also, crucially, involves *feeling* something. A compassionate response is a person-focused response; a relationship of sorts is implied and feelings are involved. Compassion therefore requires emotion. Del Mar describes it as a relational emotion (in that it is ‘other-directed’) which can be experienced in a directly interactive way (face to face), communally or as a spectator. In this sense, then, compassion is felt as part of a relational process during the course of which cognitive, evaluative and emotional responses take place (Figure 2).

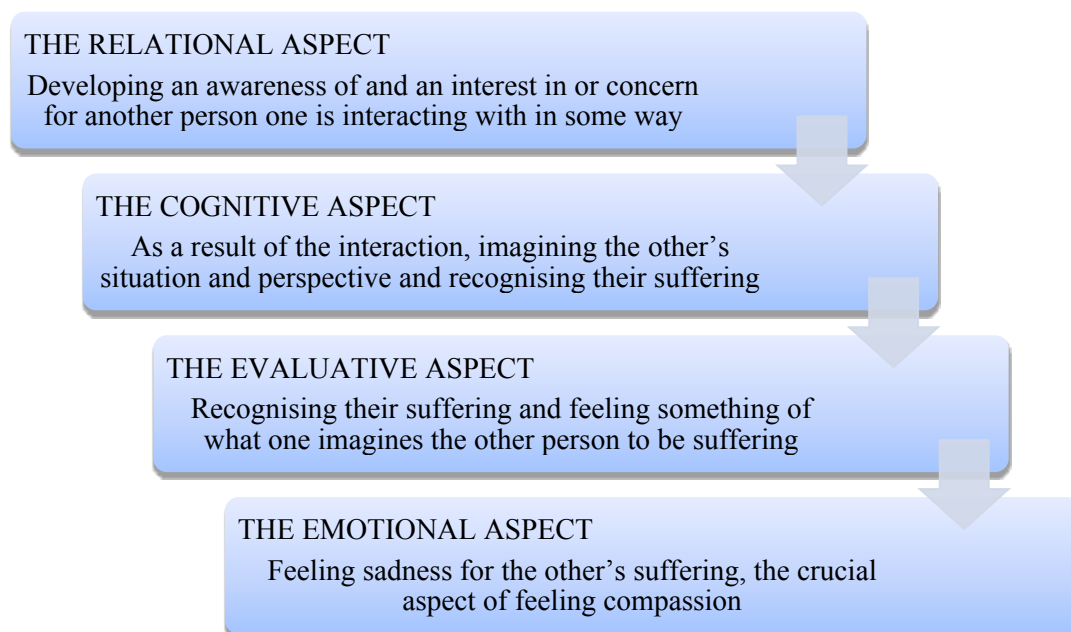


Figure 2: Compassion as a relational process

Source: Del Mar (2017, pp146-7)

For Del Mar, the ability to imagine is a key aspect of experiencing compassion: he describes imagination as a process of ‘deliberately and effortfully constructing mental images of what it might be like for someone else to experience a particular situation’ (2017 p.148). This definition references the idea of perspective, which can imply a more or less self-involving approach. The less self-involving and more robust approach anticipates the process of imagining the perspective of the other by considering all that one knows about that person and their situation to inform what one imagines they might be feeling. An other’s *perspective* is distinguished from their *viewpoint* in that someone’s viewpoint may (literally) be shared by standing where they are standing, but attempting to see from someone’s perspective requires an imaginative effort to understand how that person, as the person that they are, might be experiencing a certain situation. I will relate this idea to the way in which someone’s best interests are assessed for the purposes of the MCA (s4) (Chapter 5).

Del Mar (2017) references Nietzsche’s (2008) understanding of perspectivism. He argues that introducing perspective does not imply relativism but, rather, allows for the examination of different aspects of a situation. The greater the number of perspectives from which a particular problem or situation is perceived, the more complete (or objective) the concept of it will become. This way of understanding perspective suggests that relational processes, involving multiple perspectives, are crucial in enabling as complete a picture as possible of the ‘constellation of needs, interests and values at stake’ (Del Mar, 2017, p150). I will explore this idea further by reference to the importance in the hospice context of the multi-disciplinary team (Chapters 6 and 7).

‘Story’ is a key feature of my study. I have thought about stories broadly, both in my genealogical consideration of the ‘life story’ of the MCA and in my characterisation of judgments as legal stories linking the ‘law in books’ to the law in people’s narratives of life and circumstance. I have also worked with stories in the more traditional sense, listening to the stories told by hospice staff members to illustrate their understanding and interpretation of the MCA in practice. A narrative approach, focused on the stories individuals tell about their past and their hopes for the future, is particularly relevant to decision-making: stories have long been ‘given time and space’ in hospice and palliative care (Bingley, et al, 2008).

In my study, stories are relevant not only as data in the empirical process but also as part of the process of understanding a patient as a whole person, considered a key aspect of providing care (Herring, 2013) and particularly hospice care (Bingley et al, 2008). Narrative knowledge in medical practice focuses on the subjective world of the patient, focusing on what it is like for the patient to be ill, considering the patient’s relationship with the illness and the treatment process (Brookbanks, 2003). In the specific context of an MCA decision-making process, the patient’s story is a key aspect of a proper consideration of their best interests. The patient and the decision-maker construct a relational reality in which the history and expectations of each are an important part of the process (McMahon and Dexter, 2003). The story-telling is a cognitive process, an intra-action, in which a meaningful reality is constructed (Livholts and Tamboukou, 2015). The notion of empowerment in my thesis is related to the importance of a patient’s narrative identity in any decision made with, for or about them. A patient will be empowered in the decision-making process if their

wishes and feelings inform or influence its outcome. Thus, the patient/decision-maker relationship is a key differentiator between a paternalistic decision in which the patient is passive, and a decision in which the decision-maker attends to the patient's story and values in making the decision and thereby empowers the patient.

Narrative research does not sit within a linear conceptualisation of time (Livholts and Tamboukou, 2015): stories contract time, wander back and forth in time, are inextricably part of time and yet timeless as they are re-made each time they are (re)told and actively reconfigure the past within the context of the relational process in which they are shared (Barad, 2007; Livholts and Tamboukou, 2015). Narrative research raises questions about how the past is brought to bear in storied tellings, how cultural memory (including legal memory) is involved in historical narratives, and how the present is constituted from stories about the past, including the processes and procedures of law and practices involving 'legality', within which power, truth and knowledge are interrelated (Ewick and Silbey, 1998). Foucault, in his promotion of historicism, 'subordinates truth and knowledge to history', accepting that they are 'what our time and culture deem them to be' (Prado, 2000 p18 and see Foucault, 1975).

3.8 Method: an overview

The four phases of my study operate like four mini-studies which, between them, map the life story of the MCA from legislative intent to current hospice practice. Four different datasets underpin my study. I have used template analysis, a form of thematic analysis, to explore the archival data collected in the phase one genealogical research, the corpus of judgments considered in phase two and in the analysis of the

group and individual data collected in phases three and four. An overview of template analysis is provided below and I describe in Chapters 5, 6 and 7 how I have used the method in each phase of the study. In Chapter 8, I describe how I have used this method to synthesise my findings.

Template analysis is a flexible approach which is adaptable to a range of epistemological positions and study types (Brooks et al, 2015). Hierarchical coding is used to develop a coding template, initially based on a subset of the data, which is then revised and refined as it is applied to further data. In developing my coding template in each phase of the study I worked through the following process, based on that described by Brooks et al. (2015).

1. I became very familiar with the data by reading and re-reading them. I then began to carry out preliminary coding of the data by highlighting aspects which seemed to me to be interesting in terms of facilitating my understanding of the data.
2. Once I had identified my initial themes, I organised them into clusters around broad conceptual ideas. I carried out this process manually, by using 'post-it' notes and large pieces of paper. Once I had organised the data around my conceptual ideas, I arranged them hierarchically to create the initial template.
3. The initial template formed the basis for further templates, which I developed iteratively as further data was analysed during each phase of the study. I have described in more detail in the Chapters 5, 6 and 7 the process for each phase of the project.

4. Having analysed the data from the four phases, I created a ‘synthesising template’, bringing together the key themes from each phase to underpin the discussion in Chapter 8.

Template analysis also allows lateral links between themes to be drawn out of the data (King, 2012). King describes these ‘integrative themes’ as pervading the data, such that attempting to contain them in a single theme, even with a number of sub-themes, would inadequately reflect their commonality across the hierarchical themes. He characterises integrative themes as ‘undercurrents’ running through the data (p. 432). I have identified three such ‘undercurrents’ in my data, *compassion* (phases two and three) and *the nature of care* and *legal consciousness* (phase four). These integrative themes stimulated my interest in the related philosophical and theoretical ideas described above. I will develop each of them further, by reference to my findings, in Chapter 8.

3.9 Issues of Rigour

My relational constructionist approach does not seek (and could not accept) a single, definitive “truth” and I have not attempted to discover one. In order for my study to produce valid knowledge claims, transparency as to the reasons behind my decisions during the course of the project is key. I have documented my sources, my methods and my findings so that my study “brings readers along with [it] as ...a trail of evidence [is uncovered]” (Reissman, 2008, p.188). Transparency as to my situated position (as a hospice trustee) is important in the context of the collection and analysis of the empirical data (in phases three and four). I have strived to ensure consistency

and coherence between the four phases in the presentation of my findings, discussion and conclusions.

Whilst generalisability to other hospices (or more widely) is not my aim, I hope that the knowledge which the study creates will be useful as an interpretation of a contemporary, context-specific understanding of the MCA in current hospice practice.

3.10 Conclusion

In this chapter, I have described my philosophical position and the ideas and theoretical concepts which I have found developmental as my thinking has progressed. I have given an overview of the method which I will use and considered issues of rigour relevant to my qualitative approach. In Chapter 4, I will describe the first stage of my academic journey. Phase one is about my initial engagement with the MCA as I look back to its emergence from the legal and social policy context of the 1990s and imagine its life story from policy into legislation.

CHAPTER 4

Phase one: exploring the policy context and legislative intent behind the MCA

4.1 Introduction

In my introductory chapters, I have set out a ‘road map’ of the thesis, explained my reasons for undertaking it and introduced the ideas that have developed and guided my thinking. In this Chapter I describe my genealogical approach to exploring the beginnings of the MCA, identifying, from varied historical sources, the factors influencing its emergence and setting the scene for the mapping of its life story as the thesis progresses. I engage with the policy makers and legislators whose convictions and ideas underpinned the development of the MCA over the course of more than a decade. If my thesis is a telling of the MCA’s life story, this chapter is the story of its birth, starting with my review of a Law Commission (1991) consultation document concerning mentally incapacitated adults and decision-making. The consultation took place in the context of changing societal views about the rights of individuals lacking capacity to make their own decisions and, more generally, about their place in society.

Looking back at the cultural conversations encouraged by the Law Commission, I began considering the role of history in contemporary legal issues. My approach has been influenced by Foucault’s genealogical work, his ideas about the inter-relationship between the past and the present and that constructive engagement with the past is a crucial aspect of understanding contemporary questions (Foucault, 1975). This blurring of the lines between the past and the present will become a recurring theme in my thesis. I introduced the idea of ‘historicising’ the present in Chapter 3, Chapter 5 will look at how case law is interpretive of legal history in the present and the idea that people have past and present ‘selves’ will become relevant in considering

how the wishes and feelings of unconscious patients can be ‘heard’ through their relatives’ memories. If the past is an inextricable part of the present, embedded within contemporary practices, discourses and experiences (Tinkler and Jackson, 2014), then the way in which the MCA is understood in the present must be linked to the historical and cultural conversations that took place as it was created. These relational processes are the threads I will pull together and explore in my study.

4.2 A genealogical approach

Foucauldian genealogy focuses on the descent of the subject, descent in the sense of a lineage, a family tree or a network of relationships. A genealogical analysis traces that descent and looks for factors that might have come together to set the scene (to create the conditions of possibility) for the emergence of the subject (Prado, 2000). Foucault did not consider that anything is traceable back to a single point of origin. Rather, he looked at heterogeneous and diverse historical sources and explored the links between them in seeking to understand how the scene was set for something new to come about (Prado, 2000). He was interested in relationships with the power to effect change and to establish new ways of thinking so that over time, the construction and justification of new social practices and processes would result (Prado, 2000). He was interested in how the interplay of these powerful relationships would facilitate change, produce new relationships of power and promote new possibilities and ways of being in the world (Prado, 2000). I have interpreted Foucault’s genealogical approach to consider the birth (the emergence) of the MCA from the long consultative and legislative processes which culminated in its enactment.

My analysis attempts to untangle and explore the various threads and connections which came together at that point in history when the adequacy of the law concerning mental capacity and decision-making was questioned. In the absence of any established Foucauldian method for undertaking a genealogical analysis (Prado, 2000), I have designed and implemented a two-stage approach. In the first stage (Descent) I identified my archive of ‘data’ documents and in the second stage (Emergence), having read and re-read the documents comprising the archive, I distilled from them three key themes visible across the archive. Borrowing Karen Barad’s (2007) optical metaphor, I see these key themes as waves catalysed by the energy of the social changes described by the archive, radiating into the legislative process and being diffracted into the MCA’s central concepts of capacity and best interests. These key themes link the four phases of the thesis. I follow the wave patterns from the genealogical process, through the judicial interpretation of the MCA’s central concepts, into their organisational application by the participating hospices and finally identify their influence in hospice staff members’ decision-making.

4.3 Method: analysis of the descent and emergence of the MCA

The descent

My exploration of the historical material relating to the MCA started with the documents cited in the explanatory note to the MCA. I read them and then adopted a ‘snowballing’ approach, selecting additional documents for review as connections were identified. This approach generated a heterogenic archive of historical documents comprising legal case reports, consultation documents, policy documents, judicial opinion, parliamentary reports (including interviews with expert witnesses),

United Nations documents, press reports and political manifestos (Appendix 4). My exploration of the archive, was neither linear not chronological. I followed the references and connections both backwards and forwards in time, pulling together my telling of the MCA's life story. My proposed lineage (or life story) of the MCA, is presented in Figure 3. I have listed the key documents chronologically (the way in which the story unfolds) and have mapped 'influencing' documents against the documents forming part of the legislative process.

The emergence

I started by re-reading the Law Commission (1991) consultation, the document presenting the case for reform, and then read and re-read the archive as a whole. As I immersed myself in them, the links between the archival documents became clear. I identified as threads running through them an increasing acceptance of difference, a movement towards inclusion and empowerment and an intolerance of discrimination or misuse of power. I identified three key over-arching themes linking the social change visible in the archive to the central concepts of the MCA. These key themes are briefly introduced below and then explored in more detail as I describe the findings.

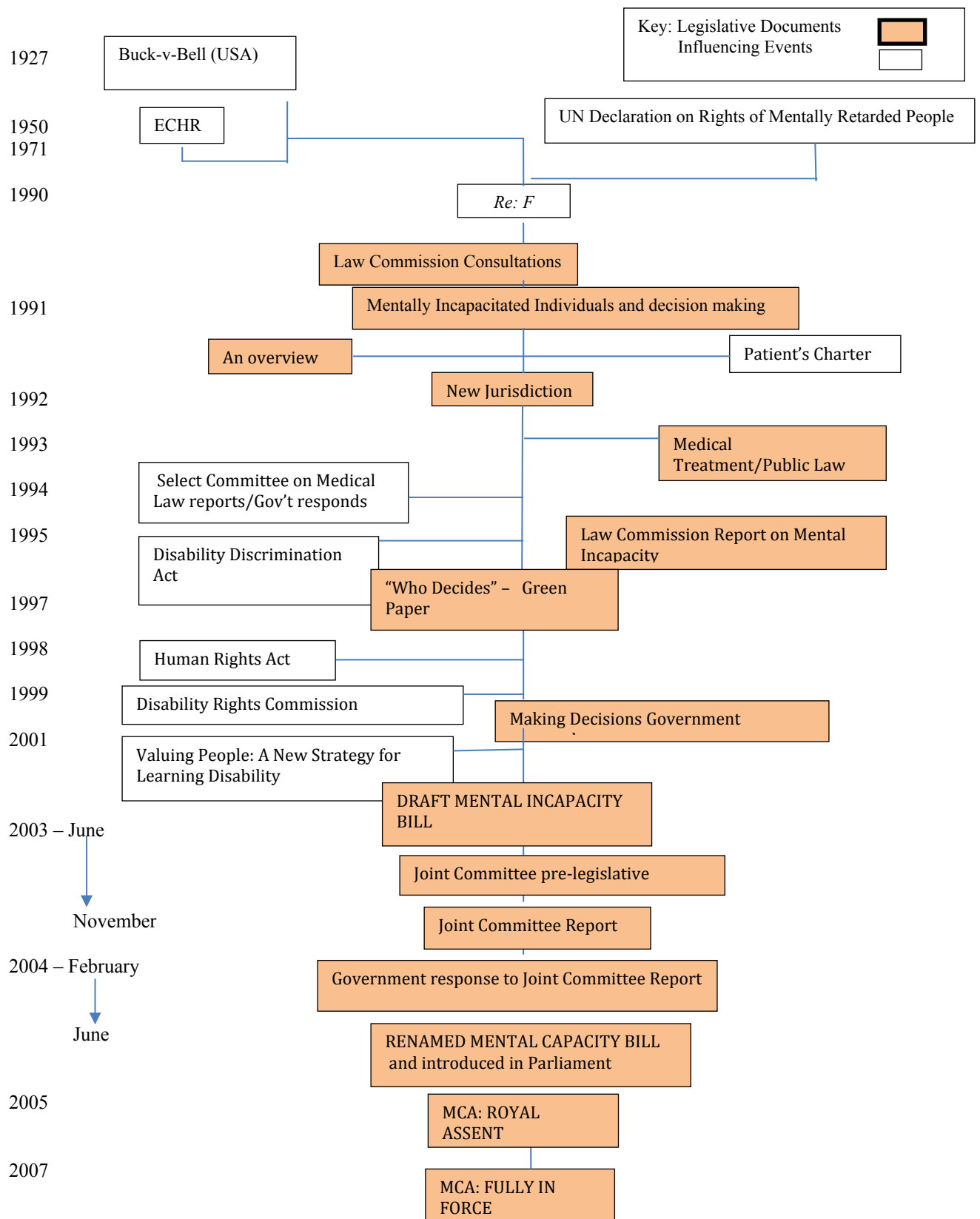


Figure 3: Analysis of the descent – a proposed lineage of the MCA

Introducing the key themes

Emergence of the Individual. The archive describes the prioritisation in social policy of the needs and rights of individual citizens. This is especially the case for individuals with disabilities, addressed specifically in the Valuing People policy document (DoH, 2001), which focused on rights, independence, choice and inclusion for people with learning disabilities. The *emergence of the individual* reflects the importance of each individual's story, their wishes and needs and their personhood, in the sense that personhood implies someone having an interest in their future narrative (OUP, 2014).

Person of value. This theme reflects the focus of the archive on realising, respecting and protecting human rights for all individuals. There is a move towards identifying and rejecting discrimination. Although linked to the *emergence of the individual*, this theme is about an individual's intrinsic worth as a member of society.

Role of law. The archive includes international conventions as well as domestic legislation and policy consultations. Typically, their focus is on law as a facilitator of empowerment and protection rather than as a means of control. There is a sense of the importance of balance, of the law's role in facilitating a level playing field between the state and individual people, that an overarching aim of the law should be to maximise well-being, that law should be evaluated by reference to its therapeutic effect.

The relationship between the key themes and the primary influencing documents and events is shown in Table 4 below. Figure 4 demonstrates the ‘diffraction’ of the key themes into the MCA’s central concepts.

4.4 Description of findings

In this phase of the study my aim was to use the archive to ‘take the temperature’ of society immediately prior to the emergence of the MCA. My analysis is deliberately focused on the ‘bigger picture’ rather than the specifics. In mapping the descent of the MCA, I have sought a broad understanding of the direction of social policy rather than examining the detail. The three key themes reflect this approach.

Emergence of the individual

Surprisingly, perhaps, I have traced *the emergence of the individual* theme back to *Buck v Bell*, a case heard in the American courts in 1927. This case was distant (both geographically and temporally) from the MCA but it became part of the MCA’s story when it was cited in *Re F* [1990]. It concerned the non-therapeutic sterilisation of a woman who lacked decision-making capacity, as did *Re F*, and in both cases the court allowed the sterilisation. In *Buck v Bell*, Holmes J declared that:

it is better for all the world if ... society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the fallopian tubes. ... Three generations of imbeciles are enough.

Table 4: Analysis of the emergence of the MCA – key themes

Document	Key issues	Themes		
		Emergence of individual	Person of value	Role of law
<i>Buck v Bell</i> [1927]	Law protects society: eugenics is about preventing ‘imbeciles’ from committing crime or reproducing			✓
	A lack of mental capacity renders an individual valueless as a person and as a member of society	✓	✓	
European Convention on Human Rights (1950)	States’ obligation to secure to everyone within their jurisdiction the rights and freedoms in the Convention	✓	✓	✓
UN Declaration on the Rights of Mentally Retarded Persons (1971)	Everyone is equal in terms of the rights they enjoy, including: <ul style="list-style-type: none"> the right to protection of their personal well-being and interests the right to protection from abuse and the abrogation of rights 	✓	✓	✓
<i>Re F</i> [1990]	Protection of freedom to the greatest extent possible		✓	
	Protection of rights to the greatest extent possible, in particular: <ul style="list-style-type: none"> Reproductive autonomy Self determination 	✓	✓	✓
	An individual’s welfare and best interests are paramount		✓	
	Specific rejection of the approach in <i>Buck-v-Bell</i> : law must seek balance between rights of an individual and the public interest. There is public interest in assuming a reasonable choice on behalf of an individual who cannot provide consent for a particular decision		✓	✓
	Judges of the Family Court seen as a compassionate power			✓

Document	Key issues	Themes		
		Emergence of individual	Person of value	Role of law
	The Law Lords acting as champions of individuals' rights where no legal framework existed to protect them		✓	✓
Patients' Charter (1991)	Seeking to rebalance relationships between patients and the medical establishment	✓	✓	
Committee of Medical Ethics Report/Response (1994)	Acknowledges a social responsibility to care adequately for those who are elderly, dying or have disabilities		✓	
Disability Discrimination Act 1995	Legislation to make discrimination against disabled people unlawful	✓	✓	✓
Human Rights Act 1998	Giving effect in the UK to the European Convention on Human Rights and providing a mechanism for the individual to hold the state to account if their rights are breached	✓	✓	✓
Disability Rights Commission (1999)	Goal: a society where all disabled people can participate fully on an equal basis	✓	✓	✓
Valuing People (2001)	Key Principles: everyone should have <ul style="list-style-type: none"> • Enforceable legal and civil rights • Independence to the extent possible • The ability to make their own choices • The ability to do 'ordinary' things; to be fully included in their local community 	✓	✓	✓

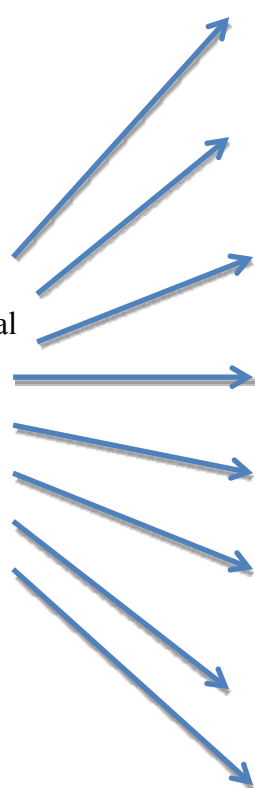
Key theme	How themes diffract into the MCA central concepts
 <p>Emergence of individual</p> <p>Person of value</p> <p>Role of law</p>	<p>Information must be appropriately provided</p> <p>Presumption of capacity must be displaced</p> <p>Participation must be facilitated</p> <p>Wishes and feelings must be sought</p> <p>Outcome must be least restrictive of rights/freedoms</p> <p>Legal framework intends to empower</p> <p>Protect from abuse and coercion</p> <p>Uphold rights and freedoms</p>

Figure 4: ‘Diffraction’ of the key themes into the MCA central concepts

The acceptance of eugenics in *Buck v Bell* was specifically denounced by the House of Lords in *Re F*. Instead, the House of Lords recognised F as a person, someone who must be respected in decisions made about her, and concerned itself with assessing her best interests. The court did not try to ascertain F’s wishes and feelings in its determination of her best interests (and has been criticised for this paternalistic approach, see Jackson, 2018) but the focus was nonetheless on F as an individual, taking into account her relationship with another patient and the importance of her being enabled to the extent possible to live her life by reference to her own desires.

The presumption of capacity underpinning the MCA (s1) and the requirement that, wherever possible, individuals should be supported to make their own decisions, reflects the emergence of the individual that can be seen in *Re F*. This has been developed in the judicial interpretation of the best interests principle since the MCA came into effect (see Chapter 5). The archive indicates support for legislation which enables rather than restricts and which maximises the ability of an individual to tell their story and to be heard. The evidence provided to the Joint Committee (House of Lords, 2003) indicated widespread support for the individual being present and influential to the greatest extent possible, and thereby empowered, in decisions concerning their future narrative (see for example para. 73).

An individual's narrative, in the context of medical treatment, facilitates an understanding of that individual in terms of who they are rather than exclusively in terms of their illness (Chochinov et al, 2015). Thus, the emergence of a person without capacity as an individual with rights is fundamentally linked to their being offered assistance in expressing what they want, even where their narrative might be difficult to understand (House of Lords, 2003). An ability to see someone in terms of who they are is grounded in their ability to communicate that information.

The way in which communication around a decision is facilitated is therefore a fundamental aspect of the relational decision-making process. The language used both influences the way(s) in which the conversation will be experienced by the individual, and, more fundamentally, the shaping of the decision itself. Language can be used simply to represent the choices available or to construct a narrative which is intended to enlist or recruit the individual into a particular outcome. In the specific context of the MCA, an ability to demonstrate capacity is intrinsically linked to an ability to

communicate (MCA s3(1)). In requiring decision-makers to make every attempt to enable an individual to participate in the decision, the MCA (s3(2)) creates space for a compassionate, supportive decision-making process to unfold.

A person of value

The *person of value* theme references the philosophical idea that human beings are valuable in and of themselves (Beauchamp and Childress, 2009). This philosophy underpins the human rights instruments that appear in my genealogy of the MCA and, in particular, the importance they accord to the dignity and worth of each human being (see, for example, UN, 1971). The entry into effect of the Human Rights Act 1998 and the Disability Discrimination Act 1995 during the period when the MCA was being discussed and drafted reflects the influence of a human rights discourse and the language of rights on policy during this period. The language of rights also incorporates obligations. Obligations to fulfill rights, to take steps to realise, respect and protect them, and obligations not to interfere with them (Carmalt, 2011). In establishing obligations, rights also imply relationships – of power, responsibility and trust (Nedelsky, 2008). The archive suggests that the MCA was intended to construct and describe such relationships. The *person of value* theme recognises the intentions of the legislators that the MCA should oblige decision-makers to empower people within decision-making relationships to make decisions for themselves wherever possible (DCA, 2007, Foreword). This reflects the interest of medical ethicists at the same time in ideas of shared decision-making (Charles et al, 1997).

The intention that the MCA empower individuals references the importance of power within decision-making relationships. Foucault (1975) theorised that power should be seen as a productive network running throughout society; that power is present in all

relationships. The rights of an individual within a decision-making relationship are therefore contingent on the co-operation of others involved. What the MCA requires of every decision-maker, however, is that the individual's story is heard and their wishes and feelings reflected to the extent possible; that the individual is 'subjectified', treated as *a person of value* and thereby empowered within the decision-making process. However, in the context of professional decision-making relationships (including doctor-patient), the experience of an individual will vary considerably.

The legislators' intent to 'subjectify' (and thereby empower) individuals who might previously have been defined and 'othered' by reason of a disability and excluded from the process of decision-making is clear from the archive. Evidence to the Joint Committee, for example, indicated that the intention was to move from an approach which can be described as 'we inform; you consent' to the less paternalistic 'we advise; you decide', (House of Lords, 2003, Ev. 54). This again reflects the contemporary interest in shared decision-making as an alternative to the paternalistic model. The rights with which the *person of value* theme is concerned are less about a social contract between state and citizen (although international conventions set the context) and more about the politics of every day life. A *person of value* is about individuals who do not have capacity to decide for themselves being empowered to determine (to the extent possible) how they live and how their bodies are treated. The Patient's Charter (DoH, 1991), and similarly patient-focused documents that preceded it, opened up a space in which the individual patient, drawing on the language of rights, could assert themselves (Mold, 2012). The MCA facilitates the extension of this space to patients who do not have capacity to decide for themselves.

The role of law

Many of the data sources in the archive are legal or legislative in character and the role of law in society is a key aspect of this study. The archival documents, both the ‘influencing’ documents and those forming part of the legislative process, can be characterised as saying something about the role of law. I have introduced the idea of law as having therapeutic and anti-therapeutic effects and being a ‘social’ power, in the sense that it is both constituted by and constitutive of social change (see Chapter 3). In distilling from the archive some ‘big picture’ ideas about the role of law in the context of the emergence of the MCA, I will suggest that even where the aims of the law (in the sense of a particular piece of legislation) are clear, its interpretation and application *must* be seen as a set of evolving practices. The relationships within which the practices take place will be influenced by the legal consciousness of the individuals concerned. Whether or not a law works well in practice is ultimately dependent upon how it is interpreted by those whose actions it directs.

Legal and medical practices and processes of ‘legality’ are powerful. Foucault’s (1975) conception of power as a complex network, within which people act to condition the options and actions of others, is particularly relevant in the context of medical decision-making. An individual can be defined by reference to a set of practices applied by people empowered by the law to do so. The paternalistic model of decision-making (we inform, you consent) renders the patient passive and the decision-maker, generally a doctor or psychiatrist, powerful. A specialised medico-legal vocabulary exists which is often inaccessible to individuals; medical terms can categorise individuals by reference to a diagnosis (Chochinov et al, 2015). Those making a diagnosis are also often the gatekeepers of the information individuals need

in order to make an informed decision. Much, therefore, depends on both the decision-maker's relationship with the individual and their interpretation of the MCA's requirements as they navigate the legal framework. The role of law is, therefore, contingent. Its effect, whether to empower or protect (in the case of the MCA), will crystallise in the context of the relationship within which the decision is to be made.

4.5 Conclusion

In this chapter I have looked back at the factors which came together to set the stage for the emergence of the MCA as a legal framework intended to 'make a real difference to the lives of people who may lack mental capacity' (DCA, 2007, Foreword). I have imagined the 'descent' of the MCA, creating an archive and a genealogy which maps its emergence from the policy context of the time. I have distilled from my archive three key themes which flow from the archival documents and diffract into the central concepts of the MCA. These key themes are important and they will re-appear through my thesis. As I re-examine them in the context of each of the remaining phases of my study, the key themes will enable me to consider how the current interpretation of the MCA compares to the intentions of the legislators present at its birth.

CHAPTER 5

A review of the judicial literature: the embedding of the MCA

5.1 Introduction

Chapter 4 described my genealogical approach to constructing the life story of the MCA as it emerged from policy. I characterised the MCA as a new power, enabling the construction and justification of new legal practices and processes of ‘legality’, creating the conditions of possibility for change. I identified three over-arching themes, the *emergence of the individual*, *person of value* and *the role of law* linking the archive and the MCA’s central concepts. In this Chapter, I explore the establishment and embedding of the MCA framework and the practices it mandates. I will return to these key themes as I review court judgments involving the interpretation and application of the MCA in practice.

The effect of law depends (amongst other things) on how it is interpreted and applied by the courts. Judicial action sits alongside political, institutional and social conceptions and understandings of law (Ewick and Silby, 1998; Smulavitz, 2010). As propositions of law, judgments combine elements of both description and evaluation and thus become interpretive of legal history as it applies in the present (Dworkin, 1985). Judicial decisions have direct consequences on the individuals involved and indirect, longer-term consequences as they are re-interpreted in the consideration of other cases brought before the courts over time. Judgments, particularly those which change the way the MCA is interpreted, can therefore provide a lens through which to consider the way in which it has been, and is being, embedded in practice. In this chapter I consider whether, and if so how, the key themes introduced in Chapter 4 continue to be reflected in life story of the MCA two decades after its enactment.

5.2

A systematic review of judicial decisions: method

There are no published methods for a review of this nature. I have adapted the requirements for a systematic literature review in the social science tradition to my search of the body of case law interpreting and applying the MCA. I designed and used a systematic strategy to ensure a comprehensive search for relevant decisions. The body of case law considering the MCA is extensive and so I applied specific inclusion and exclusion criteria to the results to enable the identification of an appropriately focused body of judgments for detailed analysis. The following question directed my review:

‘How have the courts in England and Wales interpreted the meaning of ‘capacity’ and ‘best interests’, including the role of an individual, supporting family members and carers (formal and informal), when decisions are made under the MCA about medical care and treatment?’

Criteria for the inclusion and exclusion of judgments:

Inclusion: cases considering:

- i) the capacity of an individual to make a decision about medical care and/or treatment; and
- ii) how to assess the best interests of someone who lacks capacity to make a decision for themselves about medical care and/or treatment.

Exclusion: cases

- i) decided before the entry into force of the MCA in 2007;

- ii) concerning capacity to consent to sexual intercourse or contraception;
- iii) where the primary focus is an individual's place of residence;
- iv) where the focus is on the application of the Deprivation of Liberty Safeguards;
- v) with an administrative or procedural focus (such as the allocation of costs);
- vi) concerning decisions to which the MCA does not apply (for example, marriage); and
- vii) concerning the best interests of a child for the purposes of the Children Act 1989 (assessed by reference to a different test).

Search strategy and stages of the review

I searched legal databases Westlaw UK and LexisLibrary (UK). The searches were restricted to cases heard in the English Supreme Court and the Court of Protection (the court with jurisdiction in England and Wales to make decisions under the MCA for people who cannot make decisions for themselves at the time they need to be made). Appendix 5 contains a full description of the search strategy and the stages of the review process (summarised in Figure 5 below). The judgments selected for analysis are listed in Table 5.

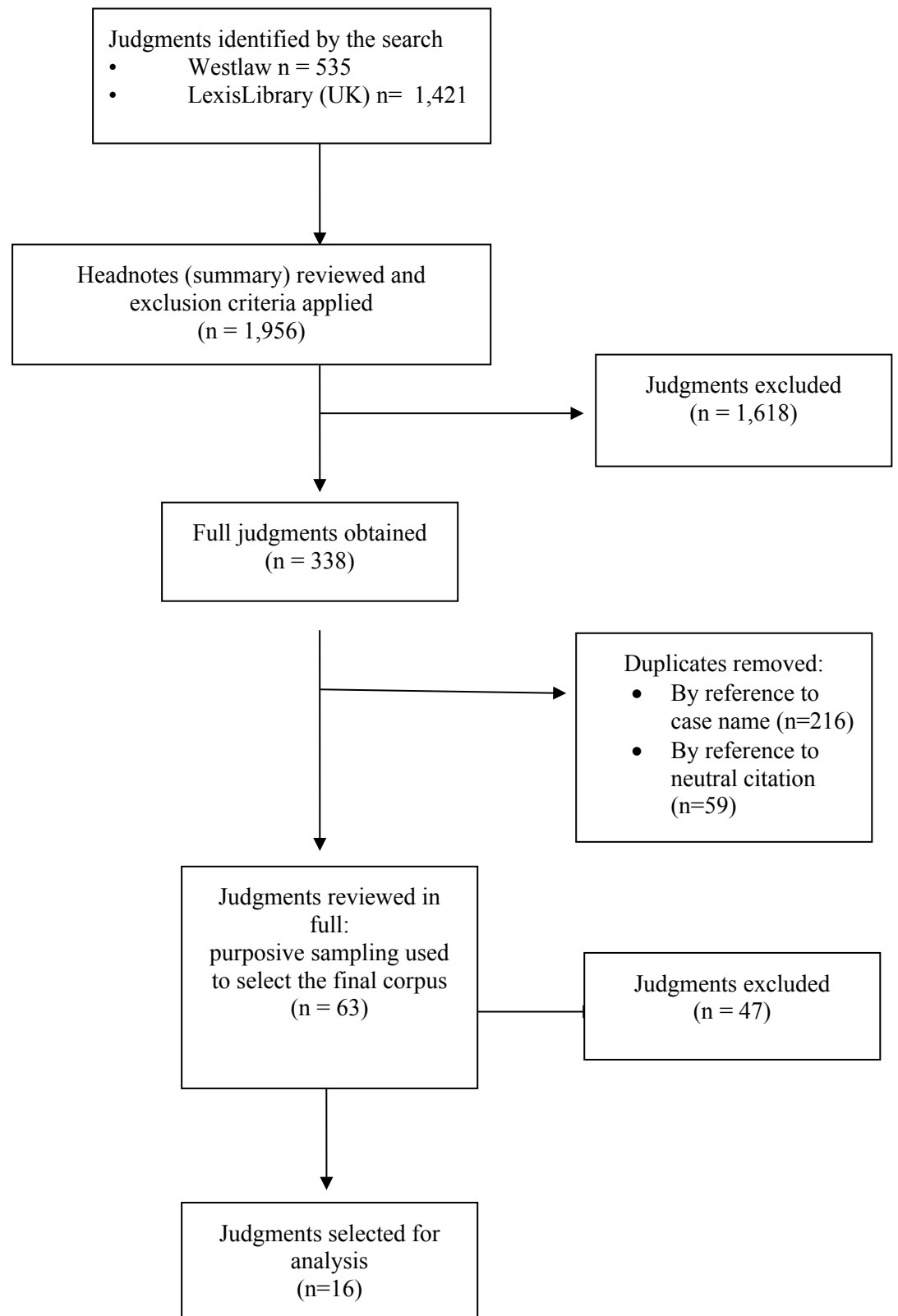


Figure 5: Stages of the case law review

Table 5: Judgments selected for analysis

Case name	Neutral citation
Aintree University Hospitals NHS Foundation Trust v James <i>Considering the best interests test in a case concerning certain treatments to prolong life. Appeal heard after the death of Mr James.</i>	[2013] UKSC 67 (Supreme Court)
Wye Valley NHS Trust v B <i>Considers the amputation of a severely infected foot against the wishes of Mr B in order to save his life.</i>	[2015] EWCOP 60
Briggs v Briggs (No.2) <i>Withdrawal of clinically assisted nutrition and hydration from a patient in a minimally conscious state</i>	[2016] EWCOP 53
AB, Re <i>AIDS case; whether HIV treatment by deception is in the patient's best interests.</i>	[2016] EWCOP 66
A University Hospital NHS Trust v CA <i>Whether delivery of a baby by caesarian section in patient's best interests</i>	[2016] EWCOP 51
Re: O <i>Whether withdrawal of mechanical ventilation in patient's best interest</i>	[2016] EWCOP 24
Betsi Cadwaladr University Local Health Board v Miss W <i>Concerning capacity of a patient to decide whether or not to refuse further treatment for anorexia</i>	[2016] EWCOP 13
An NHS Trust v CS <i>Termination of pregnancy</i>	[2016] EWCOP 10
Salford Royal NHS Foundation Trust v P <i>Life sustaining medical treatment for a patient in a minimally conscious state (MCS)</i>	[2017] EWCOP 23
Brent LBC v NB <i>Whether or not a period of intense rehabilitation and assessment is in the patient's best interests</i>	[2017] EWCOP 34
PL v Sutton Clinical Commissioning Group <i>Whether it is in patient's best interests that artificial nutrition and hydration be discontinued</i>	[2017] EWCOP 22
B v D, MoD <i>Whether stem cell treatments are in the best interests of a former soldier with traumatic brain injury</i>	[2017] EWCOP 15
IH (Observance of Muslim Practice) Re <i>Whether fasting and ritual shaving in accordance with religious requirements are in a patient's best interests.</i>	[2017] EWCOP 9
NHS Foundation Trust v QZ (A Patient) <i>Investigation to determine the cause of post-menopausal bleeding</i>	[2017] EWCOP 11
Abertawe Bro Morgannwg University Local Health Bd v RY <i>Assessment of best interests of the patient in relation to various treatments, including when treatment should not be attempted</i>	[2017] EWCOP 2
NHS Windsor and Maidenhead Clinical Commissioning Group v SP <i>Withdrawal of clinically assisted nutrition and hydration (CANH) from a patient in a permanent vegetative state</i>	[2018] EWCOP 11

Stages of the review: summary

Cases are reported under different names and citation numbers resulting in the identification of duplicates at each stage of the review. In addition, the detail of the case was often not reflected in the headnote (summary) so cases were excluded at every stage of the review process (see Figure 5).

The 63 judgments remaining after the last application of the exclusion criteria were read in full. The final included judgments [n=16] were purposively sampled using the following inclusion criteria (one or more required).

Table 6: Reasoned purposive inclusion criteria for selection of final judgments

Inclusion criterion	Reasons
Decisions of the Supreme Court	The decision-maker of last resort: sets precedent
Judgments stated to be of general application	Not restricted to a particular case
Cases where reference is made to palliative care	In case any care/treatment specific findings
Cases where the patient's voice cannot be heard	How to ascertain wishes and feelings and what weight to be given
Cases where specific consideration is given to the significance of the patient's wishes and feelings in the decision-making process	How to ascertain wishes and feelings and what weight to be given

The selection of cases for analysis was not influenced by the likelihood of the care or treatment considered being offered by a hospice (although the provision of palliative care is relevant in several instances).

The aim of my systematic review of the case law was to consider how the key legal concepts (of capacity and best interests) had been interpreted by the Court of Protection. My objective was to map the judges' reasoning against the aims of the legislators, encapsulated in the three key themes identified in Chapter 4. I looked at the rationale for the judge's application of the MCA to the facts of the particular case and recorded my findings in a detailed data extraction table. I then re-read the included judgments again, this time as narratives in which the judge told the story of the events leading to the court's involvement and used the MCA as the lens through which to consider how best to conclude the story.

I used template analysis (introduced in Chapter 3) to explore the narrative archive represented by the included judgments. As I read through them, I coded each text by reference initially to the three key themes from the genealogical analysis but allowed my analysis to broaden as I identified additional themes, such as the importance of space and time. In Table 7 below, I have summarised, by reference to each of the included judgments, the themes which I have related to that particular story. The table also shows the way in which the MCA's key concepts were applied in each case and links the legal principles to my qualitative analysis.

I have found that the broad themes I associated with the emergence of the MCA continue to be relevant to the way in which the legislation has been interpreted. The genealogical analysis has captured them, as it were, from a distance: the lens of the judicial archive allows a closer view, such that the contours of the legal landscape are ascertainable, and I explore this landscape further below. In my description of the

findings, I present the top-level themes in the order they appear in the final template (Table 8 below), with subordinate themes referenced (and italicised) in the more detailed consideration of each top-level theme.

Table 7: Showing judicial interpretation of the MCA key concepts and my themes from analysis for each included judgment

Case	Capacity/Best interests (BI)	Major themes from qualitative analysis
<i>Aintree</i>	BI: Holistic approach to patient's BI: all factors considered Strong element of substituted judgment Past and present wishes of P should be given great weight as component of the right choice for P as a human being But we cannot always have what we want – even with capacity	<i>Emergence of individual: Cecily Saunders patient</i> <i>Role of law: Patient's perspective</i> <i>Space-time</i> <i>Compassion</i>
<i>Wye Valley v Mr B</i> NB Judge met P	No theoretical limit to the weight/lack of weight given to P's wishes, feelings, beliefs and values Incapacity is not an 'off-switch' for P's rights and freedoms Wishes, feelings, beliefs and values of people with a mental disability equally important as to anyone else: potentially more important	<i>Emergence of individual/person of value</i> <i>Judge as person/compassion</i> <i>Role of law: mediator of difference/socio-legal</i>
<i>Briggs</i>	P's BI best served by giving effect to the outcome of an exercise of his right of self-determination rather than the arguments based on the preservation of his life If P's wishes ascertainable with sufficient certainty - should generally prevail over the presumption in favour of preserving life	<i>Emergence of individual: P and judge-as-person</i> <i>Significance of absence</i> <i>Space-time: /Me, myself and I/narrative wormhole</i> <i>Role of law: socio-legal</i>
<i>Re AB</i>	No weight given to P's current wishes and feelings: past wishes given considerable weight in authorising treatment by deception P's best interests served in saving her life But 'if the truth emerges to P' then matter would need to be reviewed	<i>Role of law: impartial power/black letter v socio-legal</i> <i>Significance of absence (of P and of compassion/judge-as-person)</i> <i>Space-time: me, myself and I</i>
<i>University Hospital NHS Trust v CA</i>	P's wishes and feelings affected by trauma (FGM) Balancing risk and benefit, BI served by requiring treatment against P's wishes but in such a way as to minimise both risk and distress	<i>Role of law: compassion</i> <i>Person of value: ethical landscape</i> <i>Time: as risk</i>
<i>Re O</i>	In considering P's BI, the wishes of family members allowed to prevail in consideration of additional expert evidence. Balancing P's	<i>Role of law: compassion</i> <i>Person of value: ethical landscape</i>

	rights/ family's interests in exploring all options Principle of respect for life must give way to P's other competing rights – eg respect for dignity - where life has become empty of real content	<i>Time/distance (audio visual)</i> <i>Emergence of individual – judge as person (and family members)</i>
<i>Betsi Cadwaladr Uni v Miss W</i> NB judge met P	P has capacity except in relation to treatment for anorexia BI: P's wishes and feelings were determinative: control over her future important to P NB Court decision relates only to existing/foreseeable circumstances so reassessment required if any change	<i>Emergence of individual (from disease): Cecily Saunders patient</i> <i>Person of value: patient's perspective/ethical landscape</i> <i>Compassion</i>
<i>An NHS Trust v CS</i>	Capacity: P need only comprehend/weigh salient details relevant to the decision. Must avoid 'protection imperative' BI: <i>Aintree</i> and <i>Wye Valley</i> applied 'Very considerable weight indeed' should be attached to clear wishes and feelings of pregnant mother in relation to termination even if autonomy 'qualified'	<i>Emergence of individual: significance of absence</i> <i>Person of value: ethical landscape</i> <i>Time: as risk</i> <i>Distance: protective impulse</i> <i>Role of law: mediator of difference/compassion</i>
<i>Salford Royal NHS v Mrs P</i>	BI: <i>Aintree</i> and <i>Briggs</i> applied If P's views ascertainable, they should prevail over presumption in favour of preserving life Family 'permitted her voice to be heard' and enabled her to assert her own autonomy	<i>Emergence of individual: P and judge-as-person</i> <i>Role of law: landscape of life/socio-legal</i> <i>Compassion</i> <i>Space-time: narrative wormhole/me, myself and I</i>
<i>Brent NBC v NB</i>	Capacity: consideration of whether capacity lacking <i>or</i> unsurmountable communication issues. Presumption of capacity displaced BI: P's wishes and feelings followed. Question as to whether he was unduly influenced by his mother important	<i>Emergence of individual: significance of absence</i> <i>Distance: audio-visual</i> <i>Person of value: patient's perspective</i> <i>Role of law: landscapes of life/legal consciousness</i>
<i>PL v Sutton Clinical Commissioning</i>	BI: No formal advance decision. <i>Briggs</i> followed. 'A woman who has lived an autonomous and self-determined life, a 'proper' life, is entitled to the dignity of being able to pursue a self-	<i>Person of value: the ethical landscape</i> <i>Role of law: mediator of difference</i> <i>Emergence of individual: P and judge-as-person</i>

	determined path to its end' Wishes and feelings communicated by family and friends were determinative	<i>Space-time: me, myself and I/narrative wormhole</i> <i>Compassion: role of family members</i>
<i>B v D (MoD)</i> NB Judge spoke to P	<i>Aintree, Wye Valley</i> and <i>Briggs</i> applied P's wishes and feelings were determinative despite lack of capacity Safety was not a reason to deny risky treatment: this would buy his safety 'at too high a price in terms of his happiness and emotional welfare'.	<i>Emergence of individual: all life is an experiment</i> <i>Person of value: the patient's perspective/the ethical landscape</i> <i>Role of law: mediator of difference/legal consciousness</i> <i>Time factors: time as resource/protection</i>
<i>IH (Muslim Practice)</i>	Capacity: application in context of religion considered (fasting and trimming of body hair) BI: P's best interests not supported by requiring him to fast and have his body hair trimmed	<i>Person of value: the ethical landscape</i> <i>Role of law: as mediator of difference/socio-legal</i>
<i>NHS Foundation Trust v QZ</i>	BI: <i>Aintree, Wye Valley</i> and <i>Briggs</i> considered P's independence and dignity equally important as 'paranoid and delusional beliefs' P's wishes and feelings did not prevail and treatment authorised against her wishes	<i>Person of value: the patient's perspective/ethical landscape</i> <i>Role of law: compassion (in process)</i> <i>Time factors: time as a resource</i>
<i>Abertawe v RY</i>	<i>Aintree</i> applied Relatives' evidence not conclusive as to P's wishes and feelings: treatment was not withdrawn	<i>Emergence of individual: significance of absence</i> <i>Person of value: ethical landscape</i> <i>Compassion</i> <i>Distance: the protective impulse/audio-visual</i>
<i>NHS Windsor and Maidenhead v SP</i>	<i>Aintree</i> applied. P's wishes and feelings ascertained through her relatives: included a wish that her children should not suffer from seeing her in PVS and CANH withdrawn.	<i>Emergence of individual</i> <i>Person of value: patient's perspective</i> <i>Space-time: me, myself and I/narrative wormhole</i> <i>Role of law/Compassion</i>

Table 8: Themes from the final template

Top level theme	Second level theme	Third level theme
Emergence of the individual	Cecily Saunders patient	
	Judge as person	
	Significance of absence	
	All life is an experiment	
Person of value	Patient's perspective	
	Ethical landscape	
	Legal consciousness	
The Role of Law	Law as an impartial power	
	Mediator of difference	Black letter law/socio-legal approach
		Landscapes of life
	Legal consciousness	Before the law/against the law
Space-time	Me, myself and I	
	The narrative wormhole	
	Time factors	Never say never/time as risk
		Time as protection/time as resource
	Distance	The protective impulse
		Audio-visual

Description of findings

Emergence of the individual

The *Cecily Saunders patient* references the holistic concept of ‘total pain’, including physical symptoms, mental distress, social problems and emotional difficulties (Saunders, 2000, see Chapter 2). The concept also encompasses a sense of narrative and biography, emphasising the importance of hearing a patient’s story and of understanding their experience of suffering (Clark, 2014). The judgment of Lady Hale (with which the other Law Lords agreed) in *Aintree University Hospitals NHS Foundation Trust v James* [2013] (*‘Aintree’*) reflects this focus on the whole person:

[decision makers] must look at [a patient's] welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; *they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be*; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be,' ([39], my emphasis).

This approach results in the emergence of the '*judge as person*', as distinct from the judge as an impartial embodiment of the law or the legal process. In requiring a decision-maker to consider matters 'from the patient's point of view' ([45]), *Aintree* creates a sense of the importance of the patient's personal perspective. On Del Mar's analysis, 'effortfully constructing mental images of what it must be like for someone else to experience a particular situation' (2017, p.148) is part of a compassionate response (see Chapter 3). In *Salford Royal NHS Foundation Trust v Mrs P* ([2017] EWCOP 23) (*Mrs P*) a relationship on a human level between a judge and a family member is eloquently illustrated. This case concerned the discontinuance of life-sustaining treatment from a grandmother, whose grandson had been making origami models in court:

When I retired to consider this judgment, he handed one of his models to the usher to give to me. As a simple act of kindness for a judge about to take a very difficult decision it struck me as instinctively considerate and it was very much appreciated (*per* Hayden J at [41]).

The judge refers to himself in his official capacity here, but it appears that it is the human aspects of this case which make it a ‘very difficult decision’ and it is in his capacity as ‘judge as person’ that he appreciates the gift.

However, a judge is not always willing (or, possibly, able) to try and find the patient’s perspective. A judge is embedded in the hierarchy of the law, entangled in its concerns with power and its traditional disregard for the social world (Kilcommins, 2016). Not all judges may be able to ‘oscillate between pathos and distance’ (Tamboukou, 2014, p.620) as would be required to accommodate a compassionate engagement with the patient’s perspective and the detachment required in a decision-maker of last resort. Thus whilst *Aintree* created the conditions of possibility for a judge, by considering the patient’s point of view, to introduce compassion into the assessment of an individual’s best interests, this does not always happen. In *Re AB* ([2016] EWCOP 66), for example, a case concerning the treatment of a woman with AIDS and severe mental health issues, the judge approved her treatment by deception, in a judgment which was formal, traditionally ‘legal’ in its use of latin words and phrases and in which the judge maintained a clear position as a cog in an impartial legal machine. The patient was not physically present in court and her voice was excluded procedurally:

‘She was visited just the other day by a member of the Official Solicitor’s staff, who has produced an eloquent attendance note. If anyone has any doubts as to the scale of the mental challenges faced by AB they only need to read

that note, which I am not going to read into this judgment’ (Mostyn, J. at [15]).

The absence of either the ‘*judge as person*’ or the ‘*Cecily Saunders patient*’ creates, to some extent, a sense of incompleteness in the decision-making process: ‘*significance of absence*’. Indeed, in *Re AB*, the judge concluded that: ‘if the truth emerges ... the matter will have to be reviewed’ (at [27]). The patient’s absence from the decision leaves it incomplete in the sense that it will need to be reviewed if she finds out about it. This ‘*significance of absence*’ is also reflected in *London Borough of Brent v NB, SA, AD, MB, SB* ([2017] EWCOP 34, ‘*Brent*’), which concerned a 22 year old man with cerebral palsy (MB), described as having an ‘enmeshed’ relationship with his mother, who was also his primary carer. MB’s difficulties in communicating, meant that the judge was unable to establish whether his opposition to the treatment proposed was a reflection of his mother’s opposition to the risk involved or MB’s own perspective. Hilder, J, conscious that MB’s views might not be represented, told MB’s mother that she would have to bear ‘the heavy responsibility of knowing that an opportunity to explore enhancement of her son’s life experience has been passed by’, leaving his life ‘more limited’ than it might be’ [173].

My theme ‘*All life is an experiment*’ references the entanglement of risk and decision-making. It is taken from the words of Holmes J (*Abrams v United States* (1919) 250 US 616 at 630) who considered that ‘every year if not every day we have to wager our salvation upon some prophecy based upon imperfect knowledge’. This theme reflects the conflict between paternalism and empowerment, which characterises many decisions for people who lack capacity. Holmes’ quote was referenced in *B v D*,

Ministry of Defence (B v D) ([2017] at [41]), a case brought by the mother of a former soldier who had suffered catastrophic brain damage and wanted to use experimental stem cell treatment to try and improve his condition. The Ministry of Defence and the Official Solicitor (on behalf of D, the patient) both opposed the treatment on the grounds of risk. D was keen to have the treatment ('Mum, if I don't try, I'll never know', at [57]) and emphasised his views to the judge by telephone. He did not have capacity to decide whether to receive the treatment, but the judge, following *Aintree* ([45]) in taking into account the things that were important to D, found that:

'if D is denied the opportunity to have the treatment on the grounds that this is the safer option, there is in my judgment a strong argument that his safety may be bought at too high a price in terms of his happiness and emotional welfare' (at [60]).

Person of value

The *patient's perspective* reflects the expectation that the MCA would empower individuals in the decision-making process (DCA, 2007). Lady Hale in *Aintree* (at [39]) required a focus on the *patient's perspective* when determining best interests. The best interests test is not objective or referable to a 'reasonable patient' (*Aintree* [45]) but requires consideration of the *patient's perspective*, even where the circumstances may prohibit their direct, personal involvement. Thus, even where a patient is in a coma,

insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which

should be taken into account because they are a component in making the choice which is right for him as an individual human being (*Aintree* at [45] *per* Lady Hale).

The ethical landscape puts the *patient's perspective* in the context of the 'patient as human being', rather than as an embodiment of a particular condition. A patient as a set of symptoms, the patient-as-patient, can simply be treated as the symptoms suggest. Considering a patient as an individual human being, however, calls into question their intrinsic worth, their dignity and their right to self-determination (Beauchamp and Childress, 2009). Where the decision concerns life-sustaining treatment, decision-makers must consider when the right to self-determination displaces the state's obligation to safeguard the patient's life. Following the decision in *Aintree*, the '*Cecily Saunders patient*' requires identification of the choice which is right for them as an individual human being.

The Role of Law

'*Law as an impartial power*' references the 'doctrinal' approach to law, that legal reasoning is autonomous and that recourse to non-legal reasons or justifications is unnecessary in the creation, interpretation and application of law (Kilcommins, 2016). My genealogical analysis of the emergence of the MCA suggests that, in this context, law has a different role. The judicial archive supports this view. This archive indicates that the Court of Protection has embedded a *socio-legal approach*. In the context of the MCA, and as my archive of judgments indicates, *law as an impartial power* is largely conspicuous by its absence in recent decisions. I have suggested that it is not

only the individual at the heart of the decision who emerges into the decision-making process but also, and crucially, the '*judge as person*'. Thus the law for the Court of Protection has a human face. Biggs (2017 p.173) suggests that health-care cases 'demand a compassionate and caring response' and that this is incompatible with the law as a dispassionate rule-based system. The words of Hayden, J in *Re O* ([2016]) support this view:

As the three daughters ... are all too well aware, I found it difficult at that point to disentangle their wishes ... from my obligation to protect their mother. Individuals in the situation that O finds here are entitled to respect for their own autonomy and to their own dignity. But such is the intensity of this family's feelings for their mother and their love for her that I permitted their wishes to prevail ... I wanted to strike a balance between what I feared might be compromising [O's] rights and, at the same time, offering the family every conceivable opportunity to explore the options for their mother ([11]).

These words of Hayden J underline the difference between the role of the Court of Protection, which I have characterised as a *mediator of difference*, and the role of the court in other cases. The role of the criminal court, is objectively to determine the facts of a given situation and to impose justice (Ewick and Silbey, 1998). Mediation implies helping, seeking the common ground and identifying a mutually acceptable solution. I use this word deliberately to describe the role of the Court of Protection where judges seek morally acceptable outcomes, balancing life and death, empowerment and protection, medical duty, self-determination, pain (both existential and physical) and love. A judge might accept that an individual 'in strict law' lacks

autonomy, but go on to attach ‘very considerable weight indeed’ to the ‘albeit qualified autonomy’ of a patient who expresses clear wishes and feelings in relation to a particular medical procedure (*Re CS*, [2016], [17], per Baker, J). Thus the archive suggests that, in interpreting the MCA, judges are embedding it as a compassionate power, taking a therapeutic jurisprudential approach.

My *role of law* theme also encompasses ideas of *legal consciousness* (see Chapter 3). Halliday et al. (2015) describe a use of the ‘law as a shield’ in their interpretation of Ewick and Silbey’s (1998) ‘before the law’ narrative and there are clear echoes of this in the referral of difficult decisions to the Court of Protection. In *B v D*, the former soldier’s mother, in appealing to the Court to consider her son’s best interests, was standing ‘against the law’ in the form of the Ministry of Defence, the representation of power and authority over her son as a soldier. The Ministry of Defence opposed the radical new treatment and P’s mother was thus looking for the MCA to offer a fair process and to shield her against the power of an autocratic and uncompassionate authority.

Space-time

This theme is most compelling in the cases which concern individuals who have prolonged disorders of consciousness and cannot speak for themselves. These cases typically concern questions of life and death, about the futility of treatment and about the exercise of self-determination by an individual whose wishes and feelings are available only through the recollections of family and friends. The ‘*me, myself and I*’

theme introduces ideas of space and time into the decision-making processes and their relevance in locating the *patient as person*.

In *Briggs*, the ‘*me, myself and I*’ theme is relevant to the judge’s reference to Mr. Briggs as two separate people:

‘the involvement of the treating team has been with Mr. Briggs after the accident and so a Mr. Briggs who has serious and permanent brain injuries and who is and will be totally dependent on others for his day to day physical care. And so with the severely disabled Mr. Briggs who lacks capacity. The involvement of his family and friends has been with Mr. Briggs as a wife, mother, brother, sister-in-law and friend before and after his accident and so with the loving husband, father, son and brother, popular colleague and very physically active outdoors Mr. Briggs as well as with the seriously disabled Mr. Briggs who now lacks capacity’ ([27]).

The judge considered that Mr. Briggs’ brain injuries had made him ‘a changed person who [did] not have insight into his previous wishes, beliefs and values’ and ‘no longer appreciate[d] ... how [he was] before [his] injuries occurred’ ([54]). Despite the argument that the severely disabled Mr. Briggs who lacked capacity to decide for himself was a different person from the physically active Mr. Briggs, his family ‘still regard[ed] him as the husband, father and son they loved’ and ‘understandably, ...want[ed] to achieve the result that they [were] convinced Mr. Briggs would have wanted’ ([28]). The result they sought was ‘the side effect of death’, premised on their belief that, despite the fact that the disabled Mr. Briggs could and did experience

pleasure, the physically active Mr. Briggs would consider his life (as the disabled Mr Briggs) not to be worth living.

In *Briggs*, Charles, J. (at [58]) accepted the views of others as evidence of Mr Briggs' wishes and feelings, introducing the concept of relational autonomy into MCA decision-making. This is represented by my *narrative wormhole* theme. In making decisions for individuals beyond the reach of medical science, the *narrative wormhole* seemed to encompass the link between their past and the current court proceedings. A 'wormhole' is a theoretical passage through space-time that creates shortcuts for long journeys across the universe: my *narrative wormhole* connects an individual's past and present selves. The connection is made by the friends and family of the individual, who bear witness to the wishes and feelings of their loved one. As the *judge as person* listens through the *narrative wormhole* to the voice of the *Cecily Saunders patient*, whose existential pain is relevant to the treatment of the patient-as-patient, the best interests test (MCA s4) creates a relational, space-time continuum.

The importance of connecting the past and present in this way finds reflection in the judicial narratives. In *Mrs P*, Hayden J characterises the effect of the evidence as bringing the patient into the court; 'her incapacitous state does not mean her wishes can be disregarded. Her family, each of them, has permitted her voice to be heard and thus enabled her to assert her own autonomy' ([39]) and in *Briggs*, Charles, J. concludes that:

'I am sure that if Mr Briggs had been sitting in my chair and heard all the evidence and argument he would, in exercise of his right of self-determination,

not have consented to further ...treatment [and] that his best interests are best promoted by the court not giving that consent on his behalf", ([129]).

In these cases the patient's previously held views, transmitted to the court through the recollections of family members, are characterised as an exercise of the patient's self-determination in supporting withdrawal of life-prolonging treatment. In allowing a *narrative wormhole* to influence the decision, the court is reading into its interpretation of the MCA's concept of best interests an acceptance of the notion of relational autonomy (see Chapters 2 and 3), albeit in these very specific circumstances.

Time factors are drawn out in the judicial application of the MCA in simpler ways as well. Facets of the way time is experienced both physically and as a societal construct to quantify change or risk or to express compassion, are considered in my analysis. The starting point for every decision is time-specific: does the patient have the capacity to make a specific decision at the time it needs to be made? (MCA s2(1)). Time as a factor for change is thus inherent in the legislation itself and this can be interpreted positively to allow hope to feature in a decision-making process (my *never say never* theme) or, conversely, as a reason for approving the withdrawal of treatment which has been characterised as futile (no improvement being foreseen within the expected window of time). The key point is that the patient's place in time and space, as part of a continuum of change, is an influencing factor at every part of the decision-making process.

Distance is also a thread that runs through the judgments. In *Mr B*, *B v D* and *Re W* there are direct interactions between the judge and the patient. The judge met *Mr B* and *Miss W* and with the physical meeting shared space and time with each, eliminating distance. In each case the bridging of distance between the *patient as person* and the authority of the judge is referenced in the judgment as having influenced the outcome (see for example Jackson J. in *Mr B* at [18]). The exercise of law as a compassionate power, which I have linked to the emergence of the '*judge as person*', is highlighted. There is, however, a distinction in the data between the distance maintained between the court and the patient-as-patient, both physically and as a legal process, and the patient-as-person whose voice is heard through recollections. My *audio-visual* theme refers to the fact that evidence of the condition of the patient-as-patient is often not viewed by the judge: the distance between the legal and the medical is maintained. Maybe the *Cecily Saunders patient* is harder to see when the patient-as-patient is visible in the messiness of their current condition and compassion might be provoked for the physical plight rather than from the multi-faceted perspective of the '*patient as human*', which must inform their best interests?

5.4 Conclusions

The judicial data confirm that the key themes linked to the emergence of the MCA remain important in the way in which the legislation has been interpreted and embedded by the Court of Protection. The judgments reflect the increasing importance of the patient's voice in the process, despite the fact that someone's wishes and feelings are not accorded greater significance in the MCA than any other factor in determining where the patient's best interests lie (MCA s4(6) and (7)). Phase

two of my study suggests (supporting Jackson's (2018) contention), that, where they can be ascertained, the Court will accord the patient's wishes greater significance than other factors in applying the best interests test. In this respect, the Court has gone beyond the requirements of the MCA and towards the requirements of the CRPD.

Judicial interpretation of the MCA sets the context for its application in practice. Regulatory requirements inform processes of 'legality' by reference to the legal landscape constructed by the judiciary. How the hospice sector, and individual hospices, interpret and implement the MCA is the focus of the empirical phase of the study which follows.

CHAPTER 6

Phase three: the hospice organisational context

6.1 Introduction

In this Chapter, I change the focal length of the study. Phase one looked through a wide-angled lens at the policy development and legislative processes from which the MCA emerged. The three key themes which I identified, *the emergence of the individual*, *a person of value* and *the role of law*, were developed as I brought the genealogical analysis up-to-date in phase two, looking at the Court of Protection's interpretation of the MCA. My analysis confirmed that to allow the *emergence of the individual* and to recognise their importance as a *person of value*, a compassionate attempt to understand the story of the 'patient-as-person' is key, whether the voice of the 'patient-as-person' is heard directly or through recollections of another.

In this chapter, the wide-angled approach is replaced by a hospice-specific focus as I look at the organisational processes and practices of two hospices in the North West of England. I present the phase three organisational work, using policy documents and group interviews. Chapter 7 will present the work with individual hospice staff members.

6.2 Study design: phases three and four

Phases three and four comprise two related mini-studies, exploring the interpretation and application of the MCA in the context of the two participating hospices. My relational constructionist approach (see Chapter 3) focuses on the stories told by the

participants to explain their interpretation of the legal and policy context of the MCA. In phase three I undertook a documentary review of the participating hospices' policies and procedures and then conducted a group interview to explore how the MCA was implemented by each hospice. In phase four, I conducted semi-structured interviews with staff members whose responsibilities included making care and/or treatment decisions for patients.

6.3 Ethical issues: phases three and four

Ethical approval for phases three and four was obtained from Lancaster University's Faculty of Health and Medicine Research Ethics Committee on 5th June 2017 (Appendix 6). My research proposal contained full details of the measures to be taken to ensure the safety and wellbeing of myself, the participants and any third parties involved. It was made clear to staff members that they were under no obligation to take part in the study.

My study did not require participants to be identifiable and personal information was removed on transcription of the interviews. Where a staff member would have been identifiable by reference to their job title, their consent was obtained on a clear understanding of this. Demographic information has been presented so as to maintain the anonymity of the participants. Consent from the group interview participants was predicated on their understanding that they would not be anonymous to the other members of the group and, because the group met at the hospice, to other members of staff. I was careful to try and facilitate a balanced discussion in the group interviews. My aim was to allow the participants to shape the conversation so that I facilitated

rather than led or directed the exploration of the staff perspective. Participant information documents and consent forms for phase three and four participants are annexed at Appendix 7.

6.4 Population, sampling and recruitment

Two independent hospices situated in the North West of England and meeting the inclusion criteria were purposively sampled by reference to the services offered. The hospice of which I am a trustee was excluded. The chief executives emailed an invitation to participate and signed consent forms recording their agreement to do so. Potential participants (for group and individual interviews) were identified with the assistance of the hospice CEO by reference to the inclusion criteria. They were emailed, provided with information about the study, asked to email me to confirm their interest and then to sign a consent form.

A summary of the process for phases three and four of the study is presented in Table 9. Summary information about the participating hospices is presented in Table 10. Participant Information is provided in Appendix 7.

Table 9: Phases three and four – population, sample and recruitment

	Population	Sample
Phases two and three		
Hospice selection	Hospices in NW England offering full range of services (in-patient beds, day care and hospice at home services)	Purposive sampling of two hospices offering full range of services
Phase two		
Documentary review	Policies/documents relating to the MCA decision-making process	<u>Hospice 1:</u> <ul style="list-style-type: none"> • Mental Capacity Policy and procedures • Best interests balance sheet <u>Hospice 2:</u> <ul style="list-style-type: none"> • Policy: Decisions about care and treatment • Assessment of Capacity record • Assessment of Best Interests record • Training document: Recognising Care Legislation
Group interview	Hospice staff and trustees of each participating hospice (clinical and non-clinical) with responsibility for: <ul style="list-style-type: none"> - MCA compliance; - policy development; and/or - staff training and development; 	Purposive sampling (introduction by CEO)
		<u>Hospice 1:</u> six staff members <u>Hospice 2:</u> four staff members
Phase three		
Individual staff members	Hospice staff with responsibility for making care/treatment decisions (clinical and non-clinical)	Expressions of interest to researcher
		<u>Hospice 1:</u> three staff members <u>Hospice 2:</u> three staff members

Table 10: Participating hospice information

	Hospice 1	Hospice 2
Facilities	In-Patient Unit, a Day Service, and Hospice at Home. 24 hour telephone advice line	In-patient unit, out-patient services (clinical and social) on site, community services at home. 24 hour telephone advice line
Services	Physical, emotional, spiritual and social holistic care	Specialised medical care and treatment, psychological support, occupational therapy, physiotherapy, complementary therapies and ‘diversion’ activities
Team	Nurses, doctors, counsellors, a chaplaincy/ spiritual care team and complementary therapists	Doctors, nurses, physio- and occupational therapists, social workers and complementary therapists
In-patient beds	9	19
CQC Inspection	June 2016 (Good)	June 2016 (Good)
MCA compliance (from inspection summary)	Clear about their responsibilities to people around the MCA and dedicated in their approach to supporting people to make informed decisions about their care	Working within the principles of the MCA. Need for care plans and other associated paperwork and the knowledge of some nursing staff to be in line with clinical staff and the hospice’s policies in this area.
Education provision	Internal staff development External organisations in end of life care	Internal staff development External organisations in end of life care

6.5 Phase three data collection

The group interviews took place at the participating hospices (with participants’ consent). The group interviews were semi-structured following a discussion guide (see Appendix 7). The discussions were audio-recorded (with consent) and I transcribed (and anonymised) the recordings (verbatim) as soon as possible after the conclusion of each. Table 11 sets out the demographic information for the group interview participants.

Table 11: Group Interviews: Demographic information

	Hospice 1	Hospice 2
No. of participants	6	4
Gender:		
• M	1	2
• F	5	2
Age range (years)	28-61	36-58
Nature of role:		
Clinical care	4	3
Social care	1	
Education	1	1

6.6 Data Analysis

Taking a relational constructionist view of the hospice as an organisation, my interest was primarily in the way in which the staff worked *together* to construct the organisational context of the hospice as they interpreted and implemented the MCA. The policy documents are briefly discussed below and then considered, together with the group interview data, as part of the story of the ongoing relational processes at the participating hospices. In analysing the data, I did not find any significant inconsistencies between the two group narratives and, accordingly, whilst I analysed the data from each participating hospice separately, my presentation of the findings below uses data from both hospices, attributed appropriately.

Documentary analysis

Each policy was prefaced by a statement setting out when it would be due for review. This was my starting point. Approaching a policy from the perspective that history is

non-linear, that unexpected twists and turns can catalyse the emergence of something new (although connected to what has gone before), and that, as a local relational reality, an organisation is in a continual process of becoming, I have conceived 'policy' as being something which is part of the ongoing relational reality of the participating hospices. It forms part of their local culture, but it must be subject to change. Where a policy, as in the context of the MCA, reflects a legal standard, then the continuing process of judicial interpretation of the law (itself a relational process in a continual process of becoming) provides a dynamic background, and the hospice policies reference this.

In terms of their content, the policy documents were consistent with the terminology and approach set out in the MCA. They described a compliant process in simple language situated in the context of the provision of care and treatment to patients with life-limiting conditions. The five principles of the MCA were repeated verbatim and decision-making flowcharts and pro-forma documents were available to assist with making and recording MCA-compliant decisions. The policies referenced the primary organisational aim to offer care which takes into account patients' beliefs, wishes and value systems.

Group interview data: approach

I took a narrative approach to analysis of the group interview data, analysing each organisational narrative as a separate case (thus keeping the narrative intact) and adopting Reissman's (2008) description of how to work with interview data. I applied her approach to my data as follows:

Definition of narrative: the group interview transcript is taken to represent the organisational narrative. Adopting a relational constructionist approach, I view knowledge as being co-constructed in the process of discussion (van den Haar and Hosking, 2004; Hosking, 2011).

Constructing data for analysis: each organisational narrative is considered individually, interpreted as a whole rather than broken into thematic categories for analysis. Speech is cleaned up (eg break-offs and repetitions erased). The focus is on the 'told' following Mischler's (1995) typology; my attention is to *what* is said in the group interview, rather than how (for example, the type of language).

Focus of the analysis: how the relational processes within each hospice construct the key concepts of capacity and best interests within the broad framework of the MCA and the narrower framework of the hospice policy and procedures.

Importance of context: the organisational context is key: within each hospice, knowledge about what capacity means and how decisions about care and treatment are made can be gleaned from the way law and policy are interpreted at organisational level (processes of legality).

Method of analysis

I used template analysis (see Chapter 3) to analyse the data, having spent time reading and thinking about each group interview separately. I marked up each transcript with my comments and developing codes (see an example in Appendix 11). I used the data from the first group interview to develop an initial template which I then iteratively developed using the findings from the second group interview. The final coding template is set out below (Table 12) and Appendix 9 contains all its iterations.

Table 12: Analysis of the group interview data: the final coding template

- 1. The individual in the decision**
 - 1.1. The patient as the context of care
 - 1.1.1. Narrative knowledge
 - 1.1.2. The decision as a journey
 - 1.1.3. 'Compassionate paternalism'
 - 1.2. Staff as professionals and people
- 2. Collegiate approach**
 - 2.1. Listening and hearing
 - 2.2. Testing the process
 - 2.3. Supporting relationships
 - 2.3.1. 'A problem shared is a problem halved'
 - 2.3.2. Us and them?
- 3. Role of law**
 - 3.1. Legal consciousness
 - 3.1.1. Legal conscientiousness and the liveability of law
 - 3.1.2. Law as a shield/resource
- 4. The Hospice Movement**
 - 4.1. Distinctly different?
 - 4.1.1. 'The acute'
 - 4.2. Experts in the field
 - 4.2.1. Unconscious competence
 - 4.2.2. Guardian of a proper process
 - 4.2.3. Educator and innovator
- 5. Place and Distance**
 - 5.1. 'Ceiling of care'
 - 5.2. Going home
 - 5.3. Resilience
- 6. The significance of time**
 - 6.1. The MCA journey
 - 6.1.1. 'Habitus'
 - 6.1.2. Learning from experience
 - 6.2. The patient before
 - 6.3. 'A doctor who is not in a hurry'

Influence of the three key themes

I have suggested that the high level themes (the *emergence of the individual*, *person of value* and *the role of law*) underpinned the aims of the policy makers and legislators in creating the MCA. Having reflected on their relationship to the empirical findings, I have used them as ‘organising themes’ for the analysis of the group interview data, in a sense, mapping the hospices’ present-day interpretation of the MCA against the broad policy aims from which it emerged. I do not characterise or use these themes as ‘a priori’ themes, in the sense that they are definitive of and/or seek to apply some pre-determined theory or structure, because to do so would create a sense of conflict with the ‘bottom up’ relational constructionist approach that underpins my study. However, I found these broad conceptual ideas helpful in organising the themes drawn from the group interview data. In this way, analysis of the group interview data continues the process of ‘historicising the present’ (Livholts and Tamboukou, 2015, p.64), which my genealogical approach to constructing the life story of the MCA started.

The diagram below shows the six broad themes developed from my analysis of the group interview data. The reference to ‘the individual’ refers back to the *emergence of the individual*. *The hospice movement* is a development of the *person of value* idea, encapsulating an understanding of a hospice as attending holistically to individual patients. *Collegiate* concerns teamwork and mediating difference; ‘holding’ the patient within a team where the ‘patient-as-person’ will be supported. *Significance of time* is linked to the earlier ‘space-time’ discussion and introduces an idea of time as a resource and a luxury. *Place and distance* concern differences between in-patient care and care in the community, where although the policy might be the same, the

‘diffraction’ of the policy through GPs and community (non-hospice) social workers results in differences in the process. The diagram links the themes in an ongoing ‘care orbit’.

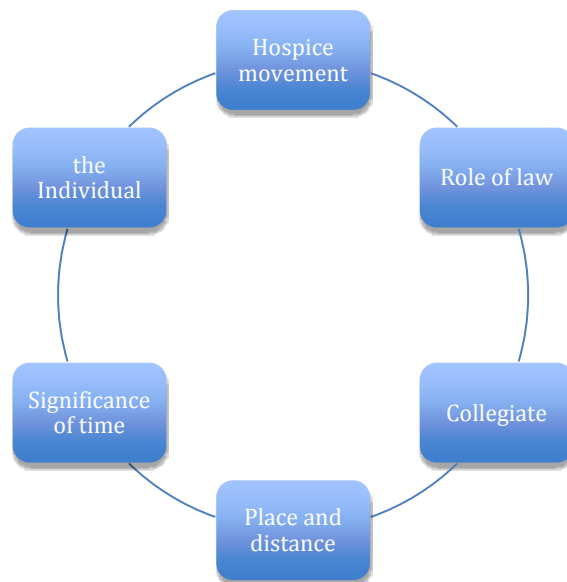


Figure 6: A ‘care orbit’ linking the themes drawn from the organisational narrative

Description of findings

I have organised the description of my findings around the six main themes summarised above, drawing illustrative examples from the organisational narrative as required. The integrative theme (*compassion*) can be considered as the force which holds the themes in the ‘care orbit’ and will be considered in Chapter 8 as the discussion brings together all the phases of the study.

An emphasis on the relational in hospice care is indicated by a sense that, although central to the decision-making process, the *individual in the decision* is not isolated within it. The individual represents the context of care at policy level and in practice.

A decision is constructed *around* the patient in conversations involving relevant professionals and family members. This reflects the holistic approach taken by the Court in *Aintree* ([2013]), addresses the patient's 'total pain' (Saunders, 2000) and is at the heart of the way in which the relational processes described in the policies and reflected in the findings prioritise learning about the patient as a multi-faceted individual.

The process of getting to know the patient proceeds as a narrative journey, starting when the patient comes under the care of the hospice so that their former life, the nature of their illness and the way in which they experience their condition, are all component parts in the construction of a context within which future decisions will sit:

If it's pre loss of capacity then there's quite a lot of work done [on] advance care plan and even some of the basic assessments you know questions like to whom can we speak about your situation, if anybody, so even at that very early stage seeking consent from patients as to who in the family you know they would like us to speak with, I suppose we just start to get the feel for what they want and how they function as individuals and human beings (H2, P1).¹

The loss of capacity for many hospice patients signals the approach of the end of life, when decisions are often required but when a patient might be increasingly unwell. The focus on engaging with a patient's narrative, reflected in the idea of the *decision*

¹ H = Hospice; P = Participant.

as a journey, allows staff to bring their knowledge of the patient to the decision-making process to support the patient and the family when decisions are required. A sense of the availability of time to listen to a patient's story and to explore with them the likely progression of their disease, allows decisions to coalesce around the 'patient-as-person' as part of a relational process. This means that the decision-making context is the '*Cecily Saunders patient*' - the 'whole' patient whose narrative is understood.

Staff as professionals and people suggests that staff also experience the decision as a journey; the process of a complex decision, organised by reference to the MCA policy, allows staff to understand and reflect on the way in which difficult decisions are made. The decision-making approach is *collegiate*; by this I mean a sharing of decisions amongst equals underpinned by a perception that decision-making is a relational process. The data describe robust but caring decision-making processes, where the patient is 'held' by the team as a whole. The role of each individual staff member as part of a multi-disciplinary team (MDT) is a key part of the collegiate process. The differing competencies and perspectives of the MDT members smooth the process: the decision is considered from all angles and the team as a whole is represented in the process. This collegiate process shares responsibility and mediates anxiety or concern with the outcome of the decision. The legal framework, reflected in the policies, is considered helpful in this process.

The *us and them* theme reflects a sense of distance between the community team and collegiate organisational culture. The supportive environment in which decisions on the ward are made is not available to community-based hospice staff, and the staff

suggested that this is a lonelier role. Care in the community is led by GPs and staff perceive their approach to be different:

in order to be a GP you have to make a lot of instant decisions on your own and that is what you have to do as a GP. And so they get used to that, making that decision and that's their decision and they go with it and I think that there is an element of that they're used to making their decision and they don't stop to necessarily ask everybody else, where we wouldn't think about making those decisions without talking to everyone else (H1, P6).

The community-based hospice staff take on the role of expert in making decisions under the MCA, but the context for the treatment or care is generally the patient's own home and the risks (and attendant responsibilities) are different. Decisions are not *collegiate*; there is a sense that tensions are not uncommon:

I suspect that there's not a huge amount of consistency in terms of how that works in the community because of the fact that you're working with such a huge range of professionals with varying degrees of expertise, probably in some of these areas, but I think also with varying degrees of desire to be the responsible person. So I suspect that a little bit does fall onto our nurses at times to really try and drive things being done in the right way (H2, P2).

Community-based staff offer robust advocacy for the patient without the collegiate, organisational support:

He said I don't want to go into hospital and die – I want to be at home. And so he was very clear about what he wanted and what he didn't want ... And so I got involved and I said, 'You know that's not right ... He doesn't want to go into hospital'. And I actually spoke to the GP ...and the GP was fine (H1, P6).

Place and distance

The focus of this theme, linked to *us and them*, is on the less obvious effects of the provision of hospice care outside the hospice. There is a perception that community-based hospice staff will (and will have to) employ a different frame of reference for decisions. Risk assessments will be made in the context not of round-the-clock availability of care and support, but almost the exact opposite. Time, for a patient in the community, is less a luxury and more of a limiting factor related to the length of time they will be able to manage safely at home:

But people choose to live in ways that we wouldn't necessarily think are great, you know they choose to go back to environments where there's potential risk - a patient's falling that's a risk for all our patients that want to go home. Sometimes you have to kind of go 'Fine, go home ... but you need to consider what the options will be if that ... doesn't work' (H2, P2).

The difficulties for patients being discharged into the community, away from the safety and the support of the ward, are not, however, used to deny them the ability to choose where they have capacity to do so. The patient's wishes and feelings are central, despite their occasional unusual personal situations:

A man who was going home, quite fit to go home, but was a hoarder. I think his house was a series of tunnels and there was a worry about sending him home because of the obvious risks. But again it was respected, he had capacity, his house had been assessed as a fire risk, the fire service had been out, all the right things had been done, he wanted to go, so ... he did (H2, P1).

The significance of place for community staff members involves a perception, characterised as '*us and them*', which suggests that they are satisfied with a lower standard of care:

(H2, P1): But I think you that have worked in the community will be a little bit more hardened than the rest working on an in-patient unit because you're so used to seeing how people live?

P4: Yeah

P1: You really see the wide variety don't you ... people managing?

P2: I suspect that most of our nurses on the ward wouldn't be able to leave the person in their house.

P1: They'd be camping out! It's a challenge, seeing people and having ... when they're on the ward I can do pretty much anything we need to do. Take the symptom management, that feels very secure ... whereas you go out to someone's home ... you do have to leave people in their homes looking pretty unwell.

The organisational narrative clearly positions the hospice as an *expert in the field* of decision-making under the MCA; there is no need to think about what the MCA

requires for patients in the context of the majority of decisions, whether that be an assessment of capacity or consideration of the patient's best interests, staff are unconsciously competent:

Yes, I think that dealing with patients who lose capacity ... we deal with a lot of the time and most of the time it's routine without actually having to think about the policy ... although we know the legal stuff it's not something we necessarily ... go through step by step with every patient who loses capacity (H1, P3).

There is a sense that hospices are *guardians of a proper process*, as they work with other settings:

That is why it's important that our team can establish the principles and actually part of our role then can actually be educating as well as supporting that individual patient's decision-making (H1, P5).

Both organisational narratives reflect on the way in which other care-focused professionals understand and engage with the MCA:

I think social workers, for example, my experience of social workers is that they're much hotter on Mental Capacity Act and best interests than the nursing and medical profession are ... when I was training [MCA] out in the community ... you know the doctors and the nurses some of them are ... are good on it but most of them, really, they don't think about it on a day to day

basis, they don't know it in the way that you know you get to know it if you've had some of these challenging cases I think (H1, P6).

There is a clear sense that, as expert and *guardian of a proper process*, staff perceive themselves as offering better care than 'the acute' or other care settings:

I mean there's times when there are some huge issues in the hospital and then people come here and those issues just seem to kind of disappear because you change the environment, change the people, time to explore, time to discuss and it just seems to ... settle (H2, P2).

The significance of time was referenced on many occasions in both group interviews. On a conceptual level, time could be said to underpin the whole concept of hospice care in that hospices offer their services to patients with 'life limiting' or 'terminal' conditions. Different references to time are woven throughout the organisational narratives. Taking them together suggests that the passing of time, although inexorable, is not imbued with any sense of threat, but that to struggle against time's passing is somehow to waste it. Although hospice patients' time is accepted to be finite, there is a sense of calm:

The issue is in the hospice we have time. And I think it doesn't get done well in the acute because everyone's, you know there's often almost too many people involved and they just don't have the time. I mean we do spend a lot of time on these in order to get it right (H1, P6).

The sense of the *MCA journey* links many of the issues discussed in the group interviews. There is an acceptance that people need time to change, which is why ‘old style’ doctors are less good at understanding and working with the MCA. The ‘*habitus*’ theme reflects my impression that ‘old style’ doctors are unconsciously competent at using their pre-MCA methods and resistant to change:

And also to be fair as well from the [MCA] you know I mean obviously that was 2005-2007 isn’t it, you know it’s a good while ago now but actually there’s a good proportion of us in health care that ... to a certain extent ... predate it you see and it is actually that you know and unless you really embed it with new learning and taking things on I think sometimes that can be hard for people, can’t it, you know what they sometimes set out with it’s hard to change it’s sometimes hard to change behaviours isn’t it, and ways of ways of thinking (H1, P5).

Legal consciousness references cultural characterisations of legality, the background assumptions about legality that structure and inform routine thoughts and are drawn upon when individuals and groups make sense of everyday life (see Chapter 3). Both participating hospices unambiguously characterise the MCA as a good thing:

It’s a number of years since we first drafted the MCA policy and I remember that we really welcomed it here (H2, P1).

That approach seems to be underpinned by a sense that the MCA provides a shield not just for the patient’s best interests, but also for the decision-makers; there is a clear

process underpinning the decision-making journey for a patient whose capacity is in doubt. Hospice staff are happy to apply the MCA: compliance is a confirmation of organisational quality and keeps patients safe. This is particularly the case where there is a difficult decision to make or where a patient has complex needs:

And I think in these more complicated cases that's where we maybe record against headings and it's just, you know, to make sure we've looked at it really comprehensively and we've not missed any ... perspectives or key points ... particularly when we are looking at best interests decision-making (H1, P2).

There is a sense here that law is impartial and objective, requiring measurable actions to ensure an acceptable outcome but, in the context of this particular law in the hospice context, this appears not to be the whole story. Medical professionals caring for patients with life-limiting conditions work *within* a relationship with their patients and are not emotionally distanced from the outcome. Law takes on a different character; rather than an impartial and distant power, it becomes a resource in the hands of the hospice. The MCA is a tool for good, with the potential, in and of itself, to be therapeutic:

I think the patient's wishes are always very key and we always try to keep that in the very centre of the whole process. I think it's always been helpful to work through a kind of logical fashion to make sure you're doing everything you can to optimise their capacity and re-assessing that when you need to and if it does come to a best interests decision then actually taking on board

everything you know about what the patient wanted from as many sources as possible (H2, P1).

Where the decision does not have a clear, universally accepted (by patient, family and treating team) and obvious outcome, the process of getting to the best, or sometimes the 'least worst', decision can be traumatic. Both participating hospices described 'debrief' meetings to map the process of a complex decision against the MCA, using the legal framework as a resource to cut through the emotion and demonstrate why the outcome was the right one:

I think what was very difficult about this case was there was a lot of emotion involved on lots of people's parts and it was trying to make sure that we were making a decision based on what was in his best interests not on what you think personally should happen and that was very difficult I think to tease that out ... having a debrief did actually help, predominantly the nursing staff, kind of on an emotional level deal with that kind of process (H1, P1).

At an organisational level the MCA is welcomed by the hospices. It is routinely used and its application is an unconscious competence of hospice staff. However, where complex care and treatment decisions need to be made, its application is overt, both as a guide to practice and also as a tool for debriefing staff, reassuring them that the correct process was followed and minimising distress by measuring actions taken against the MCA as an indicator of best practice:

I think that by following the process that we did I hope that it gave staff confidence that the right decision [was] being made for the right reasons. I think there was a lot of anger around the decision that had been made ... it was out of our control in the hospital ... and a lot of unhappiness about that decision that you wanted everyone to see how we'd come up with this decision for this reason and be confident in that decision. Certainly it would have been very difficult if people had not ... if there'd been disagreement within our team at our end ... which thankfully there wasn't (H1, P1).

6.7 Conclusions

There is a clear sense that a journey to embed the MCA into organisational decision-making is on-going. The fact that an individual patient should sit at the heart of the decision-making process is well established. The archival data highlighted the focus on an emergence of the individual into the decision-making process; the group interview data indicates that the individual sets the context for the decision. Rather than fitting the patient into the decision, the decision is now constructed to fit the patient; the patient *is* the context for the care. Staff recognise the value of the 'patient-as-person' and consciously support their personhood and attendant rights, taking a holistic view of the individual patient. They accept the patient as *someone*, experiencing physical *and* metaphysical pain.

As regards the role of law, the staff support an interpretation of the MCA as a tool for good in the context of hospice care. This is true both in the sense that applying the MCA assures organisational compliance, and also in that the application of the MCA

is considered to promote therapeutic effects. Thus, a decision-making process which follows the MCA is, in and of itself, perceived to be a good outcome for the patient. This will be developed in the analysis of the phase three data (Chapter 7) and further discussed in Chapter 8.

CHAPTER 7

Phase four: individual perceptions of the MCA

7.1 Introduction

In phase four the study moves from the organisational level to explore staff members' individual experiences of MCA decision-making. Participants were asked to narrate memorable experiences of decision-making for patients. The stories they told formed the basis for the analysis. Participants were not asked to situate their stories in any legal or policy context but simply to present and discuss them by reference to the principles that guide their care and treatment decision-making with and for patients on a daily basis.

The aim of this final phase of the study was to understand the professional perspective of making decisions with, for or about patients who lack the capacity to make decisions for themselves, particularly as regards the patient's role in the process. As with Ewick and Silbey's (1998) study, it was individuals' perceptions of the law and not the law itself in which I was interested.

7.2 Population and recruitment

The population for phase four was hospice staff from the two participating hospices (see Chapter 5). Recruitment was by purposive sampling of 3-4 staff members from each participating hospice. Inclusion criteria for the sample were either:

1. responsibility for assisting patients make care or treatment decisions; and/or

2. responsibility for religious, spiritual (or specifically non-medical) support and decision-making.

Information about the study was publicised within each participating hospice and interested staff members were invited to email me. Had the number of potential participants been too great, I would have selected a sample representative of both ‘in-patient’ and community-based staff.

Three participants were recruited in each participating hospice: the table below sets out the demographic information for the participants. References to roles and responsibilities is generalised because the use of participants’ job titles would identify them. In respect of Hospice 1, the participants in the individual interviews had also participated in the group interviews; no new staff members expressed an interest in participating.

7.3 Data collection and analysis

An interview guide was provided to participants on recruitment (see Appendix 7), asking them to choose two decision-making stories to tell. Participants were encouraged to explore the experiences chosen, concentrating particularly on the way those concerned (professionals, patient, family, etc.) took part in the decision-making process. The interviews took place at the participating hospice. The discussion was audio-recorded, with consent, and the recordings were transcribed, verbatim, by a transcriber working under the terms of a confidentiality agreement.

Table 13: Individual Interviews: Demographic information

	Hospice 1	Hospice 2
No. of participants	3	3
Gender: <ul style="list-style-type: none"> • M • F 	1 2	0 3
Age range (years)	23-53	34-57
<u>Nature of role:</u> Clinical care Clinical care/education Social care	2 1	2 1

Method

As for the group interview data, a narrative approach to analysis of the individual interview data was taken, each interview being analysed as a separate case (thus keeping the narrative intact). Data was constructed for analysis by reference to Reissman's (2008) suggestions (described in Chapter 6). The focus was participants' interpretation of the key requirements of the MCA in making care and treatment decisions for their patients, particularly as regards the role of the patients and their family (or other relevant carers) in the decision-making process.

Development of the coding template

In developing my analysis of the individual interview data, I followed the steps suggested by Brooks et al. (2015) (see Chapter 3) and developed my coding template as described below.

1. Having read and re-read each interview, I carried out preliminary coding of the data by highlighting aspects which facilitated my understanding of it. An example annotated interview is contained in Appendix 11.
2. Once the initial themes had been identified, I organised them into clusters around several broad conceptual ideas. In doing so, I considered the relevance of the three key themes to the data. I then separated the data into hierarchical themes within each broad conceptual area. The analysis of the first interview produced the initial template, which formed the basis for the analysis of the second interview. In analysing the second interview, I modified the template where the data suggested a different clustering of themes or a different hierarchical relationship and developed it to include any new themes identified. I continued this iterative process as I worked through the analysis of all six individual interviews.
3. Having developed the template through six iterations, I created a modified and combined version to underpin my description of the findings. As I organised my findings, I made further modifications in the ordering of the first level themes and the positioning of the lower-level hierarchical themes. I worked through two further iterations of the template before finalising it. This final template represents a detailed picture of my interpretation of the interview data.

The first and final templates are contained in Appendix 9. Table 14 below summarises the top- and second-level themes from the final template. Sub-level themes considered in the description of findings are italicised in the table.

Table 14: Individual Interviews: summary of top- and second-level themes

Top-level themes	Second-level themes
Circles of care	Patient at the centre (<i>focused listening, yes but no</i>), Information/communication, Role of the MDT, Perspectival imagination, MCA process as part of good care, Compassionate community
Place	Nature of care, Role of the patient in the decision, Home as a place of care
Time	The MCA journey, Change over time as a factor of care, Time as a resource (<i>time as a barrier to care, the luxury of time</i>), Time as a commodity, Remembering
Seeing the world through different eyes	Different people, different perspectives; multi-perspectival, I need to be able to sleep at night
Balancing power	The doctor was God, A little bit of me
Integrative themes	Nature of care: Legal consciousness

The themes all relate to the ways in which individuals are involved in decisions as relational processes. The individuals are not always the patients; sometimes the focus is a hospice staff member or another individual who plays a role in a particular patient's care. As was the case in the group interview findings, decision-making is experienced as a relational process.

There are two integrative themes, *legal consciousness* and *the nature of care*. *Legal consciousness* reflects the idea that each participant's view and experience of the MCA in their daily work says something about that individual's background assumptions of legality as they structure and inform the care of their patients. *The nature of care* references the way in which the participants understand what 'care' encompasses. Views about the *nature of care* infuse all the participant interviews, saying something about the relationship between good care and a compliant process. These integrative themes, together with *compassion*, as an integrative theme from the

case-law review and the group interview analysis, will be discussed in depth in Chapter 8.

7.4 Description of findings

There is considerable overlap in the coding templates for the group and individual interviews. The significance of time, place and the role of the individual are all reflected both at an organisational level and by the participants in the individual interviews. The individual interviews added a richness to the organisational data so that, for example, participants linked a ‘proper’ (MCA compliant) decision-making process to ‘proper’ (good quality) patient care. Care rather than legal compliance and procedural regularity was the key motivator for individual staff members. The care context subsumes the legal context so that, in reflecting the requirements of the MCA, the staff members are not fulfilling a legal duty but simply providing ‘proper’ care. The findings are presented below by reference to the top-level themes.

Circles of care

The theme I have described as *circles of care* references the idea of the patient being ‘held’ by the team as a whole and also to the idea of the MDT providing support to the staff, reflecting the significance of the MDT to many of the participants from the hospice in-patient unit. I have worked outwards from the idea that ‘patient-as-person’ comprises a complex interaction of physical, social and psychological factors, a person who changes as a result of experiences over time and who exists differently in the relational spaces constructed between themselves and others. I have imagined the nature of care for this complicated, multi-faceted patient-as-person as comprising a

series of overlapping circles. These ‘circles of care’ form an interlinked, multi-perspectival support system. The patient at the centre is enfolded into the care of the surrounding individuals and organisations as they interconnect to ‘hold’ the patient and often the patient’s family and/or other carers as well.

Figure 7 below gives an idea of how such circles of care might overlap and interrelate in the hospice context.

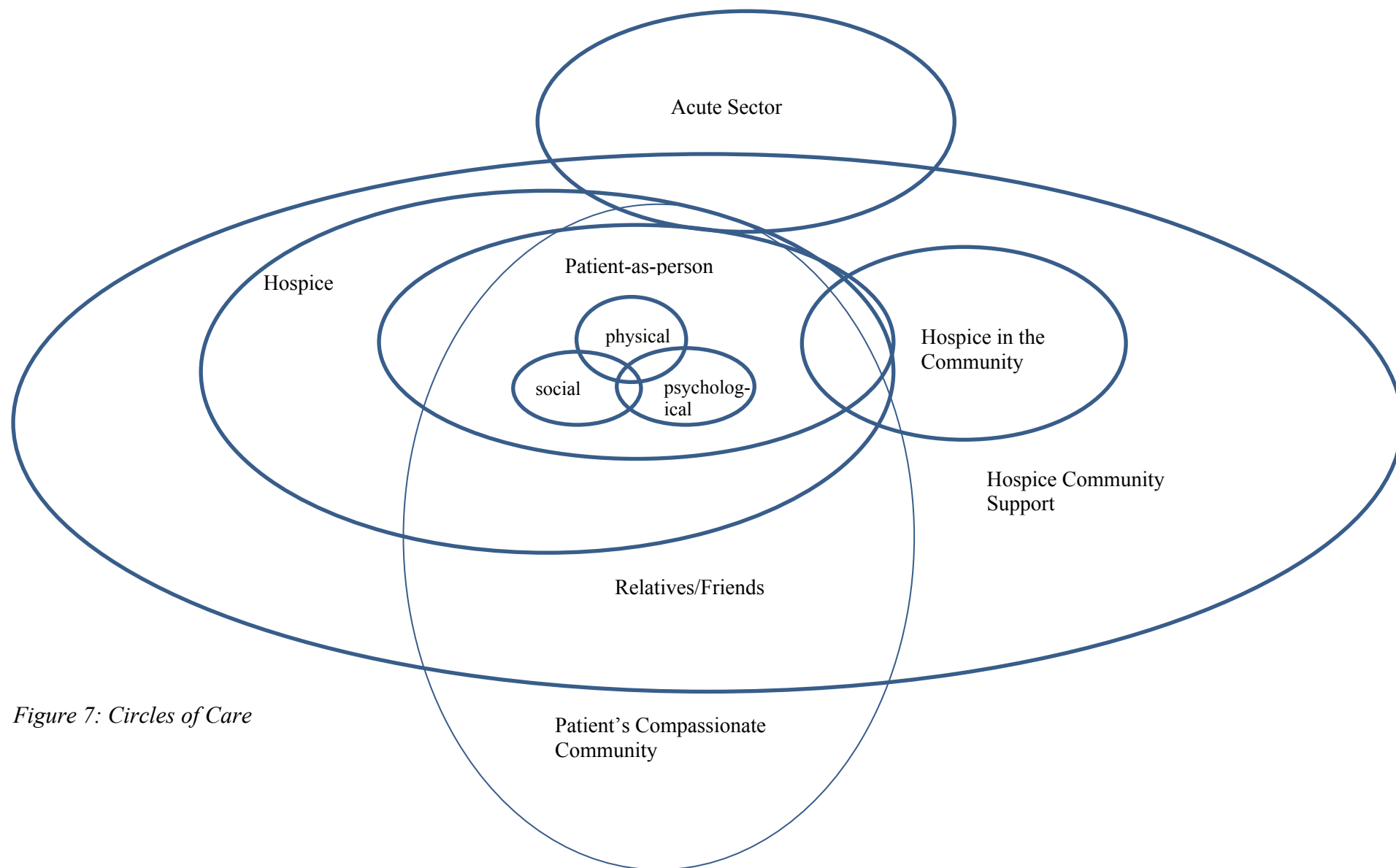


Figure 7: Circles of Care

The care described by the participants is all encompassing; their approach is to look for the patient's narrative and to reflect the patient-as-person in decision-making:

What's important to me is ... still seeing the person as an individual, I need to find out about that person, that person in that bed has had a past, so I'm interested in biography, because I think that's very empowering that you understand where that person's coming from and what life they've lived, who's in the family, like do a family tree, who's been there for them, and what's been important to them in their life, what kind of work they've done, what kind of interest they've had (H2, P3).

Both the patient and their family are enfolded into the *circles of care*: A participant describes her role as a bridge between the family and the patient within the wider circle of care, to 'hold' them through the transition between the patient's 'well' narrative and the 'illness' narrative:

We spend a lot of time talking with families about and trying to almost advocate for the patient ... I mean some families are just there, they have it already, and the patient's agenda is their agenda, but some families just don't, and it's not because they love them any less, they just don't understand what's happening to them, they don't understand the processes in the same way' (P1, H1).

Where a patient lacks capacity, the focus widens from the patient at the centre to the family or other carers nearest to the patient and their perceptions inform the care:

I think we were able to quite quickly assess that and feel that he didn't have capacity for [complex decisions] but needed to just spend a lot more time with his family to try and find out a wee bit more about what was going on. But it was a very complicated situation really and quite emotive and quite difficult ... it's important for us I think to see what was he like as a person before all this happened and hear a bit from [the family's] perspective as to how this all played out in the hospital (H1, P2).

Participants consider the patient's narrative a crucial component of their care. There is a recognition that a patient's narrative is not always contained in what is said directly and out loud. There is also a feeling that sometimes staff talk too much, listen too little and, even when they listen, do not always hear. I have characterised *focused listening* as a theme which links the hospice staff member to the patient's narrative. For some patients, *focused listening* means finding the time to sit and get to know a patient; for others, it means understanding a patient's perspective in a less obvious way and engaging differently as a result. My *yes but no* theme illustrates this. The story concerned a patient with motor neurone disease, in the context of a decision about feeding in the future:

And she did her assessment and then she said to him, 'of course there'll always be the option for you to have a peg feed and be artificially fed', and he said, 'yes but no', and she said, 'what do you mean, yes but no?', and he said,

‘yes I know about peg feed but no I don’t want it’. And she then went and spent ten minutes talking to him about what a peg feed was, what the advantages were ... and she got to the end and he was like looking at me and I was looking at him across the room, and he was having trouble with his language and speech ... so he just let her carry on, and then when she got to the end she sort of looked at him and he said, ‘yes, but no’. And I just thought he so clearly said that at the beginning but she wasn’t, she had to go through her thing of I’ve told him about this, but if everybody does that, people feel like almost bullied into treatment that they don’t want ... And it’s just for me it’s about listening, you know ... you didn’t need to be with this guy for very long to work out that he completely had capacity and he knew what he was talking about, he knew what he wanted and what he didn’t want ... and all she needed to have said is, ‘have you had a conversation with someone then about ...?’ You know when he said, ‘yes but no’, yes I know about it but no I don’t, ‘who have you had a conversation ...’, ‘well I’ve had a conversation with the MND team, they’ve talked to me about it’, that’s all she needed to know, she didn’t need to go through it all over again (H1, P1).

This also relates to my *information/communication* theme. The participant understands the importance of providing information but puts this in the context of the patient-as-person and interprets a less intuitive approach (which is conscious of and compliant with the requirements of the MCA) as burdensome for the patient. The potentially burdensome effect of staff members individually looking to ensure compliance with the MCA process is reflected in the few negative associations of the MDT within the context of hospice care. This also links to the idea of legal

consciousness and the idea of staff being on an *MCA journey*, where experience changes the way in which law is employed in guiding decisions for the patient. In this story, the participant is more experienced than the staff member whose approach she criticises. The way in which she experiences the MCA requirements is tempered by her confidence that her assessment of the patient and his knowledge of the relevant information does not require anything further.

Significance of Place

This theme explores the differences in the nature of care provided by hospice staff within the in-patient unit and hospice staff working within the community. The MDT, its existence and its importance to the provision of care is mentioned in every interview. In the in-patient context, the MDT is a *circle of care* in itself:

the most important thing I think is the team approach to something like this because all the examples tend to, you know there's not an obvious quick answer clearly and it's about kind of working through what's right for that patient, and I think here I really value doing that as a team and the input that everyone has really (H1, P2).

The participants working with in-patients describe decision-making as collegiate, multi-faceted and as encompassing every aspect of a patient's care. The patient's narrative is heard by staff members from the cleaners to the senior doctors in their different interactions with the patient and their family:

... trying to sort of capture anything we know, ... 'cos people always end up having random conversations don't they like when the housekeeping people are going in and stuff, there's a book that they can write anything they know about that patient in there, so I think we are trying to look at the patient as a whole and what would be right for them ... (H1, P2).

Complex decisions are considered from every angle and multiple perspectives inform the final outcome:

I think the more opinions you have, the more different perspectives you can have and also definitely have healthcare professionals involved, so the nurses get, patients may tell nurses different things than they tell the doctors, same way healthcare assistants might get a different perspective, even the cleaners or the domestic staff, quite often the patients will say things to them that they won't say to us, same goes for medical students ... So if we're having a multi-disciplinary approach to decisions, you can get all that information from all your different sources, which makes it a much more valuable process (H1, P3).

Hospice staff working in the community, experience MCA decision-making differently:

But I think yeah I think in the hospice it's a bit of a Rolls Royce service, it's a gold standard service but in terms of inpatient care it's actually a very small number that you're looking after, whereas community you've got greater

numbers but due to time and staff you probably don't, you just can't give the same sort of service as you can to people who are here if that makes sense? (H1, P3).

The community MDT is not made up of hospice staff working closely together in a supportive environment; rather, it is a team drawn from different community services.

The nature of care is very different, particularly as regards convening MDTs:

I found in previous situations, these meetings when you suggest, people seem to think that you're being a little bit dramatic, that actually there's nothing wrong, they can't always see the problems that could potentially happen. So we did go along and have the meeting, the GPs they're very busy, and they I think are a key person that needs to be there, and the social worker came, there wasn't really much that changed, I mean in that meeting I felt that I were leading it, although I didn't feel that probably I was the best person to lead it. I think potentially I was in a way because I'd identified the problems, but in terms of capacity there wasn't really a proper, we just sort of they went off what I said rather than actually going through each decision and asking, assessing capacity in relation to that (H2, P1).

The patient is still 'held' by the MDT but the MDT is less available, both in terms of time and in terms of place, to support the patient living at home. Where a decision needs to be made, an MDT 'meeting' might consist of telephone conversations between the professionals. Where the meeting is held at the patient's home, the

professionals involved may not be known to the patient, and have little opportunity to understand the patient other than as a collection of symptoms:

If a social worker was invited, which in that lady's case she was, then she wouldn't have, I don't know if she met her before or I'm not too sure, or whether it was just she came to the meeting, which is probably the most likely, she probably wouldn't have met her before, the district nurse and the GP, sometimes it's a GP they haven't met (H2, P.1).

The opportunities for the patient-as-person to be represented in the decision-making process, for their narrative to be understood or to be central to the professionals' consideration of their best interests, are likely to be limited. The focused listening discussed by participants working within the hospice is less likely to be a factor of hospice community care and the relational empowering of the patient, to speak and to be heard, is less likely to occur. The community-based participant describes her efforts to find the patient's narrative but acknowledges that it is difficult to ignore the intrusion of her own perception of risk into the picture she creates:

I think what you've got to try and, 'cos you've got you imagine how things might be, you've got to imagine, what I try and do is imagine for the patient what do they want, imagine being how they are which I think sometimes is difficult because as professionals you're looking at the risks and they are more worrying sometimes about what might happen and imagining the worst case scenario, so you tend to I suppose get sucked in by that. But what I do try and do is bring myself back to the person and weighing it all up ... I think it's just

getting yourself to realise that you can like reduce risks, you're never going to take them fully away, but you've got to look at everything haven't you and that's what I try and do, although I do find it difficult at times (H2, P1).

The participant is looking to give the patient a role in the process but her ability to do so is compromised by her need to ensure she properly assesses the risks:

the most important thing for me is that I sleep at night, being happy with what I've done, so I would rather go to a GP [to ask for an MDT meeting] and get on their nerves and get what I think is the right thing, even if it's over the top, I'd rather be on that side of things (H2, P1).

The realities of community care can exacerbate a disconnect between the concept of 'home' which the patient-as-person recollects and wants to rediscover and the reality of living at home for the patient-as-patient:

people ... imagine life at home the way it was several months, weeks ago. And someone who's mainly in bed and using a commode here expects to be able to mobilise and trot about at home ... so quite a few times I've said to people, 'OK go home for some weekend leave, couple of hours, see how you do, see how it feels', knowing that we know and family often know that this isn't going to work, ... so then that's informing their decision fully as to yes you can go home but you're going to need to have that extra perhaps you hadn't bargained for (H2, P2).

A patient's home eventually becomes a 'place of care', one of the options to be considered when a patient leaves the in-patient unit, the potential loss of 'home' complicating the decision-making process as the patient-as-person disappears into the care which the illness demands and is eclipsed by the patient-as-patient:

We had a chap who ... hadn't actually been at home since he was able to mobilise by himself, so a lot had changed in several weeks, and ... his partner had a lot of concerns and ... he was just getting ... annoyed and saying, 'Everyone wants to stop me going home, everyone wants to stop me'. So I had a long chat with him and I said, 'Look, we understand you want to go, we can't stop you from going, there are certain things that you would do better with, certain pieces of equipment, would you be willing to have them?' 'Yeah, yeah it's fine, it's fine'. And then I ... got a phone call ... and he just said, 'I'm really sorry, this is a terrible mistake on my part. The district nurse has offered me carers four times a day but I know that that will not be enough, I need 24 hour care. (H2, P2).

The significance of time

Time is perceived in various ways by the participants, most often as a luxury which hospice in-patient units have and other care settings may not. Participants see *time as a resource* and refer to the *luxury of time* as relating to their ability to understand the patient-as-person and tailor good quality:

I think we have more time available to talk things through and do things in a sort of a proper way. And if there's a big decision, having a proper best interest meeting with everyone that's important to be there involved. I think it's easier for us to have those discussions in the hospice than perhaps is in the hospital, where there's a lot more patients and a lot more time pressure (H1, P3).

Place and time are related where being able to choose when to speak to an in-patient allows the conversation to be optimised from the perspective of the patient's role in the process:

I think the nice thing about here is you can choose the right time of day for the patient, you can come back and revisit some of these conversations easily around the right time for that patient, it's trying to do everything you can to optimise the timings of the conversations, optimise those conversations ... (H1, P2).

However, *time as a barrier* references the possibility that the luxury of time, where it becomes the norm, can prevent access to hospice care, which remains 'a little bit of heaven for the few' (Clarke, 2018):

Sometimes there's a reluctance to admit people because of perceived 'busyness' and them wanting to give all this care to people, which is like very good care to people, but I think it's getting a balance between giving good care to people but also not being too precious and then not allowing us to then bring

more people in and I think that can be a very difficult balance ... I think something about hospices and this little in-patient unit where you are in this bubble and then it's easy to forget we're looking after nine patients but actually there are hundreds of patients out there in the community have got problems (H1, P2).

At the other end of the spectrum, *time as a barrier* references the lack of time to spend with patients in the community as influencing the quality of care:

I suppose the problem with the community is there are gaps, so ... a patient will get two carers four times a day to come and reposition them and attend to their care needs ... but then visits are quite short, they might be 40 minutes long at the most maybe, they might get three night sits a week ... but then there will be gaps. ... It's about it being realistic in a community setting (H2, P1).

Time in this sense is experienced negatively, as a barrier to 'proper' care:

I got told on the district that I wanted to provide platinum care and we could only afford silver, and that I had to pare down my platinum and that's why I'm [in the hospice]. I love the community, but I didn't want to provide silver care, when I knew what platinum looked like ... I felt that I was compromising who I was as a nurse and I wasn't willing to do it anymore (H1, P1).

The circle of hospice care, in encompassing a patient's family, supports them through the loss of the patient-as-person and into a future where memories of the patient-as-person are not eclipsed by the trauma of a 'bad death'. The *remembering* theme imagines time linking the way in which the patient-as-person was cared for at the end of their life directly to the way in which the family members remember their loved one: a 'good' death makes the memories less painful:

... dying is something that will eventually happen to us all and ... it's a hugely important thing that we'll live with once the patient's died, their family will remember that time in their lives for years and years and years. And it can have a big impact, and how death's managed can have a huge impact on those close to them, so I feel it's a very important area ... (H1, P3).

Balancing power

The Foucauldian idea that power is present and productive in every relationship is relevant to the idea that the patient sits at the centre of the overlapping circles of care. The relational caring and decision-making processes do not construct a reality where the power sits with the staff member, as was perceived to be the case in 'old-school' doctor/patient relationships:

I think probably generally in the medical profession that the doctor knew best and the doctor made the decisions and it was almost like the doctor was God, and you didn't question the doctor, the doctor just made the decisions
(H1, P1).

Rather, the all-encompassing care of a patient-as-person *empowers* the patient. Participants experience this as part of providing proper (good) care, which is important for them as people, although not always easy, and not just as a requirement of their role:

active listening and relating to people on that level I think has its challenges, personally, I think you get very involved, you know you get involved in, if you have a slightly deeper level of understanding of someone I think that can make it challenging in terms of you know we're always dealing with people who are approaching the end of their life and you want to make that the best it can and it's great when it goes the best it can, it's just really hard when it doesn't, sometimes end of life is messy, and that is really personally challenging (H1, P1).

Rather than seeing themselves as the decision-maker, participants perceived themselves almost as the patient's voice in the decision-making process, with a duty to do their best to understand what the patient would want the outcome to be and to facilitate it. Understanding the patient's narrative is key to releasing the power to the patient-as-person; active listening must be linked to compassion, to a willingness to find the patient-as-person and to uncover the patient narrative. This requires engagement on a personal level, *a little bit of me*, both from the patient and the healthcare practitioner as they mutually empower each other within the relationship:

When you're yeah when you're opening yourself up to that level of communication. 'Cos you do have to open yourself up to that, you can't be a closed book and have that level of communication with someone I don't think, they need a bit of you to know who they're dealing with (H1, P1).

7.5 Conclusion

The findings from phase four of my study suggest that, in the in-patient units of the participating hospices, use of MCA in practice reflects the intention that it both empower and protect (DCA, 2007). The participants describe relational, caring processes which, although often challenging for various reasons, are managed by the MDT in a way which supports patients, their families *and* hospice staff themselves. The organisational policy context is the same for community care, but the more thinly-spread hospice community team changes the context for MCA decision-making .

CHAPTER 8

Discussion: bringing the threads together

8.1 Introduction

Each of the four stages of my project required me to explore different areas of academic practice. As I worked through my study, I engaged with a variety of books and papers, immersing myself in theoretical and conceptual ideas and arguments and introducing fresh perspectives and ‘lines of flight’ into my thinking. In this Chapter, I will try to make sense of the layers and complexities of my reading and the thinking in which it has entangled me.

8.2 Analytic approach and integrative themes

In considering my research questions, I have explored historic policy and legislative materials, the ‘present archive’ of judicial decisions, group interview data and data collected in individual interviews. My intention in choosing template analysis as a method for considering the patterns and themes in the data across all phases of the study was that it offered me sufficient flexibility to approach the analysis inductively whilst also facilitating the diffraction of themes from the earlier phases of the project into the analysis of the data from the later phases.

Template analysis is generally used to construct hierarchical codes but it also allows integrative themes, lateral links between themes, to be drawn out of the data (King, 2012 and see Chapter 3). King (2012) has characterised integrative themes as ‘undercurrents’ running through the data (p. 432). I have developed King’s analogy by reference to Tamboukou’s (2014) idea of intra-actions (introduced in Chapter 3)

and characterised the integrative themes in my data as diffracting into the analysis of the whole. These integrative themes generated ideas like the ripples of a wave pattern as the findings of each phase flowed into my analysis of the next, connecting the questions I have asked in the present to the analysis of the data from the past.

To bring together the findings from the four phases of my study, I reviewed the analytic templates from each and, using post-it notes and large sheets of paper, grouped the themes together into four over-arching themes: *people and the decision-making journey*; *place, space and time*; *law, care and compassion* and *the role and nature of law*. These over-arching themes formed the basis of what I have characterised as a ‘synthesising-template’ (see Appendix 10 for my ‘working’ version) that combines the previous analytic templates and represents a synthesis of the themes from the previous phases of the study. Table 15 below shows the over-arching themes and their links to the four phases of study and forms the basis of the discussion in this Chapter.

The integrative themes, *compassion*, *the nature of care* and *legal consciousness*, relate to my stated aim (see Chapter 2.6) of exploring how the law is translated into practice in hospices, how patients’ values, wishes and feelings are reflected in decisions made in their best interests and whether (and to what extent) supported decision-making takes place. They do this by asking ‘big picture’ questions in the context of the legal process of decision-making for hospice patients: can the MCA allow for compassion and if so how? How does the concept of autonomy allow for the dependency of patients at the end of life? How do hospice staff experience the ‘legality’ of the MCA framework in decision-making for patients who may lack or be

losing capacity? I consider the integrative themes further below, by reference to each of the over-arching themes, starting with a consideration of the *nature and role of the law* in the specific context of MCA decision-making in hospices. In considering the nature and role of the MCA, I discuss *the nature of care* and consider my understanding of *compassion*, both as they relate (or are related to) MCA decision-making in the context of hospice care.

I develop the concepts of *care and compassion* in my consideration of *people and the decision-making journey* by reference to my interview data. The importance of *place, space and time* is then explored. Bringing these threads together, I conclude with a consideration of *legal consciousness*. The discussion of legal consciousness lays the groundwork for the answers I suggest to my research questions, set out and explored in Chapter 9, the final chapter of my study.

Table 15: Over-arching themes showing links to previous phases of the study

Theme	Phase 1	Phase 2	Phase 3	Phase 4
<i>People and the decision-making journey</i>	<ul style="list-style-type: none"> • Emergence of individual • Person of value • Power 	<ul style="list-style-type: none"> • Emergence of individual • Individual's story • Person of value 	<ul style="list-style-type: none"> • Individual in the decision • Collegiate approach • The hospice movement • People in organisations 	<ul style="list-style-type: none"> • Circles of care • The patient's narrative • Perspective – seeing the world through different eyes • A little bit of me
<i>Place, space and time</i>	<ul style="list-style-type: none"> • Power over a future narrative 	<ul style="list-style-type: none"> • Me, myself and I • Narrative wormhole • Distance and place 	<ul style="list-style-type: none"> • Hospice/acute/community/home • The patient before 	<ul style="list-style-type: none"> • Hospice/acute/community/home • Patient narrative • Luxury of time • MCA journey – legal consciousness and experience
<i>Law, care and compassion</i>	<ul style="list-style-type: none"> • Law as a compassionate power • Therapeutic jurisprudence 	<ul style="list-style-type: none"> • Compassion as integrative theme 	<ul style="list-style-type: none"> • Compassion as integrative theme 	<ul style="list-style-type: none"> • Nature of care as integrative theme • Change of care over time (old school/habitus)
<i>Role and nature of law</i>	<ul style="list-style-type: none"> • Change in focus of law • Rights and responsibilities 	<ul style="list-style-type: none"> • CoP role – socio-legal focus • Therapeutic jurisprudence • Legal consciousness 	<ul style="list-style-type: none"> • Legal consciousness • Law as a resource 	<ul style="list-style-type: none"> • Legal consciousness as integrative theme

8.3 The role and nature of law

Phase one of my study introduced the MCA as a new kind of law, concerned with a therapeutic outcome. The concepts of capacity and best interests which underpin the MCA (and this study) were not new to English law (*Re F* [1990]; Law Commission, 1991) but their grounding in a set of over-arching principles, designed to ensure that a decision-maker respected an individual's narrative and their status as a person of value in society, was a new approach, as was the MCA's stated aim to empower those whom the law had previously either ignored or marginalised (Ruck Keene, et al., 2019). The notion of empowering people whose capacity may be in doubt has to start from a consideration of what capacity means (as a legal concept) and in what circumstances someone might be considered not to have it. I made brief reference to this question in Chapter 1, but here I explore the legal concepts more deeply and suggest that, for the hospice context, my findings support an approach to capacity that is grounded in the relational principles underpinning the ethic-of-care literature (Gilligan, 1977; Tronto, 1987; Herring, 2013).

English law is arranged around the concept of an able and autonomous adult, someone whose ability, autonomy and freedom law should protect, someone whose rights to liberty and privacy (for example) exist as tools for protection from others. Proponents of an ethic of care, by contrast, start from relationships, interdependencies and responsibilities (Gilligan, 1977, Tronto, 1987, Nedelsky, 2008, Herring, 2013). They argue that the individual is *constituted in relationships*, that an individual's autonomy is underpinned and established by a supportive relational network (Herring, 2013). This focus on the individual as a relational being is consistent with the nature

of care which hospices describe as their aim, including not only the patient but the patient's family and friends, extending to providing bereavement support after the anticipated death of the patient (Hospice UK, 2017). The patient's 'total pain' (Saunders, 2000) is considered; the phase three and four findings indicate that a patient's social and relational situation, where discoverable by the hospice staff, is a key part of care and treatment decisions. The powerful social role of the expert doctor is mediated in the hospice context by the more all-encompassing relationship between the MDT, the patient and, often, the patient's family as well.

The recognition that people are relational, demonstrated in the phase three and four findings, is fundamental to an ethic-of-care approach. The interests of individuals are entangled with the interests of others: potential selves are negotiated in relationships and the self is therefore constituted in relation with others (Herring, 2013). Law typically prioritises the interests of people as individuals, treating them as bounded and separated from relational concerns (family law, for example, prioritises the best interests of the child pursuant to the Children Act 1989). The MCA follows this approach in its focus on the best interests of the person who lacks capacity, although decision-makers can look beyond individual needs if (but only to the extent that) the best interests of someone who lacks capacity to make a particular decision are inextricably entwined in the interests of someone else. It is notable that the interests of the patient's wider circle of care are relevant in many of the included judgments (see, for example, *Re O* [2016]) and also in the phase three and four data.

Proponents of an ethic-of-care approach reject the abstract, objective approach which typically informs the development of laws, preferring to focus on the particular

relational context and characteristics of a situation. The MCA is underpinned by five over-arching principles but *decision-specific context* must be taken into account. The MCA, therefore, facilitates a legal process which, consistent with an ethic of care, can accept a relational approach. In the hospice context, participants' stories suggest that the MCA is interpreted to account for the relational context. There is a sensitivity to the patient's relationships, both in the sense that they are constitutive of the patient in the present and in that they will need to support the patient into the future, as the end of life approaches.

8.4 The law and compassion

In Chapter 3, I introduced the concept of compassion as described by Del Mar (2017), and I explore below its relevance to MCA decision-making in the hospice context. Del Mar's rationale for presenting compassion as an exercise of the multi-perspectival imagination based on actually feeling compassion as a relational emotion, links processes of 'legality' with specific perspectives and relationships. His contention (as a judge) was that a compassionate attempt to understand a complex process from all relevant perspectives will produce a more robust decision.

Compassion first emerged as an integrative theme in my analysis of the judicial archive (Chapter 5), and my focus on the importance of the emergence of the judge-as-person into the decision, reflects Del Mar's view that a compassionate judge imagines the perspectives of others more richly and, in doing so, undertakes a more complete consideration of the decision. The decisions in *Re F* [1990], *Re AB* [2016] and *Briggs* [2016] are interesting to compare on this basis. My analysis found no

evidence of judicial compassion in *Re F* or *Re AB* (see Chapter 5), but, in contrast, the decision in *Briggs* reflects the judge's process of imagining how Mr. Briggs might have been experiencing his predicament, informed by the views of a past Mr. Briggs and the promise of an entirely different future Mr. Briggs, as well as the views and emotions of his family, spanning both the past, the present and the future.

Del Mar (2017), in his presentation of perspective, suggests that an individual organises their needs, interests and values by reference to their perspective of a situation. Needs, interests and values, whilst contingent and variable, are inextricably linked to an individual's experiences of the world and of their relationships within it. In imagining another's perspective, Del Mar suggests that one must try to visualise their needs, interests and values. This approach is reminiscent of Lady Hale's characterisation in *Aintree* [2013] of how a best interests assessment should be undertaken. Del Mar also makes reference to Nietzsche's (2008) assertion that a multi-perspectival approach is the best way to understand something more fully, on the basis that different perspectives reveal different aspects of things. The interview participants emphasised the importance in the hospice context of the MDT and collegiate decision-making. This seems to me to reflect a compassionate attempt (by reference to Del Mar's understanding of compassion) to work towards a decision which considers the patient's best interests in the context of their relationships, and by reference to the varying perspectives of the professionals in the MDT. The participants indicated that this multi-perspectival MDT 'filter' of the decision is central to resolving complex decisions. Del Mar's suggestion that better decisions result from such a process would support a contention, as the participants in the interviews imply, that the best way to resolve a complex decision is to incorporate

different perspectives. Thus decisions of a collegiate MDT ‘holding’ the perspectives of the patient, the patient’s relatives and the members of the MDT themselves, are perceived to be more comprehensive than those made outside the context of a supportive MDT.

The notion that the members of the MDT are involved in a compassionate decision-making process as well as the patient and the patient’s relatives, reflects Herring’s (2017) understanding of an ethic-of-care approach as a balanced, reciprocal relationship where care flows both ways, rather than being provided by a ‘carer’ to somebody who is ‘cared for’. In the hospice context, the nature of the care flowing from the patient to the hospice staff member might be represented by a willingness to trust their history and relationships to the staff member. In so doing, a patient ‘folds into’ the relationship with the staff member (see Tamboukou, 2014 for the concept of the ‘fold’) and trusts their anticipated end-of-life care and eventual dying to the hospice, with an understanding that their relations will continue to receive support after their death. Co-constructed decision-making processes in this context involve the creation of a type of relational autonomy, so that once a patient is deemed no longer to have capacity, the hospice can situate anticipated decisions within the range of outcomes they believe would reflect the patient’s wishes and feelings. Feenan (2017) suggests that more work is required on the relationships between compassion and legal concepts such as autonomy and empowerment. I suggest that a reciprocal relationship of care and compassion in the specific context of hospice care at the end of life is a good starting point for such work.

8.5 People in the decision-making journey

Phase one of the study identified, as a key theme underpinning the MCA, the emergence of the individual into the decision being made with, for or about them. The MCA creates the conditions of possibility for this to happen, but within a relational decision-making process, the nature of the relationship can either enable or frustrate that emergence of the individual. The individual interview participants centred a patient's narrative as a way of developing an understanding of the patient-as-person with a view to ensuring the patient's values, wishes and feelings are accounted for in any decisions made. They described the engagement of staff members, including cleaners, medical staff, spiritual care and social care staff, in the process of accessing and understanding a patient's narrative, their wishes, feelings, beliefs and values, from the time of first contact with the patient. This approach reflects a commitment to the principles of narrative medicine, which emphasise meaningful communication, understanding and dialogue between clinician and patient and are underpinned by theories of narrative identity (Johnston et al., 2016; Bingley et al., 2008) and underpin the shared decision-making model. This emphasis on listening to patient stories and viewing the patient as more than a collection of symptoms is present in the concept of 'total pain' described by Saunders (2000), who intended that 'hospice care' would attend not only to a patient's physical pain but also to their emotional, spiritual and psychological pain.

The Supreme Court's decision in *Aintree* ([2013]), a decision which is considered to mark a turning point in judicial consideration of best interests under the MCA (Ruck Keene et al., 2019), approved this approach and the 'patient's narrative' has become

an important part both of assessing a patient's capacity and, if it is concluded that a patient does not have capacity to make a decision, their best interests. The interconnectedness of the patient's beliefs, values and behaviours is drawn out to underpin the decision about capacity: 'a note of discord in an otherwise fairly coherent and harmonious symphony of internal behaviour' might undermine a patient's capacity (Banner and Sz mukler, 2013 p.385). Key to this process is the interactional, relational nature of the discussion; comparisons might be drawn here to Del Mar's (2017) description of perspective. The process is intended to be supportive and facilitative of the patient's capacity, wherever possible, to make the decision (as required by the MCA s1(3)). Banner and Sz mukler note that this is a process which requires an investment of time in getting properly to know and understand the patient's narrative. The luxury of time generally available to hospices to get to know a patient properly is referenced many times in the phases three and four data.

My concept of the 'narrative wormhole' came from the recurring relevance in *Briggs* ([2016]) of an individual's past, present and future as part of the decision. Where a patient no longer has capacity, an assessment of best interests is understood to bring together key aspects of the patient's past and 'fold' them through the decision in the present and into the patient's future. The 'narrative wormhole' encapsulates the idea that narratives are temporal but not necessarily linear (Bingley et al., 2008): they can link an individual to the past whilst anchoring them in the present (in that sense 'historicising their present'). They can also project into the future as an expression of what an individual hopes for. My 'narrative wormhole' represents the bending of space-time to allow the voice of the patient-past to be heard. In this way the patient can speak to the present decision-maker, maybe through a relative or carer, to

describe their wishes and feelings. Thus the patient's narrative continues into the future and is represented in the outcome of a particular decision-making process.

There is philosophical debate about whether a patient's choices from the past, made when they had capacity to decide, should determine actions in the present (or into the future) which appear to contradict with their wishes as individuals who no longer have capacity (Dworkin, 1993; Dresser, 1995). There is also debate as to whether others' views can represent an individual's narrative where the individual can no longer express it (Johnston et al., 2016). Both the judicial archive data and the interview data from phases three and four suggest that a compassionate, multi-perspectival decision-making process, informed by the patient's narrative and balanced, to the extent possible, to respond sensitively to the needs of relatives, can represent an individual's values, wishes and feelings for the purposes of a best interests decision.

8.6 Place, space and time

The 'space-time' aspects are drawn from my analysis of the interview data and my ideas about folding the patient-past into the patient-present and patient-future. The use of a 'narrative wormhole' to connect narratives from the past is drawn from the phase two analysis of judicial decision-making (particularly *Briggs* [2016]) where decisions taken in the present concerning future care and treatment have been discussed by reference to others' memories of a person's wishes and feelings. In this part of the discussion, I will consider the place and space aspects of this theme.

The interview participants made distinctions between the quality of caring by reference to place. These included distinguishing between hospice care taking place in the hospice building, in acute hospitals and in patients' homes. Distinctions were made between the hospice and 'the acute', where care was considered to have been unsatisfactory; stories referenced difficulties with ensuring a 'hospice' approach in the community context (particularly as a result of the less 'collegiate' MDT) and difficulties with discharge of hospice in-patients into the care of their relatives and the community team.

The common assumption by participants was that care in the hospice building was 'platinum care' (H1, P1) and the 'Rolls Royce' model (H1, P3). One of the participants expressed the view that, for her, working outside the hospice now was unthinkable because to do so would compromise who the participant was both as a person as a professional (H1, P1). The *hospice as expert* and *guardian of a proper process* themes reflect the unanimous views of participants that hospices understand the MCA well; however, participants considered that staff in the hospice building were better supported to reflect patients' wishes and feelings in decision-making than hospice staff working in patients' homes. In exploring the distinctions of place, I have considered Foucauldian concerns with space and place and related ideas about power in relationships, revisiting the idea that power is not a thing to be possessed but that it is always present in relational processes (see Chapter 3) and that the place in which the relational processes play out affects the balancing of power. The relational processes for my purposes are MCA decision-making processes, including capacity assessments and best interests assessments.

Foucault was certain that ‘the practice of social relations and the spatial distributions in which they find themselves’ cannot be separated and that ‘if they are separated, they become impossible to understand (1984, p.246). This is reflected in the participants’ understanding that decision-making processes taking place in the hospice building are not the same as in other places in which caring takes place. Hardy and Thomas’ (2015) findings support this: organisations are considered to be specific combinations of presences and absences where space both organises actions and influences outcomes. Participants speaking from the community perspective specifically note the absence of the supportive in-hospice MDT and the lack of the collegiate decision-making which ‘holds’ all participants in the decision-making process. Participants suggest that this increases the weight of a decision for an individual in the community, and influences the way in which the components of the decision intra-relate and diffract into the outcome (for example, the level of risk to be tolerated).

Space and place are considered to be influential in the transformation of power into material practice (Foucault, 1984; Hardy and Thomas, 2015), and this is supported by my findings in relation to the way the MCA process underpins decision-making in the community and within the hospice building. Participants working in the community have to push against resistance to MDT meetings (MDT members being drawn from across community services). Meetings to consider capacity might, therefore, be held by telephone to reduce the associated cost (both monetary and in terms of time) without all participants being in contact at any one time and often without the presence of the patient. The contrast to the in-hospice nature of the MDT and patient involvement in the decision-making process, characterised as a relational process,

reflecting an ethic-of-care mutuality, is potentially significant. Irrespective of the efforts of the community MDT, circumstances may render the patient's narrative more difficult to hear and less likely, where the patient's deteriorating health represents a threat to their capacity, to direct the outcome of a decision as to their future care.

8.7 Legal consciousness

I have characterised *legal consciousness* as an integrative theme in my analysis of the individual interviews because participants' narrative and story-telling did not always distinguish between the requirements of the legislative framework and participants' characterisation of good quality care. My study, in common with Ewick and Silbey's (1998) work, focuses on stories from everyday life. Their work involved participants from across society and their stories related to 'legality' in a wide variety of contexts but, in general, concerned law as a means of punishment or control. My study explores an empowering law (DCA, 2007) in a specific caring context where 'the contours of legality' (Ewick and Silbey, 1989, p.223) are very different. The legal consciousness I am investigating is entangled in the intra-actions between hospice staff members, patients, probably other family members and generally other members of an MDT.

Halliday et al. have taken a similarly focused look at legal consciousness in their study of the 'images of law that were drawn on and invoked by family members when negotiating the situation of their relatives with chronic disorders of consciousness, including, in some cases, the ending of their lives' (2015, p.57). They used legal

consciousness to investigate how law matters to society in specific situations (in their case, the care of those with chronic disorders of consciousness). Their conclusions suggested that the images of legality revealed in their data were rooted in the three orientations to the law identified in Ewick and Silbey's (1998) typology ('before the law', 'with the law' and 'against the law') and in the fourth orientation, 'collective dissent' identified by Halliday and Morgan (2013) (discussed in Chapter 3). The 'collective dissent' orientation introduces a sense of the solidarity of a movement, a 'wider collective voice of dissent against the power of the law' in a particular domain (Ewick and Silbey, 2015, 72).

There are two aspects of legal consciousness to explore in relation to the interpretation and implementation of the MCA in the hospice context. The first relates to Halliday and Morgan's (2013) idea of collective dissent. This starts from the emergence of the hospice as a 'movement' (Clarke, 2018), catalysed by a specific aim to resist the medicalisation of death and dying (Saunders, 2000). Saunders, and those who supported her aspirations to create a 'movement' for the provision of holistic, patient centred care, promoted the 'hospice movement' as something distinctly different from palliative care in other settings. This perception of the hospice as 'other', as different and better, was expressed by the group and individual interview participants in my study (see Chapters 6 and 7). I suggest that the hospice present can be 'historicised' (Tinkler and Jackson, 2014) in the sense that the contemporary discourse of hospice as 'other' is explicitly linked to the notion of the 'hospice movement'. The emergence of hospice as a movement, as something distinct and better is important to hospice staff and linked to their legal consciousness. This is

particularly true for those who work in hospice in-patient units and who feel that to work elsewhere would compromise who they are as people and professionals.

The other aspect of legal consciousness is the way in which the MCA is experienced by staff in making decisions with patients. The individual interviews suggest that a familiarity with the MCA integrates the legal requirements into the staff members' decision-making practice for the most part as an unconscious competence. Staff members' use of the MCA is almost automatic. However, where there is a complex decision to manage, the MDT works through a process which explicitly uses the requirements as a checklist. To this extent, the data suggest that staff members at the participating hospices stand before the law. Rather than perceiving the MCA as an autocratic and distant power, however, staff orient themselves towards the the image of 'law as a shield' suggested by Halliday et al.'s (2015) study. The MCA, in this sense, is intended to protect the rights of the patient but compliance with its requirements also enables staff members to demonstrate the quality of their own care and protect the hospice's organisational reputation (which is linked to the CQC inspection framework, introduced in Chapter 2).

'Law' as described in the participants' stories is not, however, the law of the courts and the regulatory authorities. Whilst, in its characterisation as a shield the MCA acts as a reminder of the law as a distant power, the participants' stories suggest that it has, to some extent in the context of hospice care, become synonymous with caring well for patients. The MCA requirements as to capacity assessment and, where required, a decision underpinned by a patient's best interests, are interwoven with the expectation that attempts will be made to understand a patient's narrative, to work with the patient

and their family, to establish relationships and, knowing who the patient is as a person, to ensure that their wishes and feelings are reflected in the decision made.

Hunter et al. (2016), in their analysis of the legal consciousness of housing officers charged with applying homelessness law and, in particular, in identifying a priority need for housing for 'vulnerable' people, made a connection between decisions and cultural morality. They suggested that legal provisions which mitigate against cultural norms are less likely to attract compliance, and, conversely, that laws which reflect the values of those responsible for either complying with or enforcing them, are more likely to attract compliance. The stories told by the participants in my study indicate that the nature of hospice care reflects their own commitment to caring well for their patients as they support them towards the end of life. I suggest that they perceive the MCA as a legal framework which is aligned with the cultural ethic-of-care morality of the 'hospice movement'. They identify the MCA as 'a good thing' and, as part of their perception of the hospice as expert and distinct from other settings, they explicitly disapprove of decision-making processes which do not assess capacity and best interests appropriately and in accordance with the MCA's requirements.

In the community, hospice employees worked with the MDT members to ensure, to the extent possible, the MCA process was properly used to assess capacity and make best interests decisions. This is referable to the image of law as a sword (Halliday et al., 2015). In this context, the MCA was perceived as setting a standard which must be met. There was a sense that 'old style' GPs would be more likely to make or accept paternalistic decision-making and that, due to the way in which GPs work (alone and typically by reference to short patient appointments) a collegiate, patient-

centred and relational process was more difficult to manage. One participant was willing to use the MCA 'as a sword' to enable her to redress the power imbalance she perceived existed between her and the GP. She believed that an MCA compliant process was a crucial part of caring well for the patient and that she was morally required to take action to ensure it. She uses the MCA as a sword to combat the difficulties of time and distance faced by the community MDT so that the MCA might be available to the patient (and to her as a representative of the hospice) as a shield.

8.8 Conclusion

In this chapter, I have considered the literature relevant to the four over-arching themes I have drawn from my data and described in Table 15. The findings suggest that a relational, ethic-of-care approach underpins hospice practice in the specific context of making decisions for hospice patients who lack or are losing capacity. I have considered how this relational approach can be assimilated with the importance of individual autonomy that generally underpins English law and contended that a compassionate approach to legal decision-making will produce better outcomes. Finally, I have considered the concept of legal consciousness as it can be understood from hospice staff members' use and interpretation of the MCA in making decisions. In Chapter 9, I draw from this discussion the answers to my research questions and conclude my thesis.

CHAPTER 9

Conclusions: induction and diffraction

9.1 Introduction

The story of my study started with a negative. It started with an assessment that the MCA, a ‘visionary piece of legislation for its time’, had not been well understood or implemented in practice, that its ‘empowering ethos’ had not been delivered, that the rights it conferred had not been realised and that the responsibilities it imposed had not been accepted (House of Lords, 2014 p.6). The conclusion of my study is positive. My findings suggest that the MCA *is* well understood in hospices, that its implementation *does* empower patients who lack or are losing capacity, allowing their wishes and feelings to be heard and reflected in decisions concerning their care and treatment, and that hospices and their staff members are keenly aware of their responsibilities to work within the requirements of the MCA. Further, my findings indicate that hospices provide support and training to caring staff in other settings whose knowledge and understanding of the MCA may not be as embedded as it is considered to be in the hospice sector.

The aim of my study was to explore how the MCA decision-making framework is interpreted in hospice policy and practice when decisions are made concerning care and treatment for patients who have lost capacity to make decisions for themselves. This aim was underpinned by three objectives (see 2.6 above). These relate to the issues identified by the MCA Committee and also reflect my interest in understanding how the social context from which the MCA emerged is embedded in contemporary understandings of what capacity and best interests mean today. Underpinning the

objectives is an interest in how the patient's role and power in the decision-making process is understood and recognised.

9.2 Answering the research questions

How are the legislative principles concerning decision-making for people who lack or are losing capacity, particularly as regards their role in the decision-making process and related power issues, interpreted and expressed within hospice organisational policy and practice?

The MCA's legislative principles are embedded within the policy and practice of the participating hospices. Although policies are applicable across the organisations, there are differences in the way in which the MCA is applied to caring for in-patients and to those who are living at home. Hospice staff appear to be unconsciously competent in their knowledge and application of the MCA principles and the requirements of the MCA are implicit in decisions concerning everyday matters.

For in-patients, where decisions are complex or difficult, an explicit reference to the MCA principles and decision-making framework guides the process: members of the MDT are fully involved in the decision-making process. Decisions are made in supportive engagement with the patient and, where relevant, the patient's family or other informal carers. Where a patient has never had capacity, decisions will be made in consultation with their family by reference to their narrative knowledge of the patient. Where a patient has lost capacity, the patient's narrative will inform, to the extent possible, the choice which is made by the hospice staff and the patient's

family. Where available, a ‘narrative wormhole’ is used to allow the patient’s past wishes to direct their present and future care.

Efforts are made, from the time the caring relationship with the patient begins, to build up a picture of their story. Where the patient’s condition has a predictable trajectory, discussions will anticipate future decisions, so that there is time for the patient to appreciate what might be required and to discuss their preferences. Hospices have the luxury of time to introduce and support decision-making for most patients and it is possible that, albeit using a supportive process, a hospice guides the patient towards a preferred clinical outcome. In respect of non-clinical decision-making (for example, a move back home) the patient is supported to achieve the outcome which reflects their values, wishes and feelings, even if the hospice considers that the decision is unwise. In the event that there is a discrepancy between the views of the patient and the views of their family, the hospice attempts to bridge the gap and to mediate the differences.

For patients living at home, the hospice’s representative is part of an MDT drawn from different organisations. The hospice representative acts as an expert in the requirements of the MCA and advocates for the patient when required in terms of capacity and/or best interests assessment. However, the disparate nature of the MDT in the community affects the relational processes. The comparative lack of time to access the patient’s views, wishes and feelings, and to ensure that the MCA process places the patient in the centre of the circles of care, is reported to result in a less patient-centred assessment of capacity and/or best interests. Where a patient is living alone or with a carer who also has challenges to overcome in their daily life, a

decision which is more protective of their safety would be likely to represent the preferred outcome. The hospice staff members in the community feel less supported by the hospice: the collegiate nature of the decision-making in the hospice is often not available to community-based hospice staff.

The different experiences of hospice staff in the hospice and in the community, translate into the power relations in the decision-making processes. A relational, ethic-of-care approach to interpreting and expressing MCA decision-making underpins the practice of all staff. However, the time available to the in-hospice staff and the availability of the MDT's collegiate support suggests that the hospice in-patient is more likely to be empowered in the relational process. Being empowered in this sense means being enabled to participate as fully as possible in the process, particularly as regards a patient ensuring that their values, wishes and feelings are known to the staff members. In the community, the intermittent nature of patient visits necessarily limits the time available to build a supportive relationship and, through that process, to empower the patient. Staff members' priority is to reflect a patient's wishes and feelings in any decisions made, but where a decision involves regular administration of medication or the most appropriate place of care for a patient whose condition is deteriorating, the patient's power to influence the outcome is constrained by their circumstances and the availability of a caring relationship outside that which the hospice and the community team can provide.

What is the professional perspective of the hospice patient's role in making decisions about care and treatment?

The professional perspective of the hospice patient's role is that it is central to the circles of care which surround the patient. An important part of the caring which the hospice (and each staff member) carries out is focused on understanding the patient in their relationship with their illness and in their wider social relationships. The hospice in-patient context is considered distinct because of the central focus on the patient-as-person, because of the availability of the MDT to support all participants in the decision-making process and because of the 'luxury of time' to facilitate 'platinum' or 'Rolls Royce' caring. However, the quality of care which hospice staff aspire to give is potentially a barrier to the care being available to a greater number of patients (in that there is a resistance to new admissions where staff feel the person-centred focus will be adversely affected).

Participants with experience of working in the community are equally committed to the patient playing a key role in the decision-making process but feel less able to ensure that the patient's wishes and feelings are sufficiently (in their view) determinative of the outcomes. This relates to a lack of time to spend with patients and to listen to their stories, and a sense that the community system (comprising both hospice and non-hospice personnel) cannot facilitate the involvement of the patient to the same extent as would be usual on the in-patient unit.

The professional perspective is that the supportive, collegiate decision-making encouraged within the hospice in-patient unit facilitates the empowerment of the

patient. This is related to the ability of the MDT within the hospice itself to manage the risks attending to the patient's preferred outcomes. Decisions around discharge are more difficult to manage and, whilst the patient's preferences remain the focus of the decision-making process, other circumstances are also influential. Staff members attempt to give effect to patients' wishes and feelings whilst balancing the capabilities of relatives and other community resources to support them. This involves compromise and negotiation, which the availability of time makes possible.

Hospice staff working in the community have fewer resources available to them to manage risk. The patient's wishes and feelings are subordinated to their ability to continue to manage at home. In the case of a patient who did not recognise that her medication could control her pain, for example, an increase in her pain led to a reduction in her ability to look after herself and an increase in the risk of her being unable to manage at home, despite her capacity (when medicated) to decide that home was where she wanted to stay. The decision about her remaining at home was as a result less driven by her wishes and feelings and more by reference to her safety. Had she been an in-patient, this could have been managed differently (although of course she would not then have been living at home).

The legal consciousness of the hospice professionals (in respect of the MCA) can be described as 'before the law'. They experience the MCA as 'a good thing'. It is experienced as a shield for the patient (underpinning good care), a shield for the staff (providing good care) and a shield for the hospice (facilitating compliance with regulatory requirements). The MCA aligns with their ethic-of-care morality and compliance is attractive. This legal consciousness supports their intention to empower

their patients by ensuring, to the extent possible, that patients are at the centre of decision-making concerning their care and treatment.

9.3 Contribution to knowledge

My study offers a different perspective on the way in which the MCA is working in practice. The MCA Committee's post-legislative scrutiny suggested that the MCA was neither well understood nor well used in practice such that the empowering ethos of the MCA was not being delivered. However, the MCA Committee did not consider the hospice context and my study indicates that the MCA is increasingly well understood in that context and, in the sense that participants' stories report attention to hearing patients' stories and ensuring, where possible, their involvement in decision-making processes, the MCA is well used.

My study also adds to knowledge about legal consciousness, by contributing an interpretation of the experience of the MCA in the specific context of the hospice. Halliday et al's (2015) findings indicated a gap in knowledge about the legal consciousness of medical staff and, whilst my study did not set out to address this specific knowledge gap, my findings are relevant. They suggest that, in the hospice context and in relation specifically to the MCA as a framework for guiding decision-making for patients who lack capacity, staff display a 'before the law' approach to the MCA. However, the MCA is not regarded as a distant and authoritative legal reality, but, conversely, as a supportive process, compliance with which is perceived to form part of caring well for the patient. My study supports the conclusions of Hunter et al. (2016) that the character of the MCA, in particular its congruence with the cultural

morality of the hospice staff, leads to its ‘liveability’ for hospice staff members. In respect of patients on the in-patient unit, compliance with the requirements of the MCA does not cause any friction. In the community, compliance is more likely to cause friction (for reasons of both time and financial resources) but the perception of the hospice staff that the MCA is ‘a good thing’ appears to underpin a determination to work as hard as possible towards compliance. On the in-patient unit, where a supportive MDT ‘holds’ the patient, family members and the hospice staff members, the MCA is well understood and working well. In the community, a dispersed MDT lacking in time and resource cannot support hospice staff members in the same way and, as a result, the perception of hospice staff is that the MCA works less well in hospice community services, even where place is the only variable.

9.4 Contribution to practice

I have characterised a hospice as a dynamic collection of ongoing social relational processes (Van der Haar and Hosking, 2004). My findings suggest that compliance with the MCA should be characterised as a journey (and see also DCA, 2014 which acknowledges understanding and use of the MCA is anticipated to increase over time). Consequently my findings will have value in suggesting how organisations can move towards better understanding and implementation of the MCA.

A relational, ethic-of-care based approach with an engaged and supportive MDT will best facilitate the development of a positive view of the MCA. This will increase its ‘liveability’ (in terms of the ease with which it can be incorporated into decision-making practices) and, at the same time, ensure its empowering ethos is aligned with

the values of caring staff. Although hospices appear to have an organisational advantage (so to speak) in the cultural/historical distinction of the ‘hospice movement’ from other care settings, the increased engagement of hospices with other care settings (similarly regulated by the CQC) to share best practice as regards use of the MCA to guide decision-making may facilitate change.

The availability of time to develop a relationship with patients and their family is key. This underpins the comparative success of embedding the MCA in decisions made in hospice in-patient units as compared to decisions made by hospice staff working in the community. The availability of time in community settings might, therefore, be an issue which requires financial resource (which has not been a focus of my study), but where there is time and a willingness to care in a relational way, the MCA appears to ‘fit’ the cultural morality of hospice staff.

9.5 Limitations of the study and opportunities for further work

In collecting my empirical data I have engaged with two hospices in a particular area of the country. Although one was based in an urban setting and one was based in a more rural setting, neither of them serves a racially or culturally diverse community. Similarly, the participants were all of white British origin. Whilst, in situating my research in a qualitative world-view, I had not anticipated that the findings would necessarily be widely generalisable, they might not reflect the position in urban hospices where greater cultural and ethnic diversity (of staff and patients) influences

engagement with death and dying. A further iteration of my empirical work in culturally different hospices would be an interesting project.

A further limiting factor was the small pool of participants, particularly from hospice 1, where three of the participants in the group interview were also my individual interview participants. Staff supporting the spiritual care of patients were also under-represented, with the majority of participants being medical staff. Of the medical staff, the majority were based on the in-patient unit. Further work might explore with a larger group of participants the differences experienced by hospice staff working in the community.

A further study might also investigate MCA legal consciousness more deeply. It would be interesting to consider the perspective of staff members working with the MCA in larger hospices and with a larger community-based group of hospice staff. The influence of time and resource constraints and their effect on the ‘liveability’ of compliance with the MCA in these settings is a particular area of interest.

Finally, my study has not considered the perspective of hospice patients either in terms of how they perceive their role in the decision-making process (where they have the capacity to express a view) or in terms of whether they agree that an ethic-of-care approach is adopted by hospices, with care being conscious of relationships and patient narrative to inform decisions. To the extent that processes of legality are visible to patients (potentially in the context of situations such as that underpinning my ‘*yes but no*’ theme in Chapter 7), their legal consciousness would be interesting to

explore, particularly as regards the MCA process as being related to the quality or nature of the caring a patient receives.

9.6 A final word

In understanding and interpreting the narrative and discursive materials which form the data for my study I have been influenced by the work of quantum physicist Karen Barad (2007), ‘translated’ by Maria Tamboukou (2015), specifically the over-arching notion of entanglement to explain the relational realities which individuals create as they take part together in the ongoing becoming of the social world. I like Barad’s application of the optical phenomenon of diffraction to the social world to explain how difference and change result from individuals’ inter- and intra-relation. Barad uses images of diffraction patterns to demonstrate the effects of difference which result from intra-actions. Tamboukou translates this idea into the context of narrative research. She envisages narrative researchers, participants, and the research context, data and strategies as entangled, materially and discursively. Like waves in a diffraction pattern, the parts of the narrative research process are (re)constituted through their intra-actions within the research journey.

Tamboukou describes the research process as the ‘narrative phenomenon’ within which these various components are inseparable, but as a result of which they can be configured, bounded and described so that the output of the research (the thesis in the case of my study) represents knowledge as it emerges from the narrative phenomenon. The research process creates the conditions of possibility for meaning to be enacted and for knowledge to emerge, but what can be known and by whom is

an effect of the specific intra-actions within the research process: the ‘research findings’ ‘emerge through and as part of their tangled intra-actions with material and discursive practices’ (Tamboukou, 2015 p. 624). The process is not linear and there is no single relationship of cause and effect. Rather the researcher’s choices, interventions and strategies, the ‘researcher’s cut’, mark the researcher’s position in the phenomenon as she interprets and makes sense of what is going on.

In my interpretation of both my historical archive and my ‘present archive’ of judicial decisions, I have created my own ‘narrative wormhole’. I have tried to hear the voices of the policy-makers, the legislators and the witnesses to whom they spoke in creating the MCA and then to hear the stories of judges tasked with interpreting it. With my interview participants, I co-constructed the stories of decision-making for hospice patients, whose voices were also heard from the past. In ‘folding out’ that knowledge into my thesis, my interpretation of the professional perspective is my re-telling of the participants’ stories and, whilst I have reflected those stories faithfully they have, in their retelling as ‘findings’, diffracted through my own perspective and my situation of them in my philosophical and conceptual understanding of a socio-legal, relational context. My thesis, then, is my ‘researcher’s cut’. I hope it offers a basis for taking what is working in hospice practice and adapting it for use more widely to support the empowerment of patients who no longer have capacity to make decisions for themselves.

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Appendices

Appendix 1: The key concepts of the mental capacity act

The principles (MCA s1)

The MCA is underpinned by five statutory principles which reflect the values on which the legislation is based. The principles apply to any act done under the MCA and are intended to assist with appropriate interpretation and implementation of the MCA's requirements (DCA, 2007).

The principles are that:

1. A person must be assumed to have capacity unless it is established that they lack capacity;
2. A person must not be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success;
3. A person must not be treated as unable to make a decision merely because they make an unwise decision;
4. An act done, or decision made, under the MCA for or on behalf of a person who lacks capacity must be done, or made, in their best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the outcome can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Decision-making capacity (MCA s2)

The MCA's construction of capacity is a fundamental concept (DCA, 2007). The powers enshrined in the MCA are triggered by an assessment that capacity is lacking.

Decision-making capacity is specific to a particular decision: reference to a person's capacity (or lack of capacity) therefore refers specifically to their capacity to make a particular decision at the time it needs to be made. The MCA applies the same rules whether a decision is life-changing or concerns an everyday matter (DCA, 2007).

A person lacks capacity in relation to a decision if, at the material time, they are unable to make a decision for themselves because of an impairment of, or a disturbance in the functioning of, the mind or brain. Whether the impairment or disturbance is permanent or temporary is irrelevant but if an individual is likely to regain capacity, or if capacity is fluctuating, the capacity assessment should be undertaken either when they have regained capacity or when they are most likely to have appropriate capacity (MCA s4).

A lack of capacity cannot be established, and unjustified assumptions about a person's capacity must not be made, merely by reference to a person's age or appearance, any condition they may have or any aspect of their behaviour.

Inability to make decisions (MCA s3)

A person is unable to make a decision for themselves for the purpose of an assessment of capacity if they are unable to:

- understand the information relevant to the decision,
- retain that information,
- use or weigh that information as part of the process of making the decision, or

- communicate their decision (whether by talking, using sign language or any other means).

A person is not to be regarded as unable to understand the information relevant to a decision if they are able to understand an explanation of it when it is given in a way that is appropriate to their circumstances (using simple language, visual aids or any other means).

The fact that a person is able to retain the information relevant to a decision for a short period only does not mean they are unable to make the decision.

The information relevant to a decision includes information about the reasonably foreseeable consequences of deciding either one way or another, or of failing to make the decision.

Best interests (MCA s4)

In considering best interests, the person's age or appearance, any condition they have or an aspect of their behaviour must not, on its own, be used to justify an assumption about what represents their best interests. The individual must be permitted and encouraged to participate as fully as possible in any act done or decision affecting them and their ability to participate themselves in the decision-making process must be maximised.

Where the determination relates to life-sustaining treatment no-one, in considering whether the treatment is in the best interests of the person concerned, should be motivated by a desire to bring about the person's death.

The following must be considered as part of the best interests assessment, to the extent they can be ascertained:

- the person's past and present wishes and feelings (and, in particular, any relevant written statement they made when they had capacity),
- the beliefs and values that would be likely to influence their decision if they had capacity, and
- the other factors that they would be likely to consider if they were able to do so.

Account must be taken, if it is practicable and appropriate to consult them, of the views of:

- anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
- anyone engaged in caring for the person or interested in his welfare,
- any donee of a lasting power of attorney granted by the person, and
- any deputy appointed for the person by the court as to what the person's wishes and feelings, beliefs or opinions would be likely to have been and what would be in their best interests.

Appendix 2: Theoretical models of, and approaches to, decision-making.

Model	Key characteristics
*Paternalistic	<ul style="list-style-type: none"> – ‘doctor knows best’: physician is expert and controls information provision and decision-making – patient is passive and dependent – patient’s role typically limited to providing consent
*Informative	<ul style="list-style-type: none"> – patient is active and autonomous – physician is the provider of the information to support the decision-making and enable the patient to choose – physician’s role is to ‘empower’ the patient’s autonomy in the decision-making process (Charles et al, 1997)
*Doctor-as-agent	<ul style="list-style-type: none"> – physician assists with the choice of treatment – patient’s role is to inform the physician of treatment preferences – physician is the decision-maker on the assumption that decision reflects the patient’s preferences
*Shared decision-making	<ul style="list-style-type: none"> – two-way exchange of information and decision-making preferences – active involvement of both physician and patient in the decision-making process
**Substitute decision-making	<ul style="list-style-type: none"> – the appointment of someone to make decisions on behalf of someone deemed to lack the mental capacity required to make it for themselves
***Supported decision-making	<ul style="list-style-type: none"> – persons with disabilities must be provided with the support they may require in exercising their legal capacity on an equal basis with others (CRPD Committee, 2014) – Support can include assistance with communication and understanding of the choices – Support may involve assisting a decision-maker to realise that a person with disabilities is nonetheless a person with a history, interests and aims in life and is someone capable of exercising his/her legal capacity (UN, 2006) from Davidson et al

Note:

*These models assume that the patient has capacity to consent to the proposed treatment. (Source: Tariman et al, 2012)

** This model assumes that the patient has been assessed not to have capacity to consent to the proposed treatment.

***This model adopts the CRPD approach to legal capacity, assuming that everyone has legal capacity and that those whose mental capacity (their decision-making ability) is reduced should be afforded an appropriate level of support such that they are enabled to make the decision.

Appendix 3: Supportive review: search strategy and process

The supportive review considered:

3. how the concepts of “capacity” and “best interests” are interpreted in hospices where care and treatment decisions are being made under the MCA for patients who lack or are losing capacity; and
4. whether supported decision-making takes place.

Search strategy for Identification of Studies

The following health-related and multi-disciplinary databases were searched: AMED, CINAHL, MEDLINE Complete, PsycINFO, PubMed, SCIE, Academic Search Ultimate and Web of Science. The advice of the FASS Academic Liaison Librarian (Content) specialist librarian was to make the search specific to the MCA and with her support, the following search strategy was designed.

Free text search (of abstract or title/abstract depending on the database) for each of the following:

1. “mental capacity act” AND “palliative care”
2. “best interest* assessment*”
3. “best interest* decision*”

Free text search (of all text) for

4. “supported decision making” AND “mental capacity act”.

Adding “hospice” into the search resulted in no results, or very few results being returned.

The criteria for inclusion and exclusion of studies were:

Inclusion

1. Studies using a qualitative approach and methodology.
2. Settings: all hospice settings, including “hospice at home” care delivered in the community.
3. Populations:
 - Hospice patients *AND/OR*
 - Patients’ family and friends (or other potential supporters for decision-making) *AND/OR*
 - Healthcare practitioners of any discipline working (or with experience of working) in any hospice setting *AND/OR*
 - Other non-medical hospice staff with responsibility for assisting with care/treatment decisions
4. Focus of the study:
 - Capacity assessments under the MCA *AND/OR*
 - Best interests assessments under the MCA *AND/OR*
 - Perceptions of the role of the patient/family in the MCA decision-making process *AND/OR*
 - Supported decision-making.

Exclusion

1. Studies concerning decision-making for children where best interests are assessed by reference to the criteria in the Children Act 1989;
2. Studies concerning decisions which fall outside the area of application of the

MCA; and

3. Policy papers or practical guidance for practitioners, on the basis that they restate the legislation rather than investigate its interpretation in practice.

Studies were screened for inclusion in stages. Initially, a review of the abstracts of the studies identified by the literature search was carried out and those not meeting the inclusion criteria were excluded. The full text of the articles whose focus appeared relevant to the review question were retrieved for a final assessment of relevance. There were very few studies specifically considering the hospice setting, and this was the most common reason for exclusion. Citation pearl searching was undertaken throughout the course of the review.

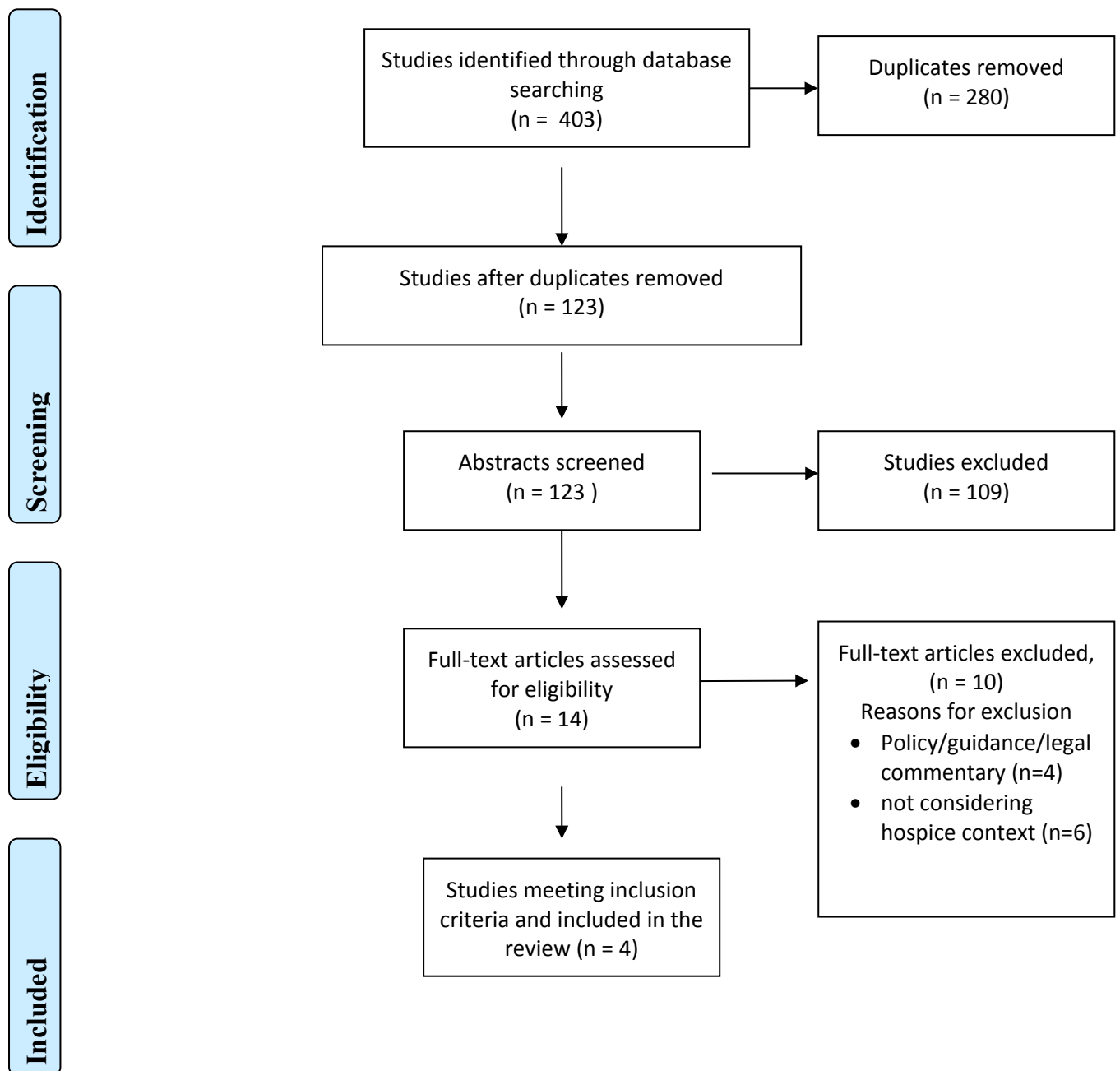
The process for screening and reviewing articles is shown in Figure A below. Tables showing:

- the full text articles assessed for eligibility and reasons for inclusion or exclusion (Table i); and
- a brief description of the design, focus and findings of each of the included studies (Table ii)

are also set out below.

Three of the studies were published shortly after the MCA came into effect (in 2007) and they reported difficulties with understanding the MCA and putting its requirements into practice. In the most recent study, Hinscliffe-Smith et al (2017) reviewed a collection of studies published between 2008 and 2013, including data

Figure A: Flowchart for literature selection



from a variety of healthcare settings and, again, findings reflected of difficulties linked to understanding and implementation of the MCA in the context (in this review) of decision-making for ‘frail and older people’. The themes identified in the analysis of the included studies, which can be grouped into four broad categories, issues with understanding the MCA, difficulties with documentation, difficulties with implementation and a focus on joint decision-making.

Looking at the discussion around these key themes a number of common concerns can be discerned which are reflected in the wider literature. These come together in a general question as to the value of individual autonomy when compared to what is described as the wisdom of a relational approach (Williams, et al., 2012). This reflects, in its focus on relationships and context, an ‘ethic of care’ interpretation of the MCA (see Clough, 2014), although this is linked to the way in which individual decision-makers experience the MCA and interpret its requirements in their own interaction with patients.

Table (i): Full text articles assessed for eligibility and reasons for inclusion or exclusion

Author	Title	Year	Included/excluded with reasons
Barton-Hanson, R	Reforming best interests: the road towards supported decision-making	2018	Exclude: Discussion of legal issues
Brown, H. and Marchant, L.	Using the Mental Capacity Act in complex cases	2013	Exclude: No hospice settings (social services, PCT, acute trust, mental health trust, campaigning groups, service provider (not identified) and advocacy provider)
Davidson, G. et al	Supported decision-making: a review of the international literature	2015	Exclude: no hospices mentioned in the discussion of the papers reviewed
Dunn, M.	Commentary of “using the MCA in complex cases”	2013	Exclude (see Brown, H. and Marchant, L. above)
Harris, D. and Fineberg, I.	Multi-disciplinary palliative care teams’ understanding of the MCA ‘best interest’ determinations	2011	Include: Possibly hospice. Setting “an NHS community service in the northwest of England where health and social-care professionals provide palliative care services to terminally ill patients” (p 21)
Hinsliff-Smith, K. et al	What do we know about the application of the MCA in healthcare practice regarding decision-making for frail and older people? A systematic literature review	2015	Include: nb two of the studies included in the review are also included studies for this project
Jenkins, K.	Mental Capacity and the MCA: A literature review	2011	Exclude: no reference in the document to hospice or palliative care settings
Johnston, C. et al	Patient narrative: an ‘on-switch’ for evaluating best interests	2016	Exclude: discussion of legal issues
McDonald, A. et al	The impact of the MCA on Social workers’ decision making	2008	Exclude: community social work, no involvement with hospice
Manthorpe, J. et al	Dementia nurses’ experience of the MCA 2005: a follow-up study	2014	Exclude: specialist dementia community nurses. No ref. to hospice
Murrell, A. and McCalla, L.	Assessing decision-making capacity: the interpretation and implementation of the MCA amongst social care professionals	2016	Exclude: local authority social workers and no hospice involvement
Udo, I. et al	Psychiatric issues in palliative care: assessing mental capacity	2013	Exclude: commentary and opinion, not empirical
Williams, V. et al	Best interests decisions: professional practices in health and social care	2013	Include: settings described as “NHS trusts, private and statutory organisations, voluntary sector and social care organisations and legal

			practices”. Possible that hospices included.
Wilson, E. et al	Working with the MCA: findings from specialist palliative and neurological care settings	2010	Include: Participants described as “having contracts of employment with the NHS as well as with the charity where the study took place”

Table (ii): Included studies with findings

Author(s)	Title and date	Study design	Study setting	Findings
Harris, D. and Fineberg, I.	Multi-disciplinary palliative care teams’ understanding of the MCA ‘best interest’ determinations (2011)	Face-to-face, one-to-one interviews to consider the beliefs and attitudes about the MCA concept of best interests in the decision-making of health and social care professionals. 11 participants.	Two settings in which health and social care professionals provide palliative care: care in patients’ own homes and care in a community hospital. NB <i>No specific reference to hospice but the description of the settings indicates a hospice at home service</i>	Discussion centered around these themes; <i>Understanding of the MCA:</i> described as ‘variable’ <i>Perspective on best interests:</i> focus on the best interests of the patient did not necessarily reflect the MCA guidance <i>Diagnosis and presumption of capacity:</i> participants appeared to link the patient’s diagnosis (eg dementia) to a lack of capacity <i>Documented patient preferences:</i> typically none available <i>Timing and consultation in decision-making:</i> discrepancy between practice in the community, where an individual would typically make a decision (to be reported later to the MDT) and in the community hospital where decisions were made by the MDT
Hinsliff-Smith, K. et al	What do we know about the application of the MCA in healthcare practice regarding decision-making for frail and older people? A systematic	Systematic literature review of qualitative, quantitative and mixed methods	Considered a variety of settings, including specialist palliative care (see Wilson et al) and community	Arranged by reference to three themes: <i>Knowledge and understanding of the MCA:</i> training in practical application required and variable knowledge of

	literature review (2015)	research (33 sources met inclusion criteria)		<p>MCA by healthcare professionals reported.</p> <p><i>Implementation/tensions in applying MCA</i>: differences noted in application in community and hospital-based palliative care settings. Importance of ‘getting to know’ the patient identified. Difficulties in practical application of MCA to ‘everyday acts of care’.</p> <p><i>Alternative perspectives of the MCA</i>: among family carers and non-healthcare professionals a lack of understanding of the MCA is reported</p>
Williams, V. et al	Best interests decisions: professional practices in health and social care (published 2013, data collected 2011)	<p>This paper is the qualitative part of a larger, three-phase multi-method design including;</p> <p>i) online survey;</p> <p>ii) telephone interviews; and</p> <p>iii) face-to-face interviews</p>	<p>Contrasting settings selected: NHS trusts, private and statutory organisations, voluntary and social care organisations and legal practices.</p> <p><i>Note: hospice is not specifically mentioned but the reference to voluntary organisations, and reference in the study to the comments of a palliative care nurse, has been taken potentially to include hospice settings.</i></p>	<p>Three themes explored:</p> <p><i>Managing risk</i>: primarily balancing risk against quality of life with a focus on the level of support required/available</p> <p><i>Blurred notions of capacity</i>: a capacity assessment often described as part of a wider process of assessing options and risk, allowing the capacity assessment to ‘blur’ into the assessment of the risk to the individual of the circumstances in question</p> <p><i>Joint decision-making</i>: preference for a team-based process, involving the individual. Reluctance for one person to have to make an assessment but importance of having someone lead the team-based process and take responsibility for the decision. MCA viewed positively as a ‘shield’ for all</p>

				concerned.
Wilson, E. et al	<p>Working with the MCA: findings from specialist palliative and neurological care settings (2010)</p> <p><i>NB the focus of the study is achieving ACP in the context of the MCA</i></p>	Semistructured interviews: individual face-to-face interviews, joint interviews, telephone interviews and a focus group (26 participants)	3 neurological units and 3 specialist palliative care settings. The palliative care units are charities providing in-patient, day-care and community specialist palliative and end-of-life care (<i>not called 'hospices' but described as such</i>)	<p>The following themes discussed:</p> <p><i>Understanding capacity</i>: generally understood but some participants demonstrated confusion about the meaning of capacity. Preference for decisions through the MDT</p> <p><i>Documentation</i>: Confusion as to terminology leading to communication difficulties with patients and a lack of confidence to discuss ACP. Issues about balancing paperwork with care: focus on the appropriate timing</p> <p><i>Best interests</i>: focus on documenting best interests decisions. The distinction between 'daily living' decisions and 'more challenging' treatment decisions often blurred and leads to difficulties in understanding whether/how to record</p>

Appendix 4: Index to the archive underpinning the genealogical analysis of the descent of the MCA

1. *Buck v Bell* 274 U.S. 200 (1927)
2. Council of Europe (1950) Convention for the Protection of Human Rights and Fundamental Freedoms
4. United Nations (1971) Declaration on the Rights of Mentally Retarded Persons
5. The Times (1989) Call to aid mentally impaired Issue 63298 p2
6. *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1
7. Law Commission (1991) Mentally Incapacitated Adults and Decision-Making: An Overview, Consultation Paper No 119
8. Department of Health (1991) Patient's Charter (London: HMSO)
9. Law Commission (1993) Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction, Consultation Paper No 128
10. Law Commission (1993) Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research, Consultation Paper No 129
11. Law Commission (1993) Mentally Incapacitated and Other Vulnerable Adults: Public Law Protection, Consultation Paper No 130
12. House of Lords Select Committee (1994) Report of the Select Committee on Medical Ethics HL 21-I
13. Government Response to the Report of the Select Committee on Medical Ethics (1994) Cm 2553
14. Law Commission (1995) Mental Incapacity: Item 9 of the Fourth Programme of Law Reform: Mentally Incapacitated Adults, Law Com No 231

15. Disability Discrimination Act 1995
16. Lord Chancellor's Department (1997) *Who Decides? Making decisions on behalf of mentally incapacitated adults* (CM3803) London: TSO
17. Human Rights Act 1998
18. Disability Rights Commission established (1999)
19. Lord Chancellor's Department (1999) *Making Decisions: The Government's Proposals for Making Decisions on Behalf of Mentally Incapacitated Adults : a Report Issued in the Light of Responses to the Consultation Paper Who Decides?* London: TSO
20. Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century* CM 5068
21. Department for Constitutional Affairs (2003) *Draft Mental Incapacity Bill* (Cm 5859) London: TSO
22. House of Lords Joint Committee on the Mental Incapacity Bill (2003) *First Report, Session 2002-03, HL Paper 189-I HC 1083-I*
23. The Times (2003) *Patents' Bill 'will help to protect lives'* Issue 67706 p.19
24. The Times (2003) *Right to 'living will' part of new legislation* Issue 67801 p.11
25. 16 The Times (2003) *Why our mental health law needs help* Issue 67899 p.5[S2]
26. Government's Response to the Report of the Joint Committee on Mental Incapacity (Cm 6121, 2004)
27. The Times (2004) *Living wills make right to decline treatment legal* Issue 68106 p.13

28. Department for Constitutional Affairs (2004) Mental Capacity Bill
29. Mental Capacity Act 2005
30. Department for Constitutional Affairs (2007) Mental Capacity Act Code of Practice

Appendix 5: Legal contextual review: search strategy and stages of the review process, data extraction table and consideration of initial themes

In my search of the body of case law in the area of interest, I designed and have used a systematic strategy to ensure a comprehensive search. The body of case law considering the MCA is extensive so specific inclusion and exclusion criteria were applied to the results to enable the identification of an appropriately focused body of judgments to be collected for detailed analysis.

Review question:

“How have the English courts interpreted the meaning of “capacity” and “best interests”, including the role of an individual, supporting family members and carers (formal and informal), when decisions are made under the MCA about medical care and treatment?”

Criteria for Inclusion and Exclusion of judgments:

The body of relevant case law is wide-ranging. The MCA is intended to apply generally to decision-making for people who lack capacity, although decisions on certain matters (for example marriage, mental health matters and voting rights) are specifically excluded (ss27-29 MCA). Certain areas of medical treatment for which the courts have developed specific tests for capacity (eg contraception; capacity to consent to sexual relations) have also been excluded. The following inclusion criteria were applied to the cases returned by the searches:

Inclusion:

Cases considering the issues below, irrespective of whether they are brought by or on behalf of the individual, the individual’s family or other carer (whether formal or informal) or by an individual’s medical team:

- iii) cases considering the capacity of an individual to make a decision about medical care and/or treatment; and

- iv) cases considering what constitute the best interests of an individual who has been assessed as lacking capacity to make a decision about medical care and/or treatment.

Exclusion:

- viii) cases which consider capacity to consent to sexual intercourse or to the use of contraception;
- ix) cases where the primary focus is an individual's place of residence;
- x) cases whose focus is the application of the Deprivation of Liberty Safeguards rather than the treatment or care of the patient;
- xi) cases with an administrative or procedural focus (such as a power of attorney or the allocation of costs);
- xii) cases which consider the capacity of an individual to make decisions to which the MCA does not apply (for example, marriage);
- xiii) cases which consider the best interests of a child for the purposes of the Children Act 1989; and
- xiv) cases which were decided before the entry into force of the MCA (in 2007).

Search strategy for identification of cases

Searches of legal databases Westlaw UK and LexisLibrary (UK) were carried out. The searches were restricted to cases heard in the English Court of Protection and the Supreme Court. The Court of Protection is the court with jurisdiction in England and Wales to decide (by reference to the MCA) welfare matters for people who cannot make decisions for themselves at the time they need to be made.

Search strategy

Concept 1: assessment of legal capacity for the purposes of the MCA

Concept 2: best interests assessments for the purposes of the MCA

- * role of the individual
- * role of family, informal and formal carers

Concept 3: supported decision-making

Detailed Search: Westlaw UK

Concept 1
Westlaw case law database: subject/keyword search health AND “Mental capacity”
Westlaw case law database: free text search “mental capacity assessment”
Westlaw case law database: subject/keyword search health AND “persons lacking capacity”
Concept 2
Westlaw case law database: subject/keyword search health AND “best interests”
Westlaw case law database: free text search “best interests assessment”
Concept 3
Westlaw case law database: keyword search “supported decision-making”
Westlaw case law database: free text search “supported decision-making”

Detailed search: LexisLibrary (UK)

A search of LexisLibrary cases database was carried out;

1. adding topics “Health Law” and, in the advanced search section selecting all available judgment dates, all case types and using the specific search terms (derived from headnotes) in the summary box; and
2. using the free text search function with the topic of “Health Law” added.

Concept 1
“mental capacity act” , “mental capacity”
“persons who lack capacity”
“test for determining capacity”
“mental capacity assessment*”

Concept 2
“best interests”, “best interests of patient”
“best interests declaration”
“best interest* assessment*”
Concept 3
“supported decision making”, “supported decision-making”
“decision making”
“powers to make decisions”
“inability to make decisions”

Stages of the review

Duplicates were removed in stages: cases are reported under different names and citation numbers resulting in the identification of duplicates at each stage of the review. In addition, the detail of the case was often not reflected in the headnote so cases were excluded at every stage of the review process.

The 63 judgments remaining after the last application of the exclusion criteria were read in full. The final included judgments [n=16] were purposively sampled using the following inclusion criteria:

- decisions of the Supreme Court;
- judgments stated to be of general application;
- cases where reference is made to palliative care;
- cases where the patient’s voice cannot be heard; and
- cases where specific consideration is given to the significance of the patient’s wishes and feelings in the decision-making process.

The selection of cases for analysis was not influenced by the likelihood of the care or treatment considered being offered by a hospice (although the provision of palliative care is relevant in several instances). As the focus of this review is the judicial construction and application of the MCA concepts

of capacity and best interests, the judgments selected for analysis are those which contain the most interesting discussions of the law as it is applied to the case being considered.

Table showing Judgments selected for analysis

Case name	Neutral citation
NHS Windsor and Maidenhead Clinical Commissioning Group v SP <i>Withdrawal of clinically assisted nutrition and hydration (CANH) from a patient in a permanent vegetative state</i>	[2018] EWCOP 11
Abertawe Bro Morgannwg University Local Health Bd v RY <i>Assessment of best interests of the patient in relation to various treatments, including when treatment should not be attempted</i>	[2017] EWCOP 2
NHS Foundation Trust v QZ (A Patient) <i>Investigation to determine the cause of post-menopausal bleeding</i>	[2017] EWCOP 11
IH (Observance of Muslim Practice) Re <i>Whether fasting and ritual shaving in accordance with religious requirements are in a patient's best interests.</i>	[2017] EWCOP 9
B v D, MoD <i>Whether stem cell treatments are in the best interests of a former soldier with traumatic brain injury</i>	[2017] EWCOP 15
PL v Sutton Clinical Commissioning Group <i>Whether it is in patient's best interests that CANH be discontinued</i>	[2017] EWCOP 22
Brent LBC v NB <i>Whether or not a period of intense rehabilitation and assessment is in the patient's best interests</i>	[2017] EWCOP 34
Salford Royal NHS Foundation Trust v P <i>Life sustaining medical treatment for a patient in a minimally conscious state (MCS)</i>	[2017] EWCOP 23
An NHS Trust v CS <i>Termination of pregnancy</i>	[2016] EWCOP 10
Betsi Cadwaladr University Local Health Board v Miss W <i>Concerning capacity of a patient to decide whether or not to refuse further treatment for anorexia</i>	[2016] EWCOP 13
Re: O <i>Whether withdrawal of mechanical ventilation in patient's best interest</i>	[2016] EWCOP 24
A University Hospital NHS Trust v CA <i>Whether delivery of a baby by caesarian section in patient's best interests</i>	[2016] EWCOP 51
AB, Re <i>AIDS case; whether HIV treatment by deception is in the patient's best interests.</i>	[2016] EWCOP 66
Briggs v Briggs (No.2) <i>Withdrawal of clinically assisted nutrition and hydration from a patient in a minimally conscious state</i>	[2016] EWCOP 53
SB (A Patient)(Capacity to Consent to termination) Re <i>Capacity assessment: patient with mental illness (detained under MHA) who had made arrangements to terminate a pregnancy she had</i>	[2013] EWHC 1417 (COP)

<i>previously wanted.</i>	
Aintree University Hospitals NHS Foundation Trust v James <i>Considering the BI test as it had been applied by the CoA in a case concerning certain treatments to prolong life. Appeal heard after the death of Mr James.</i>	[2013] EWSC 67

Data Extraction

The cases selected for analysis were read again for the identification of themes, in particular for themes related to the key themes identified in the stage one genealogical analysis. The themes identified were recorded in a data extraction table. (see table (xx) – *to be inserted later*).



Applicant: Caroline Redhead
Supervisors: Katherine Froggatt & Sarah Fovargue
Department: Health Research
FHMREC Reference: FHMREC16070 05

June 2017

Dear Caroline

Re: Exploring decision-making in a hospice context for patients who lack or are losing capacity

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 Committee, 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 at the email address below (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 me if you have any queries or require further information. Tel:-

01542 592838

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in black ink that reads "Diane Hopkins".

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.

Appendix 7 Phases three and four participant information (group and individual interviews)

Index

Hospice documents

- A. Letter of introduction for the participating hospices.
- B. Hospice Information.
- C. Hospice consent form.

Group Interview documents

- D. Letter of introduction to the potential participants in the group interview.
- E. Group interview Participant Information Sheet.
- F. Group interview consent form.
- G. Discussion guide for group interview (indicative topics).

Individual Interview documents

- H. Publicity/flyer for the staff newsletter - information about the individual interviews.
- I. Expression of interest form for individual interviews.
- J. Consent form for individual interviews.
- K. Participant Information Sheet for individual interviews.
- L. Interview guide for individual interviews (indicative topics).

Other

- M. Demographic information collection form for interview participants.

A: Letter of introduction for participating hospices

[On Lancaster University Headed notepaper]

[Researcher email
and contact telephone number]

[Addressed to the CEO of the hospice being approached]

[date]

Dear [Name]

Lancaster University PhD research project
Exploring decision-making in a hospice context for patients who lack or are losing capacity

I am hoping to recruit two hospices in the North of England to participate in a research project which I am carrying out as part of my PhD in Palliative Care at Lancaster University.

The research involves talking to hospice staff and trustees about making care and treatment decisions for patients who have a reduced ability to understand and to participate in the decision-making process. I attach a detailed information sheet for you to look at, together with a pack of supplementary information and the consent forms which I have compiled for staff and trustee participants in the project.

Please don't hesitate to contact me if you would like to discuss the project any further. If I haven't heard from you by [one week from the date of the letter] I will [give you a ring/email you] to discuss your interest in participation.

Yours sincerely,

Caroline Redhead



EXPLORING DECISION-MAKING IN A HOSPICE CONTEXT FOR PATIENTS WHO LACK OR ARE LOSING CAPACITY

My name is Caroline Redhead and I am conducting this research as a student in the PhD (Palliative Care) programme at Lancaster University, Lancaster, United Kingdom. I am also a lawyer and volunteer as a hospice trustee.

What is the study about?

This study is concerned with decision-making for hospice patients who lack or are losing decision-making capacity as their illness progresses. The focus of the study is the way in which hospice patients living with life-limiting illnesses are involved in decisions concerning their care and treatment. The aim of this study is to explore how relevant legal principles and policy guidelines are interpreted in decision-making with, for or about hospice patients.

Why has this hospice been approached?

You have been approached because I would like to recruit members of your staff and trustees to participate in the study.

Does my hospice have to take part?

No – participation is entirely voluntary. If your hospice would like to take part but would prefer not to be identified in the findings or any academic papers which are written or presentations given as a result of the study, that can be facilitated.

What will be required of the hospice if we take part?

The role of the hospice would largely be facilitative. There are two distinct phases of the study where hospice staff expertise will be required and I will ask for your help to identify staff members and trustees who meet the inclusion criteria and approach them about taking part in the project. It is important to note that no staff member must feel under any obligation to participate. Any who consent to participate will be free to change their minds without any consequences.

Group interview participants

I am interested in exploring in a group session how the MCA and other regulatory requirements (for example the Code of Practice and CQC regulations) are reflected in your policies and any staff guidance or training documents, particularly as regards the role of the patient in the decision-making process. I would be hoping to recruit up to 6 staff members and trustees who are knowledgeable about the requirements of the MCA and responsible for policy-making, education or training for your hospice. I anticipate that the group will need to meet for 1-2 hours (one meeting).

I will be guided by you as to which staff members would be most appropriate but my starting point would be;

- CEO;
- MCA/DoLS lead;
- a staff member with responsibility for policy development;
- a staff member with responsibility for staff training and development;
- a member of the board of trustees (with relevant responsibilities if a specific role exists); and

- a senior medical team member (doctor or nurse).

I would like to ask for your guidance in identifying and your permission to approach specific staff members and trustees with the appropriate responsibilities and experience and invite them to take part in the group interview.

Individual interviews

I am also interested in understanding how care and treatment decisions are made on a daily basis for patients who lack or are losing capacity, both the process of assessing a patient's capacity and the decision-making itself, particularly the way in which the patient is involved in the processes, and to what extent their wishes and feelings inform the decision. I would like to explore the role of the hospice staff member in the decision-making process and how family members and/or other supporting individuals are involved. Each interview will probably last between 45 minutes and an hour.

I will be looking to recruit 3 or 4 members of staff responsible for providing medical or spiritual care and support who would be willing to talk to me individually. I would like to recruit staff members from across the hospice so that the sample is representative of both "hospice based" staff and peripatetic staff who work for a "hospice at home" service. Staff members;

- who have responsibility for assisting patients with care and treatment decisions; and
- staff members who are responsible for spiritual (or specifically non-medical) care, such as religious or more broadly spiritual support.

I will ask for your permission to advertise the project (however you feel most appropriate – maybe through a staff newsletter?) to staff members who may be interested. It would be helpful for the group discussion and the storytelling interviews to take place at the hospice.

Informed consent is required from all participants who express an interest and I have prepared separate information sheets and consent forms for group and individual interview participants. I have also prepared some sample publicity material. A copy of each document is attached for your information.

Support for participating staff members

It is possible that participants might find that participation a burden on top of their usual workload or that storytelling interviews might cause distress to the participants sharing their experiences. I will need to talk to you about sources of support at your hospice which would be available on a confidential basis to any staff member who experiences distress as a result of participating.

What about data protection and confidentiality?

Staff members who take part in the group discussion will not be able to remain anonymous to the other members of the group, although I will not identify the participants by name once the discussion is transcribed.

Staff members who agree to take part in the individual interviews will not be identified to other members of the hospice and their stories will not be linked to their names, job titles or other identifying information as part of the data analysis. If the interviews take place at the hospice, this will mean colleagues might become aware that they are participating and they will be asked about this when they are recruited.

General information about the participants (such as gender, ethnicity, length of time in their role at the hospice) will be collected but if gender and ethnicity would make participants identifiable, the data will be described generally. If an individual can be identified from their role at the hospice (if, for example, there is only one particular role) they will be asked for their consent on this basis. Any

identifying personal information which is mentioned during either the group interview or any of the individual interviews will be anonymised during transcription. The data collected for this study will be stored securely and will only be accessible by me and my PhD supervisors.

There are some limits to confidentiality. If what is said during the group interview or any of the individual interviews to me (or to another of the participants in the group interview) makes me think that someone is at significant risk of harm, I may have to break confidentiality and speak to my PhD supervisors and you and/or, if appropriate, the individual's line manager) about any actions which might be required. I will make this clear to the participants in the consent documentation and at the beginning of each interview.

What will happen to the results?

A report summarising findings from both hospices will be shared with hospice managers.

The project is an academic study and I will use the results together with my own analysis in a PhD thesis. This will be submitted to Lancaster University for assessment. I may also give presentations and compile articles for publication in academic or professional journals.

Are there any risks?

There are no risks anticipated for the hospice as a result of participation in this study.

Are there any benefits to taking part?

There are potential professional benefits for the group interview participants in having discussed and specifically considered the way in which policy is written, how decisions are made for patients who lack or are losing capacity to make decisions for themselves, including a greater awareness of the nature of supported decision-making. This may assist the hospice to consider and discuss how changes can continue to be made to hospice practice in the context of the Law Commission's review of the MCA framework and to develop a training programme based on any practical learning which arises out of this project.

I will provide (and pay for) refreshments for the participants and reimburse them any travel expenses they incur as a result of their participation.

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.

What should I do now?

If you are willing to permit me to approach your staff members as outlined above and invite them to take part in the project, please email me accordingly at c.redhead@lancaster.ac.uk. I will then visit you, ask you to sign a consent form (copy attached) to confirm your approval and begin the recruitment process.

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

If you have any questions about the study, please contact me, Caroline Redhead;
c.redhead@lancaster.ac.uk

Alternatively, please contact either of my supervisors at Lancaster University;

Professor Katherine Froggatt; k.froggatt@lancaster.ac.uk

Dr Sara Fovargue; s.fovargue@lancaster.ac.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 me, you can contact:

Dr. Mark Limmer

Division of Health Research

Faculty of Health and Medicine

Furness Building

Lancaster University

Lancaster

LA1 4YG

Tel: (01524) 594154

Email: m.limmer@lancaster.ac.uk

If you wish to speak to someone outside of the Palliative Care Doctorate Programme, you may also 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.



Hospice Consent Form
Study Title: Exploring decision-making in a hospice context
for patients who lack or are losing capacity

I have invited your hospice to take part in a PhD research project. The purpose of this project is to look at how decisions about patient care and treatment are made with, for or about patients receiving palliative care in a hospice setting who lack or are losing decision-making capacity.

By signing below, the authorised signatory confirms that consent is given for the Hospice to participate in the project, and;

1. that the appropriate representatives of the Hospice have read the Hospice Information Sheet (copy attached) and the additional documents listed in the schedule to this form;
2. that representatives of the hospice have had the opportunity to ask any questions and to have them answered and they understand and agree to participate in the study as described in the Hospice Information Sheet and the additional documents listed in the schedule;
3. that participation by the hospice is voluntary but that once consent has been given and recruitment has started, the hospice will not be able to withdraw from the project;
4. that the researcher will share and discuss data with her supervisors as needed and that participants give consent on this basis; and
5. that any personal information given by participants about will remain strictly confidential unless it is thought that there is a risk of harm to myself or others, in which case the researcher may need to share this information with her research supervisors and possibly with hospice management.

[Hospice name], acting by its authorised signatory/ies [name(s)] consents to take part in the above study.

..... Date:
Name:

[add more signatories as needed and amend execution clause as required depending on constitution of the participating hospice]

[Cont.]

SCHEDULE of documents describing the study

Hospice documents

1. Letter of introduction for the participating hospices, directed to the CEO to instigate the management approval process.
2. Hospice Information Sheet - to give information about the study to facilitate a management decision as to whether or not to participate.
3. Hospice consent form.

Group Interview documents

4. Letter of introduction to the potential participants in the group interview.
5. Group interview Participant Information Sheet.
6. Group interview consent form.
7. Discussion guide for group interview.

Individual Interview documents

8. Publicity/flyer for the staff newsletter - information about the individual interviews.
9. Expression of interest form for individual interviews.
10. Consent form for individual interviews.
11. Participant Information Sheet for individual interviews
12. Individual interview guide

Other

13. Group interview demographic information collection form.
14. Transcriber confidentiality form.

D: Letter of introduction for group interview

[on Lancaster University headed notepaper]

[Researcher email
and contact telephone number]

[Addressed to the hospice staff member/trustee being approached]

[date]

Dear [Name]

Lancaster University PhD research project

Exploring decision-making in a hospice context for patients who lack or are losing capacity

I am carrying out a research project with the assistance of two hospices in the North of England as part of my PhD in Palliative Care at Lancaster University.

The research involves talking to hospice staff and trustees about decision-making for patients who have a reduced ability to understand and to participate in decisions concerning their care and treatment arrangements. I am hoping to recruit a group of staff members and trustees from your hospice to participate in a group interview and [CEO's name] has suggested that you have the experience which I am looking for. I attach a detailed information sheet for you to look at, together with an indicative topic guide for the group interview.

If you would like to participate in the group interview, please would you email me at the above address? Please don't hesitate to contact me either by email or by telephoning me on the above number if you would like to discuss the project any further. If I haven't heard from you by [one week from the date of the letter] I will [give you a ring/email you] to discuss your interest in participation.

Yours sincerely,

Caroline Redhead



EXPLORING DECISION-MAKING IN A HOSPICE CONTEXT FOR PATIENTS WHO LACK OR ARE LOSING CAPACITY

Group interview participant information sheet

My name is Caroline Redhead and I am conducting this research as a student in the PhD (Palliative Care) programme at Lancaster University, Lancaster, United Kingdom. I am also a lawyer and volunteer as a hospice trustee.

What is the study about?

The focus of this study is the way in which hospice patients living with life-limiting illnesses are involved in decisions concerning their care and treatment.

Why have I been approached?

You have been approached because in your role at the hospice you are involved in policy decision-making and/or education in the area of the MCA and I would like to invite you to participate in a group interview which will take place as one of the phases of the study.

Do I have to take part?

No – participation is entirely voluntary. If you initially decide you would like to take part but later change your mind, you will be able to withdraw at any part of the process. If you decide to withdraw after the interview has started, any contributions you have made to the discussion will be included in the analysis of the data.

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

I am interested in exploring in a group interview how the MCA and other regulatory requirements (for example the Code of Practice and CQC regulations) are reflected in your policies and any staff guidance or training documents, particularly as regards the role of the patient in the decision-making process. I would be hoping to recruit up to 6 staff members and trustees who are knowledgeable about the requirements of the MCA and responsible for policy-making, education or training for your hospice.

I anticipate that the group will need to meet for 1-2 hours (one meeting). The group interview will take place at the hospice.

What about data protection, anonymity and confidentiality?

Staff members who take part in the group interview will not be able to remain anonymous to the other members of the group, although I will not identify anyone by name when the discussion is transcribed. General information about you and the other group interview participants (such as gender, ethnicity, length of time in their role at the hospice) will be collected but if gender and ethnicity would make participants identifiable, the data will be described generally. If you are identifiable from your role at the hospice (if, for example, there is only one person in your role) then you will need to consider if you are comfortable with this before you consent to participate.

The group interview will be audio-recorded and then transcribed either by myself or a professional. The data collected for this study will be stored securely and only I will have access to it, although I will discuss the data with my PhD supervisors as needed. In addition:

- audio recordings will be destroyed and/or deleted once the PhD has been awarded;
- computer files will be encrypted and the computer itself will be password protected;
- at the end of the study, hard copies of meeting notes and other documents will be kept securely in a locked cabinet at Lancaster University for ten years. At the end of this period, they will be destroyed;
- any reference to individuals in the typed version of the group interview will be anonymised. I may use anonymised direct quotations from the group interview in reports, presentations or publications from the study. No names, or potentially identifying general information, will be attached to them;
- if you think you would be identifiable from the general information collected about you (if, for example, you are the only person in your role at the hospice) this information will be treated as confidential and will be kept separately from the group interview data.

There are some limits to confidentiality. If what is said to me or to another of the participants during the group interview makes me think that someone is at significant risk of harm, I may have to speak to my supervisors or, if appropriate, the individual's line manager about any actions which might be required. We will discuss this again at the start of the group interview.

What will happen to the results?

A summary progress report will be prepared for the hospice management after analysis of the data collected in the study.

The project is an academic study and I will use the results together with my own analysis in a PhD thesis. This will be submitted to Lancaster University for assessment. I may also compile articles for academic or professional journals and/or give presentations.

Are there any risks?

I don't anticipate that there are any risks associated with you taking part in the group interview, although you may feel that participation will increase your workload. However, if you experience any distress following participation you are encouraged to let me know and speak to [name] at the hospice who will be able to provide you with confidential support.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. Any expenses you incur in participating will be refunded and refreshments will be provided.

There are potential professional benefits for the group interview participants in having discussed and specifically considered the way in which policy is written, how decisions are made for patients who lack or are losing capacity to make decisions for themselves, including a greater awareness of the nature of supported decision-making.

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.

What should I do now?

If you have any questions about the study, or you would like to volunteer to take part, please contact me, Caroline Redhead; c.redhead@lancaster.ac.uk

Alternatively, please contact either of my supervisors at Lancaster University;

Professor Katherine Froggatt; k.froggatt@lancaster.ac.uk

Dr Sara Fovargue; s.fovargue@lancaster.ac.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 me, you can contact:

Dr. Mark Limmer

Division of Health Research

Faculty of Health and Medicine

Furness Building

Lancaster University

Lancaster

LA1 4YG

Tel: (01524) 594154

Email: m.limmer@lancaster.ac.uk

If you wish to speak to someone outside of the Palliative Care Doctorate Programme, you may also 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.



Consent Form: group interview (phase 2)

**Study Title: Exploring decision-making in a hospice context
for patients who lack or are losing capacity**

You have been invited to take part in a PhD research project. The purpose of this project is to look at how decisions about patient care and treatment are made with, for or about patients receiving palliative care in a hospice setting who lack or are losing decision-making capacity.

Before you consent to participating in the study please read the group interview participant information sheet (copy attached) 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 researcher, Caroline Redhead.

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. | <input type="checkbox"/> |
| 2. I understand that I will not be an anonymous participant in the study and that my employer and my work colleagues will be aware of my involvement. | <input type="checkbox"/> |
| 3. I confirm that I have had the opportunity to ask any questions and to have them answered. | <input type="checkbox"/> |
| 4. I understand that the group discussions will be audio recorded and then made into an anonymised written transcript for analysis as part of the study. | <input type="checkbox"/> |
| 5. I understand that audio recordings will be kept until the PhD has been awarded and that they will then be deleted. | <input type="checkbox"/> |
| 6. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. | <input type="checkbox"/> |
| 7. I understand that once the group interview has started, I will not be able to ask for my data withdrawn. | <input type="checkbox"/> |
| 8. I understand that the information from the group discussions will be anonymised and may be published. | <input type="checkbox"/> |
| 9. I consent to information and quotations from my participation in the group interview being used anonymously in a thesis, papers, presentations, conferences and training events. | <input type="checkbox"/> |

10. I understand that any information I give will remain strictly confidential unless it is thought that there is a risk of harm to myself or others, in which case the researcher may need to share this information with her research supervisors and possibly with my line manager

☐

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

☐

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

☐

Name of Participant _____

Signature _____

Date _____

Name of Researcher _____

Signature _____

Date _____



EXPLORING DECISION-MAKING IN A HOSPICE CONTEXT FOR PATIENTS WHO LACK OR ARE LOSING CAPACITY

Group interview discussion guide Indicative topics for discussion

- How the general legal context of the MCA is interpreted for the hospice context e.g., what are the key issues from the hospice perspective?
- What the documents envisage the patient's role in the process should be and the role of the staff members providing care to the patient; Who leads the process?
- What is the role of the patient's family and friends.
- How the policy envisages assessments of capacity taking place; what is anticipated in terms of communication in both a capacity assessment and a decision-making process; how staff are expected to communicate with a patient when assessing capacity and during the decision-making process (including the level of information which is provided); how a non-verbal patient would be assessed and supported.
- What "best interests" looks like in a hospice context; whether decisions which are taken in a person's best interests are ever underpinned by a desire to make sure the patient is properly looked after rather than to make sure the decision reflects what they say they want, if the two are not the same.
- Whether a supported decision-making approach is appropriate in the hospice context; whether existing policies anticipate this and if so, what that might mean; whether a best interests approach can ever be a supported decision-making approach.
- Whether medical decisions are taken differently from other decisions; whether there might be a different approach where staff are acting in a professional (and therefore expert) capacity.
- Whether there is a difference in approach in hospice at home services or whether the nature of decision-making is the same for in-patients, day hospice patients and patients who are receiving care in their own homes.
- Whether advance decisions to refuse treatment and advance care planning are commonly seen and what difference (if any) this makes to the decision-making process.
- Any other relevant issues.

Supporting documents

The following documents will underpin discussion in the group interview;

- hospice policies which are relevant to the MCA and decision-making for patients who lack or are losing capacity, including the process of assessing capacity;
- any supporting guidance for staff regarding the MCA policy/ies; and
- staff training documents (if any) which relate to MCA decision-making in the hospice.

Terminology

Supported decision-making means the process of providing support to people whose decision-making ability is impaired so that, wherever possible, they can make their own decisions. This can be contrasted with *substituted decision-making*, where an individual makes decisions on behalf of someone else on the basis of an objective standard, such as best interests. The MCA requires all practical steps to be taken to help someone make a decision before an assessment of incapacity is made but, if a person's capacity cannot be established, the MCA permits decisions to be made on their behalf in their best interests.



Lancaster University PhD Research Project
Exploring decision-making in a hospice context
for patients who lack or are losing capacity

Would you like to take part in this research?

- Do you provide clinical care and support to hospice patients with responsibility for helping patients make decisions, both as regards treatment and other issues?
- Are you responsible for helping with religious or spiritual (specifically non-medical) support and decision-making?

What would be involved?

- You would be asked to talk to me, individually and confidentially, about your experiences of helping patients with decision-making.
- I would be interested in how you see your role, the patient's role and the role of any family members/friends in the decision-making process.
- In particular, I would like you to tell me the story of two decisions which you remember particularly, thinking about the issues you encountered and how you resolved them.

When and where would the interview take place?

The interview would take place [in the autumn of 2017] at the Hospice [unless you would feel more comfortable meeting at a different location]. It would take around an hour.

Is there more information available about the project which I can see before I decide?

Yes – please email me, Caroline Redhead at c.redhead@lancaster.ac.uk and I will send you some more details.

What do I do if I want to take part?

You can either collect an expression of interest form [from the Hospice reception] and return it to me at the address set out on the form

OR email me, Caroline Redhead at c.redhead@lancaster.ac.uk to let me know you are interested **or** telephone me on [*number to be provided*].

I: Expression of interest – individual interviews



**PHD RESEARCH PROJECT
EXPLORING DECISION-MAKING IN A HOSPICE CONTEXT
FOR PATIENTS WHO LACK OR ARE LOSING CAPACITY**

Expression of Interest Form- Individual Interviews

I am a staff member at a hospice which has agreed to take part in the above project. I am interested in taking part in this project. I have read and understood the “Individual interviews Participant Information Sheet” (copy attached).

Please sign below and complete the following (but only provide contact details you are happy to share):

Name: _____ Date: _____

Email:

Work phone:

Mobile phone:

Postal address:

Please return this form either by post or by email to Caroline Redhead, the Lancaster University PhD student who will be carrying out the study. Caroline will be in contact with you to discuss the project, answer any questions you may have about the research and ask whether you would like to take part.

Caroline’s contact details are:

Caroline Redhead
Division of Health Research
Faculty of Health and medicine
Furness College
Lancaster University
Lancaster
LA1 4YG
Email: c.redhead@lancaster.ac.uk
Tel: [TBC]



Consent Form: individual interviews (phase three)

**Study Title: Exploring decision-making in a hospice context
for patients who lack or are losing capacity**

You have been invited to take part in a PhD research project. The purpose of this project is to look at how decisions about patient care and treatment are made with, for or about patients receiving palliative care in a hospice setting who lack or are losing decision-making capacity.

Before you consent to participating in the study please read the individual participant information sheet (copy attached) 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 researcher, Caroline Redhead on [number TBC].

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. | <input type="checkbox"/> |
| 2. I understand that if the interviews take place at the hospice, I may not be an anonymous participant in the study and that my employer and work colleagues may be aware of my involvement. | <input type="checkbox"/> |
| 3. I confirm that I have had the opportunity to ask any questions and to have them answered. | <input type="checkbox"/> |
| 4. I understand that my interview will be audio recorded and then made into an anonymised written transcript for analysis as part of the project. | <input type="checkbox"/> |
| 5. I understand that audio recordings will be kept until the PhD has been awarded and that they will then be deleted. | <input type="checkbox"/> |
| 6. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. | <input type="checkbox"/> |
| 7. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn. | <input type="checkbox"/> |
| 8. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published | <input type="checkbox"/> |
| 9. I consent to information and anonymised quotations from my interview being used in a thesis, papers, conferences, presentations and training events. | <input type="checkbox"/> |

10. I understand that the researcher will share and discuss data with her supervisors as needed. ☐
11. I understand that any information I give will remain strictly confidential unless it is thought that there is a risk of harm to myself or others, in which case the researcher may need to share this information with her research supervisors and possibly with my line manager. ☐
12. I consent to Lancaster University keeping transcriptions of my interview for 10 years after the study has finished. ☐
13. I consent to take part in the above study. ☐

Name of Participant _____

Signature _____ **Date** _____

Name of Researcher _____

Signature _____ **Date** _____



EXPLORING DECISION-MAKING IN A HOSPICE CONTEXT FOR PATIENTS WHO LACK OR ARE LOSING CAPACITY

Individual interview participant information sheet

My name is Caroline Redhead and I am conducting this research as a student in the PhD (Palliative Care) programme at Lancaster University, Lancaster, United Kingdom. I am also a lawyer and I volunteer as a hospice trustee.

What is the study about?

The focus of this study is the way in which hospice patients living with life-limiting illnesses are involved in decisions concerning their care and treatment.

Why have I been approached?

You have been approached because in your role at the hospice you either provide clinical care and support to patients and have responsibility for assisting patients make decisions about medical care and treatment or religious/spiritual care and support.

Do I have to take part?

No – participation is entirely voluntary. If you initially decide you would like to take part but later change your mind, you will be able to withdraw at any part of the process. If you withdraw during or after your interview, you will be able to choose whether their interview is included in the analysis or deleted. You will have up to two weeks from the date of the interview to decide to withdraw.

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

I am interested in understanding how decisions are made on a daily basis for patients who lack or are losing capacity, both the process of assessing a patient's capacity and the decision-making itself, particularly the way in which the patient is involved in the process, and to what extent their wishes and feelings inform the decision. I would like to understand how you view your role in the decision-making process and the role of any family members or other supporting individuals.

I anticipate that your interview will probably last between 45 minutes and an hour. If you are comfortable with this, it would be helpful for the interview to take place at the hospice. If not, arrangements will be made for the meeting to take place elsewhere. I am hoping to recruit 3-4 staff members to participate in the project. If more than 4 express an interest in taking part, the participants will be selected with a view to involving staff members from across the hospice, including hospice-based staff and those who work for the hospice at home service, and involving staff members who providing medical and non-medical care and support.

What about data protection and confidentiality?

Your name and any personal information you share with me will be confidential. I will not use your name or the names of any individuals you mention during the interview when it is typed up.

I will need to use some general information about you - such as your gender, ethnicity and how long you have worked in your current role at the hospice but if you would be able to be identified from any of this information I will use a general description so that individuals will not be identifiable.

The interviews will be audio-recorded. I am intending to transcribe the interviews myself, but should that not be possible, a transcriber confidentiality agreement will be put in place.

If you agree to take part, I will not identify you to other members of the hospice and your stories will not be linked to your name, job title or other identifying information as part of the data analysis. If the interviews take place at the hospice, colleagues might become aware that you are participating and if you would like to participate but to be interviewed elsewhere, please make that clear when you volunteer.

The data collected for this study will be stored securely and only I will have access to it, although I will share and discuss the data with my PhD supervisors as needed. In addition:

- audio recordings will be destroyed and/or deleted once the PhD has been awarded;
- computer files will be encrypted and the computer itself will be password protected;
- at the end of the study, hard copies of meeting notes and other documents will be kept securely in a locked cabinet at Lancaster University for ten years and then destroyed;
- any reference to identifiable individuals in the typed version of the interview will be made anonymous. I may use anonymised direct quotations from your interview in reports, presentations or publications from the study but no names, or potentially identifying general information, will be attached to them;
- if you think you would be identifiable from the general information collected about you (if, for example, you are the only person in your role at the hospice) this information will be treated as confidential and will be kept separately from the interview data.

There are some limits to confidentiality. If what you say to me during the interview makes me think that someone is at significant risk of harm, I may have to speak to my supervisors and/or, if appropriate, your line manager about any actions which might be required. We will discuss this again at the start of the interview.

What will happen to the results?

A summary progress report will be prepared for the hospice management after analysis of the data collected in the study.

The project is an academic study and I will use the results together with my own analysis in a PhD thesis. This will be submitted to Lancaster University for assessment. I may also compile articles for academic or professional journals and/or give presentations.

Are there any risks?

I don't anticipate that there are any risks associated with you taking part in the group interview, although you may feel that participation will increase your workload.

However, if you experience any distress following participation you are encouraged to let me know and speak to [name] at the hospice who will be able to provide you with confidential support.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. Any expenses you incur in participating will be refunded and refreshments will be provided.

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.

What should I do now?

If you have any questions about the study, or you would like to volunteer to take part, please contact me, Caroline Redhead; c.redhead@lancaster.ac.uk

Alternatively, please contact either of my supervisors at Lancaster University;

Professor Katherine Froggatt; k.froggatt@lancaster.ac.uk

Dr Sara Fovargue; s.fovargue@lancaster.ac.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 me, you can contact:

Dr. Mark Limmer: Division of Health Research, Faculty of Health and Medicine
Lancaster University

LA1 4YG

Tel: (01524) 594154 Email: m.limmer@lancaster.ac.uk

If you wish to speak to someone outside of the Palliative Care Doctorate Programme, you may also contact:

Professor Roger Pickup: Associate Dean for Research,
Faculty of Health and Medicine (Division of Biomedical and Life Sciences)
Lancaster University

LA1 4YG

Tel: 01524 593746 Email: r.pickup@lancaster.ac.uk

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



**EXPLORING DECISION-MAKING IN A HOSPICE CONTEXT
FOR PATIENTS WHO LACK OR ARE LOSING CAPACITY**

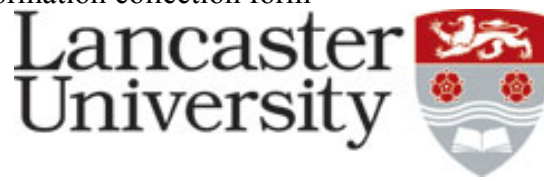
Indicative individual interview guide

The following is a list of the issues which we might discuss in the interview:

- Your role in the hospice
- What interested you about the project and why you wanted to participate
- Decision-making as a part of the care you provide;
 - What type of decisions
 - How you decide if someone is capable of making the decision
- How you make a decision in a patient's best interests
- What do you think the patient's role in the decision-making process should be?
 - How important are the patient's wishes and feelings?
 - What if you disagree with the patient?
- What role do you think the patient's family/friends should have in making decisions?
- Do you think a good relationship with the patient is important when it comes to making a difficult decision? Why?

Thinking about decision-making processes which you remember particularly, tell me the story of two decisions from start to finish, thinking about the issues mentioned above in the context of each decision. If you felt strongly about any particular part of the decision, please explain which part and why.

M: Demographic information collection form



**PROJECT: EXPLORING DECISION-MAKING IN A HOSPICE CONTEXT
FOR PATIENTS WHO LACK OR ARE LOSING CAPACITY**

Demographic information collection form

Please complete the form below. You are not required to give any information which you prefer to keep confidential. This information will only be used to give a general description of the study participants and will not be used to identify any individual participant.

Please delete as appropriate:

Group interview participant

Individual interview participant

Please circle as appropriate:

M

F

other

Age:

Ethnicity: please describe

Current role in the hospice:

Appendix 8: Group interview templates (all versions)

Initial template: Group Interview 1

- 1. Role of the individual**
 - 1.1. The patient as the context of care
 - 1.1.1. Narrative knowledge
 - 1.1.2. The decision as a journey
 - 1.2. Staff as professionals and people
- 2. Collegiate approach**
 - 2.1. Listening and hearing
 - 2.2. Testing the process
 - 2.3. Supporting relationships
 - 2.3.1. “A problem shared is a problem halved”
 - 2.3.2. Us and them?
- 3. Role of law**
 - 3.1. Legal consciousness
 - 3.1.1. Law as a shield
 - 3.1.2. Law as a resource
- 4. The Hospice Movement**
 - 4.1. Distinctly different?
 - 4.1.1. “The acute”
 - 4.2. Experts in the field
 - 4.2.1. Unconscious competence
 - 4.2.2. Guardian of a proper process
 - 4.2.3. Educator and innovator
- 5. Place and Distance**
 - 5.1. “Ceiling of care”
 - 5.2. Going home
 - 5.3. Resilience
- 6. The significance of time**
 - 6.1. The MCA journey
 - 6.1.1. “Habitus”
 - 6.1.2. learning from experience
 - 6.2. The patient before
 - 6.3. “A doctor who is not in a hurry”

Initial Template: Group interview 2

- 1. The individual in the decision**
 - 1.1. The patient as the context of care
 - 1.1.1. Narrative knowledge
 - 1.1.2. The decision as a journey
 - 1.1.3. “Compassionate paternalism”
 - 1.2. Staff as professionals and people
- 2. Collegiate approach**
 - 2.1. Listening and hearing
 - 2.2. Testing the process
 - 2.3. Supporting relationships
 - 2.3.1. “A problem shared is a problem halved”
 - 2.3.2. Us and them?
- 3. Role of law**
 - 3.1. Legal consciousness
 - 3.1.1. Law as a shield
 - 3.1.2. Law as a resource
- 4. The Hospice Movement**
 - 4.1. Distinctly different?
 - 4.1.1. “The acute”
 - 4.2. Experts in the field
 - 4.2.1. Unconscious competence
 - 4.2.2. Guardian of a proper process
 - 4.2.3. Educator and innovator
- 5. Place and Distance**
 - 5.1. “Ceiling of care”
 - 5.2. Going home
 - 5.3. Resilience
- 6. The significance of time**
 - 6.1. The MCA journey
 - 6.1.1. “Habitus”
 - 6.1.2. learning from experience
 - 6.2. The patient before
 - 6.3. “A doctor who is not in a hurry”

Final Template: reviewed during the analysis of both Group Interviews

- 1. The individual in the decision**
 - 1.1. The patient as the context of care
 - 1.1.1. Narrative knowledge
 - 1.1.2. The decision as a journey
 - 1.1.3. “Compassionate paternalism”
 - 1.2. Staff as professionals and people
- 2. Collegiate approach**
 - 2.1. Listening and hearing
 - 2.2. Testing the process
 - 2.3. Supporting relationships
 - 2.3.1. “A problem shared is a problem halved”
 - 2.3.2. Us and them?
- 3. Role of law**
 - 3.1. Legal consciousness
 - 3.1.1. Legal conscientiousness and the liveability of law
 - 3.1.2. Law as a shield/resource
- 4. The Hospice Movement**
 - 4.1. Distinctly different?
 - 4.1.1. “The acute”
 - 4.2. Experts in the field
 - 4.2.1. Unconscious competence
 - 4.2.2. Guardian of a proper process
 - 4.2.3. Educator and innovator
- 5. Place and Distance**
 - 5.1. “Ceiling of care”
 - 5.2. Going home
 - 5.3. Resilience
- 6. The significance of time**
 - 6.1. The MCA journey
 - 6.1.1. “Habitus”
 - 6.1.2. learning from experience
 - 6.2. The patient before
 - 6.3. “A doctor who is not in a hurry”

Integrative theme: **Compassion**

Appendix 9: Individual interview templates (first and final versions)

Hospice 1, Individual 1

1. Time

- 1.1. The MCA Journey
 - 1.1.1. 'the current culture'/old school new school 4, 5, 6, 7, 12, 20, 22
 - 1.1.2. habitus/experience as a barrier – 21, 39, 51, 54
- 1.2. Change over time as a factor of care – 16, 17, 18 45, 58, 77
 - 1.2.1. Going home 98
- 1.3. Time as a resource 14, 17, 18, 47
 - 1.3.1. Time and patient-centred care 16, 17, 18, 45, 77
 - 1.3.2. The luxury of time 46
 - 1.3.3. Time to learn 57
- 1.4. Time as a commodity – 47, 68

2. Patient Narrative

- 2.1. Active listening -24, 78, 90/91,
- 2.2. Perspectival imagination 66/67, 27, 28
- 2.3. As a factor of decision making – 49, 73, 86
- 2.4. The nature of care 90/91, 99, 29, 37, 48
 - 2.4.1. A “care package” 63, 14-17, 27

3. Circles of care 59,61, 74, 75, 94, 95

- 3.1. Communication is key 63,70,81, 97 (creating pictures)
 - 3.1.1. “yes but no” 71
 - 3.1.2. the limits of knowledge 89/92 and 32/34/41
- 3.2. the role of the MDT 84, 85, 106
- 3.3. Perspectival imagination 65, 66, 88, 91
 - 3.3.1. “You’re the bridge” 82, 83 [and 56]

4. Everyone sees the world through different eyes

- 4.1. Different people, different perspectives – 19, 40, 42, 57
- 4.2. I need to be able to sleep at night – 101, 102, 103

5. A balance of power

- 5.1. The Doctor was God 9, 23, 12-16 [and nb 78 – we talk too much)
- 5.2. “A little bit of me” 84/5

INTEGRATIVE THEME: legal consciousness 30, 33, 35, 38/9, 50-52, 72, 104

Individual Interviews: Final template (further modified during analysis)

- 1. Circles of care**
 - 1.1. Patient at the centre
 - 1.1.1. Patient Narrative
 - 1.1.1.1. Active listening
 - 1.1.1.1.1. “yes but no”
 - 1.2. Information/Communication
 - 1.2.1. the limits of knowledge
 - 1.3. the role of the MDT
 - 1.3.1. The effect of place
 - 1.4. Perspectival imagination
 - 1.4.1. “You’re the bridge”
 - 1.5. MCA process as part of good care
 - 1.5.1. I need to be able to sleep at night
 - 1.6. Compassionate community
- 2. Place**
 - 2.1. Nature of care
 - 2.1.1. Inside the hospice
 - 2.1.2. outside the hospice
 - 2.1.2.1. ‘ceiling of care’
 - 2.1.2.2. The hospice ‘in the real world’
 - 2.1.2.3. A “care package”
 - 2.2. The role of the patient in the decision
 - 2.3. Home as a place of care (shared responsibility)
 - 2.3.1. Home as a risk
- 3. Time**
 - 3.1. The MCA Journey:
 - 3.1.1. ‘the current culture’ /old school new school
 - 3.1.2. habitus/experience
 - 3.1.2.1. as a barrier
 - 3.1.2.2. as an ability to improvise
 - 3.1.3. changing nature of the team
 - 3.2. Change over time as a factor of care
 - 3.3. Time as a resource
 - 3.3.1. Time and patient-centred care
 - 3.3.1.1. Time as a barrier to care
 - 3.3.2. The luxury of time
 - 3.3.3. Time to learn
 - 3.4. Time as a commodity
 - 3.5. Remembering
- 4. Everyone sees the world through different eyes**
 - 4.1. Different people, different perspectives: multi-perspectival
 - 4.1.1. Perspectival imagination
 - 4.2. I need to be able to sleep at night
- 5. A balance of power**
 - 5.1. The Doctor was God
 - 5.2. “A little bit of me”

INTEGRATIVE THEMES: the nature of care *and* legal consciousness

Appendix 10: Working version of the ‘synthesising’ template, with italicised notes

1. People and the decision-making journey

- 1.1. The patient and the patient’s story [*relational aspects, narrative approach, non-linear, compassionate paternalism: link to narrative wormhole*]
- 1.2. Circles of care [*multi-perspectival, relational approach, expanding the patient’s story beyond the patient, offering care to the people intra-related to the patient: includes staff members and the MDT*].
- 1.3. A little bit of me [*folding – patient/staff member fold into the story of the patient’s care: relational process which informs a patient-centred decision*]
- 1.4. Organisations as people [*in solidarity?*] [*multi-perspectival, compassion as a relational process which describes organisational context*]

2. Place, space and time

- 2.1. Hospice, acute, community and home [*place, space and power, paternalistic hospice – driven by compassionate paternalism? Place and time as distinguishing factors in the nature of care*]
- 2.2. Me, myself and I: the narrative wormhole [*The nature of time: folding*]
- 2.3. The decision-making journey [*Habitus, expertise, experience: conditions of possibility for a re-balancing of relational power linked to willingness to embrace change, historicising of the present*]

3. The Role and Nature of law

- 3.1. Care, compassion and law [*MCA key concepts from a relational perspective, ethic of care, compassion, relational aspects, re-imagining rights as relational*]
- 3.2. Legal consciousness [*develop towards legal conscientiousness, moral context, weight of experience to counter the weight of the law*]

Integrative themes

- I. Compassion (Legal contextual review/Group Interviews)
- II. Nature of care (Individual Interviews)
- III. Legal consciousness (Individual Interviews)

**Appendix 11: Sample interview transcripts with
 comments and developing codes**

Hospice 1: Group interview 19.12.17

For the tape recorder this is Caroline Redhead. I am talking to my first group interview at a hospice about the policy and procedural approach to the MCA.

December 19th [2017]. Thank you very much everybody for coming.

Have you got any other questions about the material you have had and that you have had to read that you would like to ask before we start?

[no...]

Has everybody had a chance to look at the Group Interview Discussion Guide?

[yes]

I have got some other copies if you would like... would you like another one?

[yes]

The discussion guide is just – I have just set out some things I think it would be interesting to talk about but it is not intended to be restrictive.. um ...so if there are any other issues that you think it would be interesting to talk through then, you know, please just introduce them...

So my first one is just the general legal context...of the MCA and how it is interpreted in the hospice context. If anybody has got anything they would like to start off with and say...

[thank you]

...about that, whether the hospice is a particular context, or how you as a hospice interpret...the various requirements... I know that you begin with...in your policy you start off with the principles... the five principles being listed there at the front and being interpreted for your hospice...would you like to say anything about that?

Commented [CR1]: Role of legislation: the 5 principles are taken into the Hospice's policy straight from the MCA

Participant 1

I mean, yeah, it's very useful to have it.... In terms of reminding ourselves what the principles are... I think... whenever we've had a situation where...where there has been kind of a need to think about... in a bit more detail about the Mental Capacity Act and how that relates to that particular patient, I think we have tended to then all come together at that time and then kind of think about the specifics for that situation and things and then refer at that point to the policy... it's quite useful to have it there and to have an awareness and understanding of it...but try to put it very much...look at each situation individually and kind of try to take a group..kind of team-based approach where possible which I think has worked...really well...certainly I think has worked very well and in terms of us as a clinical team on the ward, then involving different doctors, nurses, nurse practitioners but it has always then been really helpful to then bring [Participant 2] on board as..kind of... Head of Clinical Services at that point just as an extra person to be...especially when they are quite complicated situations...which we have had quite recently is really helpful...um I am not sure that's really answered your question?

Commented [CR2]: Role of law: Positive approach to the law

Commented [CR3]: Patient and situation specific

Commented [CR4]: Collegiate/team based approach: NB inpatient unit

Commented [CR5]: Role of law: positive approach to the law

Commented [CR6]: Decision-specific application

Commented [CR7]: Team approach

Commented [CR8]: Inpatient ward: always team based

Commented [CR9]: Senior involvement in the process where necessary

Commented [CR10]: MDT in practice: collegiate approach

Researcher [and general laughter]

No, no that's fine... doesn't need to be answered it's just really a general discussion about how it works and how you interpret it in the context of the organisation, you know, that's the... the... I am trying to look at it on two levels... one is the organisational level to see how, you know, you craft your policies based on the MCA and how the education flows out of that to staff members and the next stage will be to talk to individuals about how they personally make decisions with... with patients who have to make decisions about certain things. So for this group it would be great just to hear about... about how the organisation you know works... um

Participant 1: yeah

Participant 2: The policy which is in place was... written... before... quite a number of people were in... we've had some staff changes... so when I started this was in its final stages of being developed by... predominantly by two of the doctors that were here before us... And [to Participant 6]... so you would be just coming into... post at that time as the nurses had quite a bit of involvement but... it was fairly well framed... framed up at that time... But I know it had been created through a lot of discussion... um and also... um... with our links to [St John's Hospice]... drawn upon their experience because they already had [..... coughing]... and one of their doctors worked... a bit across the two hospices... so, um, that's what I know of the creation of the existing policy... um ... but we draw upon other guidance when we need it as well, don't we...

Commented [CR11]: The collegiate approach extends to interpreting the MCA into the policy. Discussion/communication and input from across the Hospice team

[Yes...]

So we have examples of slightly different situations and we've then gone and looked at what other Trusts...local trusts and other trusts...and organisations have said about more specific situations to help inform our practice...so I don't think we feel... constrained... we feel guided by this but not constrained by it...

Commented [CR12]: No complacency – developmental approach: willing to take advantage of others' experience.

Commented [CR13]: Role of legislation: positive and facilitative. Helpful and not restrictive

[Yeah, yeah...]

Participant 3: Yeah..I think that... dealing with patients who lose capacity...we deal with a lot of the time and most of the time it's routine without actually having to think about the policy...although we know the legal stuff it's not something we necessarily...go through step by step with every patient who loses capacity for example a patient who's come into the hospice for end of life care and becomes less well and then isn't able to communicate decisions about...with a syringe driver or medications...and then we generally...try and sort of develop a good relationship with the ...close family members... and that's what generally guides what...what we feel would be in the best interests of the patient through knowing the patient before they lost capacity and discussions with...discussions with family and close friends...

Commented [CR14]: Theme of unconscious competence? Article about experienced clinicians and unconscious competence
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5056026/> It's embedded knowledge: second nature

Commented [CR15]: Unconscious competence

Commented [CR16]: Importance of relationship building and communication as a tool both to build the relationship but also to facilitate the implementation of the MCA best interests assessment. Embedded understanding of the MCA which guides practice. Implementation is compassionate:

[yep]...

and [working] with the nursing staff as well without always necessarily going through...referring to a policy ...you know going through the steps for capacity because by that time its quite obvious that they don't have...

Commented [CR17]: Embedded awareness – unconscious competence

[yeah, yeah]

capacity... and

Participant 1: tending to be when there's much more complicated...complex situations

Participant 3: yeah more complex....complex... or if there's tension or conflicts...um between...um..family, nursing staff, medical staff...um that's when guidance in the policies...and sort of...wider guidance that's available... such as GMC becomes quite useful

Commented [CR18]: Complexity or conflict: policy/legislative/regulatory guidance useful. Role of law: is the law a shield here? [Kitzinger paper <https://onlinelibrary.wiley.com/doi/full/10.1111/lest.12042>] Make sure that the complexity is properly worked through by reference to the MCA checklists

Researcher: does that happen quite frequently...that there's conflict...or?

Participant 3: Pretty infrequently to be honest...it's not...it does happen but you're talking every few months rather than every few days or weeks I'd say...

Commented [CR19]: So a consciously policy/legislation driven approach is uncommon. Mostly the knowledge is embedded: unconscious competence

[Yeah, yeah...]

Participant 1: I think it's probably the type of situation where we could...you know there are...a few examples which we probably could all talk about the same examples...kind of few key examples that have been very complicated that have involved a big team discussion and kind of a lot of work around them...but like

Commented [CR20]: Team approach/sharing of responsibility/ everyone equally aware of where the legal issues might lie

[Participant 3] says not... on a daily basis or on a weekly basis it's not kind of as complicated as that...

Commented [CR21]: Complexity also requires a team-approach. MDT input

Participant 2: And I think in these more complicated cases that's...um... where we maybe record...against headings

[Yeah]

and it's just, you know, to make sure we've looked at it [yeah...] y'know really comprehensively and we've not missed any ...perspectives or key

points...particularly when we are looking at best interests decision-

making...um...would you say when we are maybe a bit more ...rigorous about

showing the process on the best interests and...in..after your MDT [multi-disciplinary team] meetings you would often do a capture, wouldn't you, um...round a patient in relation to

Participant 3: yeah...it's not a complex or if it's conflict or if it's a bit of a grey area as to whether a patient has capacity or not and there's an important decision to be made and then we do certainly always make sure there are discussions...and careful

how we document it whether someone had capacity or not by....by [...]

Participant 2: We've got a fairly recent appointment...coming up for a year now...

we've got a social worker in our team...so she will um be involved in, uh, quite a lot of that...quite a useful person for the individual interview

[yeah, yeah...]

...and...she's brought a useful perspective in as well. She does quite a lot of the

individual work at times when, uh, uuuh, yeah - when there are challenges,

particularly when there are challenges with families, you know may be different

perspectives

Commented [CR22]: Law as a shield: shield for the patient and for the hospice?? Embedded understanding of the MCA = awareness of the situations when a detailed approach is required.

Commented [CR23]: Granular approach: thorough and focused

Commented [CR24]: Showing the process: concern is not that the process would be incorrectly carried out but that the evidence of the process is clear and thorough. Role of law here: shield?

Commented [CR25]: The discussion is distinct from...

Commented [CR26]: ...the evidence.

Commented [CR27]: Collegiate decision-making – inpatient unit

Commented [CR28]: Embracing holistic, multi-faceted approach. Does this reflect the nature of hospice care? Deliberately holistic in approach

Commented [CR29]: Challenges/different perspectives – disagreement about the best decision?

Researcher: And is that just for non-medical decisions or does she assist kind of across the board of different decisions?

Participant 1: Certainly we wouldn't exclude her...from that. I mean we tend to... kind of if it is a complicated decision... anyone that has been involved at all is useful to have in the discussion but I think that [social worker]'s role is mainly around... certainly if there's an issue about discharge planning and capacity and decisions about home and things...that's kind of been very helpful but yeah I don't think we necessarily exclude her from anything in particular.

Commented [CR30]: Collegiate, holistic approach

Commented [CR31]: Decisions about place of care: new theme – significance of place?

Researcher: And do you usually have the same process for decisions that are hospice at home, you know, patients that aren't resident in the hospice? Is that a similar process or are there different things that...

Participant 1: That's a bit trickier because ...patients are, they're kind of medically... it's the GPs that are medically responsible for them and their care in the community...and I suppose that we're...the hospice at home girls going in are kinda...working alongside the district nurses and the MacMillan nurses...but certainly that's a very different set-up in the community compared to us being clinically, medically responsible for the patients in the in-patient unit

Commented [CR32]: Significance of place

Commented [CR33]: Legislative context is the same: context of care is different. Significance of place in terms of the role of the hospice

Participant 4: Same thing with the day services really

[yeah, yeah]

as the GPs and the district nurses are um you know we're not necessarily responsible for that clinical side, responsible perhaps for what happens within this room but not necessarily for what happens...but obviously we're guided by all the principles anyway but also then really if we have any concerns take it back to the GPs, GPs the district nurses in regard to obviously obviously in conjunction with whoever it is that we might have a concern about really.

Commented [CR34]: Role of the hospice as expert in the context of the MCA?

Participant 2: We've very recently had a situation, um, a patient in the community with a high level of complexity really and we had um, a case conference, didn't we, with the GP and um... you and I went from the hospice plus a hospice at home nurse, a district nurse to try and get that all round um representation...and, um, there was some talk in that meeting about you know capacity and then...and then it..it was a very difficult situation around best interests, wasn't it,

Commented [CR35]: Hospice as expert. Hospice does not have clinical responsibility here but acting as guardian of the proper process

[it was...]

and I think we were sort of able to advise...

Commented [CR36]: Hospice as expert

Participant 1:... I think we were able to maybe kind of, be a bit more forthcoming...that capacity needs to be assessed and this is why we think it needs to be assessed... and kind of putting forward arguments for things that we felt should be done in that situation but...and actually we'd offer to... help with that but the GP was very much wanting to take the lead in that situation...which was fine...

Commented [CR37]: Hospice as expert: "forthcoming" – insistent and requiring compliance??

Commented [CR38]: Unspoken impression is that the GP's expertise is less than that of the Hospice

Participant 2: But I think you were, you were, you know, very supportive but directive around things needing to be documented around uh the discussions which had been had with the patient...and um...the advance planning and being very clear about the um...the potentials...

Commented [CR39]: Hospice as guardian of the process

[talking over each other a little here]

Participant 1: there was an advance decision wasn't there...

Participant 2: yes but...

Participant 1: that had been put in place but it wasn't ...it wasn't really very specific to...to the things that might actually happen to this patient so we kind of just suggested that maybe... that was re-done with kind of more specific things...more kind of examples of what could go wrong

Commented [CR40]: Hospice as expert: in both the process (guardian of the correct process) but also the patient's likely trajectory in terms of progression of the illness...

Participant 2: yes....which is specific...which is where in situations that we perceive may very well happen...and that was...that was all documented and that was...that was useful and so...we will get involved in a multi-disciplinary capacity

Commented [CR41]: Guardian of process. Underlying impression is that the law is used as a shield here. Shield for the hospice (as evidence of the correct process) but also shield for the patient: if the advance decision is not specific to the particular types of treatment/decisions then will not be effective

[Participant 1 – yeah, yeah]

into the community like that...but it's not...it's not that often is it?

Commented [CR42]: Significance of place

No, no

Researcher: so do you start having those conversations when somebody is admitted?
Does the conversation about what they might want or what their thoughts or feelings are...does that start at kind of an early stage when somebody comes into the hospice?

Participant 3: Yeah, yeah...um...we try to do ... sort of planning for...because we don't have medical cover at the hospice 24 hours then that's a useful way of introducing us to...so that if something was to happen overnight and the GP got called for example would they or would they not want to go to hospital...or...something along those lines...um

Commented [CR43]: Significance of place

Commented [CR44]: Significance of place

Participant 1: Kind as the ceiling of care, really so that's kind of...and I think that's not something we've always been brilliant at but I think we've got a lot better at now...em that's trying to work out what's, yeah, the ceiling of care for that person and really that does need to be decided kind of on admission along with obviously a resusc. decision for that patient...em to guide the nurses as like [P3] said there's not anyone from 6.30 at night until 8 am the next morning kind of hospice medical cover...em... so I think that's been...that's been helpful but it's always you know a good opportunity if appropriate to kind of explore whether they've got any other advance decisions and stuff but whether that's done on day one or whether its done over the next... very much depends on the individual and what's hapenning with them really...what's the main problem...em...

Commented [CR45]: Dynamic practice: MCA journey

Commented [CR46]: Patient focus in the context of organisational capacity to care being limited

Commented [CR47]: Patient-specific and patient focused. Embeds the EI focus from phase one into organisational practice

Commented [CR48]: Time is a factor: significance of time in Hospice care

Researcher: When you say “ceiling of care” what does that mean...sorry?

Participant 1: So that means like [P3] said, kind of how active do they want the care to be...we wouldn't treat infection with IV antibiotics here in the hospice so if they kind of became septic overnight would they want us to ... there's an out of hours GP that covers...would they want us to call them out and actually would they want to go to hospital for IV antibiotics if that was clinically indicated...or...or not, and quite a few patients kind of decide that actually they don't want to go back to hospital for any reason whatsoever so it's just kind of eh making sure they're aware of what we can and cannot do here in the hospice setting em and what their thoughts are on going to hospital should anything um should anything kind of happen...em overnight really.. but obviously that can be refused depending on what's happened with them and if they em deteriorate and become less well ...then... then that might change but on the nursing handover sheet there's kind of...em a box for the resusc status what the ceiling of care would be just to help try and guide the nurses really...em...out of hours

Researcher: Do you have those kind of conversations with the families as well? Or usually mostly with the person themselves...the patient themselves?

Participant 1: I think it depends on..on the situation really, certainly try and include families where at all possible but...but yeah...everyone's different. I mean most people probably bring someone with them when they come in to be admitted...and

Commented [CR49]: Active not palliative??

Commented [CR50]: Significance of place

Commented [CR51]: Significance of place: “ceiling of care” in the hospice

Commented [CR52]: Ceiling of care

Commented [CR53]: Patient focus and significance of place: ceiling of care

Commented [CR54]: Situation specific decision-making

usually you're having conversations with families when you're admitting someone but not 100% of the time but...but yeah you try to include families if...if patient was happy with that...em yeah...kind of do whatever was appropriate at the time really...but usually there is some sort of family discussion on day one

Commented [CR55]: Supportive process: supportive decision-making as a part of that? This is not necessarily where capacity is lacking: just the general approach

Commented [CR56]: Patient-centred in approach

[yeah, yeah]

Researcher: And if there are complicated decisions to be made how does the process work – in terms of assessing the capacity of the patient and, you know, seeing whether they are going to be able to make any aspects of those decisions themselves before you move to a best interests approach and how does...how does that kind of work in practice?

Pause...

Participant 3: Normally...you wouldn't necessarily follow it... unless you had... doubts about a person's capacity then you wouldn't necessarily formally go through a process of assessing it... you would ...for example when you were admitting someone normally if you had any doubts about somebody's capacity you would probably... pick them up as you...you went through and then probe further if you had concerns...um...where that might be sort of just...testing how much they could retain information...by...seeing if...like check if they remember something you talked about at the beginning of the assessment ...or...em or asking what...if...testing if they can make a balanced decision or if maybe asking if you could see any problems with a) or b) or... what the.... you know possible risk or benefits of option a) or option b) might be and that's sort of the kind of things we do to..to test

Commented [CR57]: This describes an embedded consciousness of the legislative requirements. Unconscious competence. Cf lines 2-4 above.

Participant 2: So I think we quite often have patients who have, um, potentially fluctuating

[Participant 3: yeah]

..levels of ability to...to make decisions and that can be, um , medication related or situation related and, uh, so it's revisited then, regularly, isnt it...

Participant 3: yeah exactly it's, yeah. It also depends on the decision because somebody might have the capacity to make a decision about what they want for their breakfast butum... *[don't necessarily a formal]* assessment to see if...when there's a big decision to be made and ...there's doubt and that's when you're probably more keen to properly explore it.... You wouldn't necessarily if there wasn't any big decision to be made straight away you wouldn't necessarily do a formal assessment of capacity because it has to depend on what the decision is.

Commented [CR58]: Unconscious competence

[Pause]

Researcher: And as the relationship with the patient develops then presumably that will become...you know, part of your general knowledge base...going forward anyway?

P3: Yeah

P1 I think ...the times...the kind of examples I can think of ...when we've kind of got to the point of formally assessing someone's capacity, there has been a very obvious

decision that that's been around so kind of a patient who'd come in ...em...who'd then wanted to go home but there was a lot of concerns about his home environment and the safety of being at home... and there was a very complicated situation really, so actually that was...and even, like [P2] said somebody who was quite fluctuating at the time and so that was important to kind of actually look very much specifically at that decision around going home and actually he was somebody who we assessed... and [PX] went to assess his capacity...em...on one day...and he did not have capacity with regard to the specifics around going home, but actually was kind of withdrawing from medication...em... and clearly had been taking a lot more at home than we thought he had been taking so when we gave him more medication the next day he was like a different person...and then we re-assessed his capacity he then actually did have a capacity to then make a decision around going home in a way that he couldn't have done the day before and so I think...we certainly have an awareness of trying to maximise someone's capacity ...and the fact that we might then need to re-assess that later depending on what's going on...but I think it tended to come up when there's been a specific... decision...that we've been kind of assessing for really....I think...from examples that immediately come to mind.

Commented [CR59]: Significance of place: here it is the place of care. Balance of risk. The higher the perceived risk the more formal the approach. Law as a shield.

Commented [CR60]: Is this conscious competence? The higher the risk the more conscious the compliance has to be with the legislative requirements?

Researcher: And how do you see the patient's role in the process, in the decision-making process?

P1: I mean I think it's always key to try and learn as much as you can about that patient and...um.. what their wishes are and what...what...you know for him, what was it about being home that was...that was kind of so important and trying to get to

the crux of what was driving him to want to go home when clearly some people were very worried about him being at home... em and what... and trying to get as much information from other family ..you know other people involved in terms of...you know...exactly why are we worried about that situation and stuff and trying to get as much detail as possible...but...em...yeah, I think the patient's wishes are always very key and we always try to keep that in the very centre of the whole process....em...yeah. I think it's always been helpful to kind of work through you know a kind of logical fashion em..to make sure you're doing everything you can to optimise their capacity and re-assessing that when you need to and things and if it does come to a best interests decision then actually taking on board everything you know about what the patient wanted... em from as many sources as possible, really, em, I think we've tried to do that where we can

Commented [CR61]: Patient focused approach. Analysis of the decision-making capacity is focused on the reasons to go home from the patient's perspective

Commented [CR62]: Patient centred process

Commented [CR63]: Legislative process is embedded

Researcher: Do you have difficulties with communication... in general or is it usually... are you usually able to ...have some kind of contact with the person where you can understand what they want and they can understand what you're asking? So as a slightly separate issue from the capacity, do you have problems with people who may be quite ill...you know telling...letting you know what they want or letting you know how...

[Yeah]

P5: There are lots of communication difficulties with patients aren't there, for lots of different reasons. I mean certainly in the Living Well afternoon at the moment we have..... a couple of people at the moment with neurological problems who have a lot of difficulties making themselves understood because of the neurological difficulties really...and it's actually helping them, as much as you possibly can, you know,

to...to... so, you know so that we can communicate effectively with them...albeit how do we do that...do they have different methods...you know, are they, you know have they got different ways of communicating, different boards or various things...

[communication boards]

...different communication aids, you know, but not everybody always manages to use them do they? So it's obviously, you know, it's making sure that you really have a full understanding... and, you know, a good knowledge of that person...and try and find out as much about them as you possibly can so that...you can help them to be supported to make ...ah..because the fact that you can't understand them doesn't mean to say... you know, they've got full capacity....it's just that it's just that making it understood, isn't it?

Commented [CR64]: MCA embedded in practice.

Researcher: So from the Living Well perspective, what...what kind of decisions would be made in...in your area?

P5: I have to say not very complicated ones really. It's...I mean we do have quite a lot of people in who...you know have..have a dementia-like illness, so in some respects may not have capacity necessarily to make, you know, perhaps financial decisions or various things like that but on a day-to-day capacity, you know, they definitely have capacity for the things that we're asking around day care and ...and what do they want to do, where do they want to sit...there's, you know its not hugely complicated really from that decision-making... but obviously if it did get to that stage... you know obviously there would be a wider, multi-disciplinary sort of

Commented [CR65]: Unconscious competence: decision-specific approach as standard

engagement...engagement with that...but not for a while, for a long while, have we really needed to do that really....so you know it's just supporting people as much as you possibly can for them to get, you know, their...their thoughts and their wishes, you know what they what they want really.

Commented [CR66]: Collegiate, team-based decision-making . Day care setting: in the hospice. Significance of place.

Researcher: And does that cover non-hospice resident patients? Does that cover care in the community and hospice at home patients as well?

Commented [CR67]: Compassion- role of law? An interpretation of therapeutic jurisprudence in the implementation of the MCA framework in the context of everyday decision-making but in a compassionate way. Also EI coming out of the legislation and into organisational practice

P5: I don't really deal with that nowadays so...

[They all live at home]

P5: they just come here for the afternoon and then they...they go away but generally the assessments that we do are usually done at home in their home setting, you know, and you get a bit of an idea of what's going on and how they're being looked after and you know what they need...at that point really and then what we can possibly help them with further...but it's usually with all the community services really rather than... you know, and other hospice services as well being referred into as well isn't it, so...

Commented [CR68]: Significance of place. Does it affect the nature of decision-making? Does it change the balance between empowerment and protectionism?

Researcher: So how much do you think supported decision-making...takes place in the hospice?

P2: Well I see a lot of it and as [P5] says I am sometimes called in to support – well it's complexity – but um, but equally I see a lot of um, er, people talking together... talking with families, talking with patients and um, er...you know my feeling is that

Commented [CR69]: Supported decision-making in the context of the MCA framework

it's ..it's done very well in terms of different staff that are involved as well as the patient and key family members...and it's documented well, and it's very well reviewed, regularly so that assumptions are not made that that's the position...you know, but that it's..er revisited. But as [P5] says it tends to be around the big decisions...er..., that you can maybe see... a slightly more... erm... slightly more of the process is overt. Whereas its in situations [P3] was discussing these are happening while you're assessing the patient anyway, aren't they, they're kind of inherent and inbuilt into your approach. Erm and it would only be that if ...erm... a concern is raised and that decisions are needing to be made, such as a discharge or ...I'm just trying to think if we've had any around treatment... refusal, you know suggestions being made about what would be best in terms of treatment and the patient not wanting...not wanting that. We've not had anything that has escalated up to a big... up to a high level, in that regard have they, because you do those adjustments and compromise along the way, don't you...

[Yeah, yeah]

Researcher: so you think that's probably because of your relationship with the patient that you get to that stage?

P2: Yes

Researcher: And everybody's kind of on board with the way the decision's going?

P2: Yes

Researcher: Rather than feeling that they are having a..a decision that's medically best for them... imposed on them kind of thing

Commented [CR70]: Assumptions are not made: the decisions are genuinely based on the wishes of the patient and family. Do the patient's wishes take precedence?

Commented [CR71]: Communication in decision-making: collegiate decision-making

Commented [CR72]: Big decisions – increased risk – conscious adherence to the process – role of law as a shield. The evidence protects the decision-making process as well as the patient.

Commented [CR73]: Unconscious competence: "inherent" cf "overt"

Commented [CR74]: Time is a factor here ("along the way...") and also the feeling that the decision-making process is a journey. Also communication and compromise. So negotiation is a factor. Significance of place in terms of a willingness to take this approach.

P2: Mmmm. Yes, yes. Well I have certainly got..get that sense with not being in with you giving daily patient care.

P1: I mean it's difficult because you don't always have time to...to kind of necessarily have built up a really good relationship. I mean the complicated situation we've had recently was kind of as soon as the patient arrived on the ward...I think there was an appreciation of..this is a very complicated situation we need to look at so we certainly didn't know him or his family very well at that stage...but I think ... em...even still I think we were able to work through the process and kind of ... I think that was a very good example of all working very well together to kind of work out what was in his best interests really...but that was kind of as soon as he arrived...it was an appreciation of this wasn't a very good situation...

Commented [CR75]: "Overt" – immediate recognition of the difficulties. Team response. Still a journey – but an urgent one in this case. Collegiate response. Patient centred.

P6: I think the [process] is always there in the background, you know, doesn't matter what practices you practise, urm, but I don't think we would ever impose a medical treatment on somebody... it would always be... it would be offered but actually it's about what does this person want and what's their preferences and wishes around it...so it's not...nothing's an imposition... it is a two-way discussion and theirs is the final decision if they've got the capacity to make it and if not that's when you get into the more complex... best interests but that again would still be taking into account what do we already know about this person... have they had any thoughts on whether they would want something like this or not so it would still be there in the background taken into account.

Commented [CR76]: Unconscious competence. Hospice as guardian of the proper process.

Commented [CR77]: Role of the individual in the decision-making journey. Role of the hospice.

[Mmm, mmm]

P2: And we sometimes have initial conversations...er...around...what...what are the options and...and what are the benefits and risks of those, you know, so so that when the further conversations are then had with the patient...erm... that's been thought through, so that you can have a much more informed conversation with them about, you know, these are.... From our perspective, these...well these are some of the options that we can see that are, that are possible for you, interested in what you consider the options as well. But patients sometimes need that, don't they, in terms of, you know, what might be possible ways forward so that they can start to....engage a bit more in the choices they need to make...yes they may need to make, you know if it's in terms of whether they...um... where, if they might be needing to move on to either going home or a different care setting....

Commented [CR78]: Decision-making journey:

Commented [CR79]: Role of the patient – notice the emphasis here on the choices the patient needs to make.

Commented [CR80]: Place of care decisions are common. Significance of place in the nature of the decision.

Researcher: Are you able to tell me any more about your difficult decision-making process that you just mentioned. The patient that came in that you didn't know very much about?

P1: I don't know how much...I don't know how much detail I can really go into

Researcher: I don't need any names or anything like that but just what the issues were...would be really interesting...

P2: You don't need to give the diagnosis either but just...

P1: Yeah...yeah. I mean it was basically a patient who was sent...came transferred over from hospital to the hospice for end of life care...em he had been NG feeding – so kind of feeding through a tube...down his nose and that had been stopped in the hospital...em and sent for end of life care when he arrived at the hospice... em... Basically he wasn't...our feelings were that he wasn't necessarily...dying and our concerns really were that the feeding had been stopped in the hospital without...there had been no formal assessment of his capacity and there'd been no... best interests decision, really, that had happened in terms of stopping the feeding and that happened a couple of days before, kind of on the Thursday evening and he came to us a few...er.. five days later. So I think our concerns really were around... kind of... what was in this patient's best interests? Em... We kind of did our own capacity assessment and...and he did not have capacity to make a decision around re-starting the feeding but we were very uncomfortable with... the way in which that feeding had been discontinued... in the hospital setting. So then kind of over... the course of...of a few days we embarked on a number of different conversations, really, with his ...family...em and around around the whole situation really as to whether or not the feeding should be re-started but...that was kind of was not ...an easy decision to make and [P2] had a template really that looked at the different options of kind of re-starting feeding...em... I think the thing that made it quite tricky was they had stopped the feeding but they were still giving boluses of water...em...with the medication...so he was still having something...em..so the options being kind of..em..stopping feeding and stopping boluses of water and stopping everything, doing what we were doing which was [not a very good option] or re-starting the

Commented [CR81]: Hospice as expert/guardian of the proper process

Commented [CR82]: Conversation/communication important to describe the picture as the hospice sees it

feeding and looked at the risks and benefits of each option...and.. and how that would impact on the patient..em....and we had a..a sort of healthcare professional meeting with the nurses and the medical team and nurse practitioners and [P2] was involved in that to kind of think from our perspective what did we think was...in this patient's best interests and then kind of married that alongside conversations with his parents and what their feelings were, really, about the situation...em...which was incredibly difficult 'cause they had just been through this roller-coaster of months in hospital and had been told that he was dying...and...and so it was very...they had been through an awful time really...so ...em...we wanted to get back to them from our perspective what we think is the right...in his best interests for the following reasons and see what...what they thought...what they wanted to do really.

Commented [CR83]: Team exploration of the options at the start of the decision-making journey

Commented [CR84]: Involvement of the family in the decision is described in terms of an intimate relationship

P3: Was tricky because the family were a bit all over the place because of everything they had been through so they were changing their mind about what was...about what was the right or wrong thing to do from hour to hour basically in the first few days.

P6: And quite a lot of their decisions seemed to be based on their ability to cope with him, didn't it

Commented [CR85]:

P1: Yeah...

P6: and that sort of was an element of that, yeah, so it wasn't about what was just in his best interests but actually how they could... what they could cope with and that then makes it a really tricky situation because he was obviously going to be very dependent on them.

P2: And it was such a leap for them to...to go from being almost being given a fait accompli that he was dying and therefore coming to the hospice to die, to the hospice then turning round to say to them that might not be the case... but it wasn't just as straightforward as that, you know...

Commented [CR86]: Significance of place. The way in which the hospice is perceived or introduced as a place to die

P1: Very difficult – because they had questioned the decision the day before, like, in hospital that they didn't think...is he really dying...and things and they'd be told yes he is so then to come here the following day and for us to immediately go actually we are not really sure was *incredibly* difficult for them for the family...em and for us...because you don't obviously want – you are not trying to cause distress and upset but equally I think there was a real uneasiness on our team's part...as soon as kind of we understood a bit more about the situation as soon as he got here really that we needed kind of to look into this a little bit more

Commented [CR87]: Hospice as guardian of the proper process. Hospice as expert

P2: And the best interests...it was challenging at that point because..um..the option to re-start feeding had its own risks attached to it...um so that.. that wasn't...no option was straightforward really

Researcher: And how did that process play out in the end? Did everybody agree with one course of action that ended up being what you...what you did?

P1: We started making a team-based decision – we think it's in his best interests ... When we then kind of communicated with his family they were happy to go with what we were suggesting really. I mean this happened over a few days....Erm...so that's what we did, em, that day...we re-started the feeding...um... yeah...and it was the right... well I think it was the right decision

Commented [CR88]: Collegiate decision-making.

[laughter]

...and he is now back home again. [Pause] But very...very difficult for everyone really, I think. 'Cause I think also it kind of ...by re-starting the feeding...that was embarking on something that's not really within a hospice remit of kind of managing NG feeding and things so actually by doing that then sort of transferred his needs back to the acute setting and...em...there was lots of other factors involved as well but it kind of reached the stage where actually we weren't the right place for this person any more...em ...and had to send him back to the....well it was the right thing to do to send him back to the hospital setting so that these things could be properly addressed in the acute setting which...which was tricky...em... 'cause yeah you want...I think... and I think people found that difficult because obviously we were concerned with what happened in the acute setting in the first place...so...we'd kind of quite a big effort to escalate...things up...to the higher levels at the hospital to try and make that transition back again...as successful as we could do....

Commented [CR89]: Significance of place:

Commented [CR90]: Place of care: significance of place

Commented [CR91]: Hospice as expert/guardian of the proper process

Researcher: And...and when you'd been through that process...what happened with encapsulating what you had done in learning for.. other people, you know, going forward...or for staff training...do you...does your...kind of internal...all of those decisions and discussions that you have, do you then do you do anything with them in..in the context of training...your other members of staff that weren't involved or...that kind of thing?

P2: No, no we really need to try and do that a little bit more. We have de-briefs so um...um we have multi-professional debriefs and we're trying to get that a little bit more robust...and regular but..er yes, there's probably a stronger tie that could be made...um

Commented [CR92]: Learning from practice. Dynamic organisational learning??

P1: With why that went so well...

P2: Yes, yes...with, with learning. I don't know what you feel about that [P4]?

P4: I think that...I think...um.. it's not always needed to look at what didn't go so well but needed to look at what went well, as well, um, and that's...from many perspectives...

P2: Mmmm, mmmm...

P4: So I think, yeah, it just...we we possibly...could be looking at to do a more formal...review of, of what we've been doing and, and using that as, as learning experiences. I suppose it's done in a way informally in that lots of people were

involved in that case, weren't they, so...and...a lot of staff were involved...and so you get it on an informal basis...but maybe just organising that just a little bit more so that...um...you've got more construct...construct to it...in terms of the actual learning...and so that if a situation arised...arose again, and maybe, you know, same team of doctors or maybe other members of the team had changed, then you've actually got a record there of actually...well actually this is this is what we followed...and...and that's how...how it worked, the process we used.

[P2: Mmmm, mmmm – throughout]

Researcher: And why do you think that one did go well, what were the things that you drew out of it that were the reasons why you thought it went well?

P1: I mean I think it felt like we were making a decision....I think what was diff.. what was very difficult about this case was there was a lot of emotion involved on very... lots of people's parts and it was trying to make sure that we were making a decision based on... on...what was in his best interests not on... what you think personally should happen and that was very difficult I think to..tease that out and I think by...and I think that's why afterwards, kind of having a debrief did actually help, predominantly the nursing staff, kind of on an emotional level deal with what...kind of process that I think was probably the number one priority for them. Obviously then we can think about how else we learn from that....but the um... I think that the process that was put in place, certainly the best interests decision, breaking down these are individual...these are the different options and for each

Commented [CR93]: Formal learning vs experiential learning

Commented [CR94]: Hospice as expert. Capturing the learning as an organisational memory

Commented [CR95]: This highlights a difficulty in the overlap between the hospice as an arbiter of appropriate legal decision-making and the hospice as a compassionate organisation providing care. The legal contextual review highlights a conscious separation by the judge of his role as the arbiter of the legal decision-making from the messy proximity to the process in the clinical setting. [P1]'s words here reflect the difficulty of achieving the appropriate balance. This is also reflective of a conscious competence in the MCA process

Commented [CR96]: Role of the hospice as protector of its staff??

option spending a bit of time saying right the benefits would be this, the risks would be this by doing... following this process I think it made it a lot more clear cut that actually the best interest decision for this patient is this for this reason and that's actually taking out anything of what you personally think should happen...em

Commented [CR97]: This is the balance sheet approach

[Yeah, yeah]

P6: I think that's there where having the MCA comes into play..

Commented [CR98]: Role of law: a tool to facilitate the process

P2: Yes...

P6: Because when you've got that complexity it..it..it...you...you..you..it brings you back...it gives you a base to come back to and say, well actually....you get much better...by following it you get much better...best interests decisions where you need to use it...because you've got that construction of being able to look at it, break it down into its simplest form...uh.. ensuring that actually this is truly in the individual's best interests it is not in *our* best interests

Commented [CR99]: Maintaining the balance. Keeping the decision objective. Removing the messiness and the proximity by inserting the law as a buffer between the emotion and the process. The role of law is positive and supportive.

P5: I think from an education point of view as well, like [P1] said, there's a lot of emotions flying about is that actually it reminds people what that best interests decision means so that you can always come *back* to the to the five principles can't you, the code really...so that actually it's reminding people what that best interests decision is all about which, because there's emotions involved a lot of the time, there's a lot of other stuff going around that people think *might* be in the best interest

but it isn't necessarily what that's all about, they're coming at it from a slightly different perspective sometimes... so it's good to have it because you can keep coming back to it..

P6: I think that case was particularly difficult because

[Yeah, yeah it was]

because he had special...he'd always had special needs...so it was difficult to know whether he'd ever had capacity..to have made that decision even if...do you know what I mean...before he was even ill

[yeah, yeah]

he probably wouldn't have had capacity to make that decision...so then to make that decision in what his wishes would have been....it just made it even more complicated...you know...whereas if you've got family who say well they're that sort of person and they're...that's the sort of... you've got a bit more to go on, but with him we were just really having to...to.. to sort of dig deep to find out what all the complexities were and to..to work out you know what...what...what we felt...and so that's what was difficult because normally..family would have a lot of input in terms of what they think would their best interests but it was difficult with him because of him being so severely...um having such severe special needs and it was difficult to know that he'd ever been able...he would never have been able to have a conversation with them...about what his wishes would have been...you know and so... so it was very much...making it on a...trying to make it on a... on a level playing field really wasn't it without...

P2: And of course when the parents asked about well, you know, how..good could he get..you know..could he recover back to his original...um...level of quality of life nobody could really answer that, and that was a big cause of anxiety for them...um...so that was a real challenge wasn't it.... And I think also from the education point of view...the...I was very conscious that...um...there were some staff that were...um...almost seeing it a little bit too black and white...you know it was obvious we should start feeding him again through...the through the tube...um because that was the only humane...humane thing to do because he didn't seem to be obviously dying...but um...the balanced scoresheet...um we put it on the unit the day before, didn't we, with the various options, and...to get staff to start thinking what are the benefits but also what are the risks...to really help staff realise that this is, this can't be a quick decision...because...um even if we agreed that...yes...the you know the right principle is that...that he is no longer kept without any nutrition, um the..the...the risks needed to be understood and mitigated and that needed...we needed to bring in then a dietician to support that, you know, you see what I mean, it wasn't...these weren't straightforward...so I suppose there was quite a lot of learning...from the process in terms of needing to look at all sides of..um... the situation...er

Commented [CR100]: Decision making in shades of grey. The "obvious" solution may not be the correct one

Commented [CR101]: Balance sheet approach as a tool for the staff – facilitation of a clearer understanding of the whole perspective. Hospice as guardian of a proper process.

Commented [CR102]: Reflective organisation?

P1: I think that by following the process that we did I hope that it gave staff confident that...confidence that the decision being made was being the right decision being made for the right reasons... I think there was a lot of anger around the decision that had been made...it was out of our control in the hospital and a lot of..em unhappiness

Commented [CR103]: Hospice as guardian of the proper process

about that decision that you wanted everyone to see how we'd come up with this decision for this reason and be confident in that decision...em...certainly it...it...it would have been very difficult if people had not...if there'd been disagreement within our team at our end...which thankfully there wasn't...but em...yeah...

Commented [CR104]: Significance of place: context of care. Hospice as expert/guardian of the proper process

Commented [CR105]: Collegiate decision-making: how does disagreement work in these circumstances?

P6: But the informal learning in those situations, the complex ones that we've had, I think the informal learning is invaluable... I don't...I don't think that if you even talk about that situation in a learning environment...and I have used some of them in a learning environment, talking about the mental capacity act or about, um, best interest decisions...but they don't have the same weight as being in those meetings and...and listening to the different conversations that are happening and certainly since I have been here, you know, staff will come out of those meetings and saying oh actually I understand what the mental capacity act really means now that's when it they really... you know because in a dry learning environment it's not the same but when you are actually, when you've got that patient in front of you and you know exactly the person you're talking about um... and you...and you can look around all the different angles of it you can't do that the same way in a...in a classroom but you know they've actually got the... they know what the different pictures of what the different choices look like...and they can see it and...and... that really does...I think it really is just invaluable that learning

Commented [CR106]: Learning organisation. Hospice as expert. Hospice as guardian of the proper process.

P4: It's it's like a... to actually sort of see...um... in the practical situation of real life...that is the greatest learning of it

P6: Definitely, yeah and that's helped, I think that helps the staff think about it for the next time. It puts them straight...away it puts them in a better position for thinking about capacity for thinking about best interests decisions in a different way, I think... on the unit than they would have been even five years ago

Commented [CR107]: Learning organisation. MCA journey.

P2: Yeah...

P6: Because we have, you know, we have sort of taken on this process...

Commented [CR108]: Hospice as expert/guardian of the process. MCA journey. Learning organisation.

Researcher: And is this something you think that the hospice does particularly well?
...Or differently, do you do it differently from other organisations do you think?

P1: I think in this case we did it better than the hospital!

Commented [CR109]: Hospice as expert

[laughter]

I mean...I think... I suppose having worked I've worked in four different hospices, em, and actually I think in other hospices I have worked in they've kind of had a similar ...sort of structured process that has worked very well in these complicated decisions...so whether it is...certainly I've seen it done well in the hospice setting in general...em... that has been my experience anyway

Commented [CR110]: Hospice as expert

P6: The issue is in the hospice we have time...

Commented [CR111]: New theme: the significance of time. Time as a factor in good decision-making

[Yeah, yeah]

...and I think it doesn't get done well in the acute because everyone's...you know there's...there's often almost too many people involved...and um... and they just don't have the time... I mean we...you know we do spend a lot of time on these in order to get it right and I just think sometimes there's not...I'm not making that as an excuse...but I do think that that's sometimes true...but then I think social workers, for example, my experience of social workers is that they're much hotter on mental capacity act and...and best interests than the medical...you now sort of the nursing and medical profession are...but nurses in general...when I was training mental capacity act out in the community... you know the doctors and the nurses some of them are... are good on it but most of them, really, they sort of like..they don't think about it on a day to day basis...they don't...they don't *know* it in the way that... you know you get to know it if you've...you've had some of these challenging cases I think

Commented [CR112]: Significance of time. Consider the difference between "too many people involved" and the collegiate approach. Why is one good and the other part of the problem with "the acute"

Commented [CR113]: Consider the approach to decision-making as something which is affected by the responsibilities of a particular role.

P2: I think the care is so... individual , you know personalised here and the relationship builds up...you know more quickly and I think...I think it's...probably...um... you don't dodge the situation here because it's...it's sort of in your... it's in your face more isn't it and we've got a fewer number of people looking after...the, the patients and the family..I think in a larger organisation it's...it's easier to think that somebody else is doing that or somebody else is gonna pick it up and then it ends up that nobody really has fully addressed..um...you know had the..had the time to build up that relationship and then taken the responsibility to, you know, to... um ...um to to follow that through ...and er that's a time thing

Commented [CR114]: The Hospice difference? Patient-centred care is a real thing? There is time – significance of time – and there are relationships.

Commented [CR115]: Size of the organisation – as it relates to the ability to build a relationship – and the significance of time again.

[P6? And then pressure builds up]

P2: And but it was also just I think the way larger organisations work too many people involved sometimes and no one person takes the full responsibility...I think here that's done very well.

Commented [CR116]: Too many people. No individual decision-maker? But this seems to contrast with the focus on collegiate, team-based decision-making. ??

[Mmm, mmm]

P5: And care homes are probably... some are very good some are...less good. That's variable. Some are very good at it from my visits... I've been going out to quite a few and we've had lots of staff coming in for training...and I think...um... you know, generally yeah we've got there are some very good ones out there but equally there are some, there are quite a few that don't use it as well as it could be... like it's that best interests...it's the best int...ultimately it's that best interests bit – whose best interests is this conversation about? These decisions?

Commented [CR117]: Significance of place. What is the purpose of a care home? What is the purpose of the Hospice? Consider the paramedics' experiences of end of life care decisions study:
<http://emj.bmj.com.ezproxy.lancs.ac.uk/content/33/10/722>

Researcher: So what do you think makes the difference between those organisations?

P5: I think it's having confidence – I think it's having the confidence...to...to... because everybody..has everybody has the mental capacity act...they'll have... should have their policies there...um ...I think it's remembering to go back to it and actually use it in its... in its base sense of its truest form...you know that it's about this person...

Commented [CR118]: Hospice as expert/guardian of the proper process. Focus on the individual: implementing EI

P2: Making sure that it's embedded

Commented [CR119]: Unconscious competence

P5: And that it's embedded

[Mmmm – that it's embedded...]

P5: But I think they're a lot better than they were

[P4 (?)Definitely]

P5:...I think they're a lot better from the verbal sort of feedback and impression...they are a lot better than they were but um...yeah its remembering to go back to that – the principles

Basically if you follow the five principles...then... it gives you that framework, whatever the situation...um...you should keep it there and remember what the focus is

Commented [CR120]: Role of law as a supportive function

Researcher: And do you think that most people interpret the five principles in the same way? Or do you think that there are differences in what people pull out of them as being the most important aspects to focus on?

P5: I think they understand....When we ask the questions, not everybody remembers what the five principles are out there, do they? [Laughs] No – not everybody. Or they

may be reluctant to say but they don't always...they don't always remember. They remember the stages of the...of assessing capacity but they don't always remember the core principles...um...they remember the presumption of capacity

P6: I still think best interests is cloudy...in a lot of people's minds. And I think...I was talking to some medical students last week about...advance care planning, best interests and um...and mental capacity act and they were saying that...that their experience in the acute is that there are some consultants...and doctors...who are really "old school" about best interests...and and that best interests is what I medically think is their best interests

[It's what they think, yeah]

And she said that they said that a lot of the younger, newer consultants and you know seniors are actually coming along...that...there there's a change in culture

[P1 yeah...]

as the new the new people are coming in and they think it's very distinctly "old school" and "new school", which I thought was quite interesting.

P5: I think that's that's replicated out at practice in GP practices isn't it? Again it's that... there's very much this division between the old and new school. Similarly with, with communication skills...

[yeah, yeah]

Commented [CR121]: Hospice as expert. "old school" – MCA journey. Significance of time. Also the "habitus" argument from the "old habits die hard" paper (see comment 14 above)

Commented [CR122]: Habitus. MCA journey

P4: I think it's that aspect you know that people struggle a little bit I think, I think with the the allowing an unwise decision for instance as well. And might mix that up with capacity to make that decision as well so...you know... and it isn't necessarily like that but I do think that, you know, it needs to be in an education sort of situation and unpicking that then people understand it...but they might not necessarily agree with it I think sometimes as well, to a certain extent, you see it all comes from different people's different perspectives, doesn't it, as to..as to their beliefs really... yeah

P1: In many ways I feel like I've learned a lot through these examples and through being lucky enough to work in a situation where you've been able to kind of work through examples...and...but actually not everyone has that opportunity... in care homes and things it's very diff...it's all very well having the principles written down but actually applying them to an individual situation is.. is very tricky and even though I think we do do it well in the situation it's still a complicated thing and probably lots of people... as part of that conversation...and so it is its really hard if you've not that...luxury of experience and things to.. kind of examples to have worked through in the right setting and stuff...so...it's tricky...

Commented [CR123]: Significance of the setting (place). MCA journey.

Researcher: What do you think has made the difference between the "old school" and the "new school"?

P6: Training. [Laughter] I think..I think there's been a lot more

P2: Education

P6: Yeah I think there's been a lot more education

P5: And also... I don't I don't... and also to be fair as well from the Mental Capacity act you know I mean obviously that... was it 2005-2007 isn't it, you know it's a good while ago now but actually there's a good proportion of us in health care that didn't have that... didn't have that to a certain extent...

[Predate it]

...that predate it you see and it is actually that you know and unless you really embedded with new learning and taking things on I think sometimes that can be hard for people, can't it, you know what they sometimes set out with it's hard to change it's sometimes hard to change behaviours isn't it, and ways of ways of thinking. It's like taking it through education it can be hard to do that...

Commented [CR124]: MCA journey. Habitus.

P6: It's like 10 years and you think some of those people that were training when the mental capacity act came out and there was a lot more staff training starting on... about mental capacity... those people now will be coming into more senior positions and I think that will make a big difference as well.

[Yeah, Yeah]

You know it takes a long time to become a GP or it takes a long time to become a registrar... er, er a senior reg or a consultant so I think we're starting to see a trickle of those people now in the more senior positions and they'll be the ones that... like the

medical students are...are more aware of how they...you know they make their decisions and they approach the patients....so I think it's..I think it's partly just that actually it's just taken an awful long time you know I think it's just funny that they seemed to think that in two year's time everything would suddenly become rosy in the garden and we'd all take on board the Mental Capacity Act and actually...[laughter] ten years later we're still struggling along

[General laughter]

Commented [CR125]: Significance of time. MCA journey.

P5 It's changing people's belief systems that's the real trick

Commented [CR126]: Habitus. Also consider MCA as condition of possibility rather than the answer.

P6 But it's changing [P2 Yes it is] ...it is changing...it is improving in terms of I think...listening...but you still get... people who just don't understand...and it's a medical decision and that's what the medical decision...I had a...um...a situation with...it was actually a family friend as opposed to someone I was nursing who...um...he had dementia but he had capacity to make the decisions for himself...so he completed an advance decision to refuse treatment, so he didn't want to go into hospital...and he, he very specifically only wanted to go into hospital if he could be...I said to him what if you break your arm and he said well that would be different 'cause I could go into hospital and they could fix it and I could come home again. He said I don't want to go home...to go into hospital and die – I want to be at home. And so he was very clear about what he wanted and what he didn't want and then um he became really unwell...and he deteriorated he'd been in hospital um he'd been in hospital...he'd been in and out of hospital a lot with bad chest infections, the family

had been round the bed loads of times waiting for him to die and then he'd you know recovered and gone home again...and um he spent his whole life saying I just want to be with Jesus, you know, just leave me and let me be with Jesus that's what he kept saying all the time...and um...and then he became really poorly and he'd had um err a hemorrhage, a bleed the previous year and they'd rushed him into hospital decided that they weren't gonna do anything about it and then rushed him back home again...by now he was even worse than he was a year ago, very frail, he was dying, he was dying at home, he'd stopped eating, he'd stopped drinking, he was dying at home but because he'd had this bleed...um...in in the day, the doctors wanted to rush him into hospital...and it was obvious that if they rushed him into hospital he would die in hospital... and the GP, who I know really well, is a really good *[emphasis]* GP and in... in his mind if someone's bleeding they go into hospital because they need emergency care and and he said you know he said to... my m'friend who was the daughter he said to her you know you've got 24 hours you're you're doing the wrong thing, you're making the wrong decision here he should be in hospital and that's where he should be and you've got 24 hours to change your mind *[her voice rises here – sounding disbelieving]* and so she was left feeling like so what do I do I've got to send him into hospital and...so I got involved and I said you know that's not right...you don't have...you're making the right decision he doesn't want to go into hospital and I actually spoke to the GP next and the GP was fine...once we laid it [yeah, yeah], once we laid it out, do y'know what I mean? But this guy had got an advance decision to refuse treatment, she was his LPA and she was saying she didn't...but the doctors still wanted to send him into hospital. And he's a good GP, he's a really good GP, but he just didn't understand [yeah, yeah] the situation...you know and it's those sort of decisions that I think are happening..and...because of old

Commented [CR127]: The influence of the role? Acute and palliative?

school thought but it's just like...you know if someone's got a red flag you do that...if someone's got you know if someone's got a reason to send them into hospital you send them into hospital [P1, yeah] rather than actually stopping and evaluating the whole situation from that person's perspective [*here she slows down the pace of her speech*]. It's just a different way of looking at it.

Commented [CR128]: Habitus. MCA journey. Influence of role.

Researcher: So presumably the different setting makes a difference? The GP you know kind of on the front line and then other people who live with, like yourselves, who treat patients on a...

P6 I think some of the GPs... I did a lot of work with GPs when I was doing the Deciding Right training and someone once said to me...and I think it's a really imp...important thing that really helps me to understand they said that in order to be a GP you have to make a lot of instant decisions on your own

[P1 Yeah]

and that is what you have to do as a GP and so they get used to that, making that decision and that that's their decision and they go with it and I think that there is an element of that that they're used to making their decision and they don't stop to....

[to think]

...necessarily ask everybody else..

[P4 to ask everybody else, yeah yeah]

Commented [CR129]: Nature of the role - influences decision-making practices. Importance of setting/place

..where we wouldn't think about making those decisions without talking to everyone else

[yes, yes]

P4 It's just the sort of... kind of the consensus approach isn't it

[yes, yes]

P6 And you need your doctor, you need your GP to be like that a lot of the time, don't you, you know it's just just that sometimes they need to stop for a minute...and ask around

[Long pause.]

Researcher: That's really interesting. [Laughter]. Thank you all very much. I feel as if we've kind of come to a...to the end of...um.... the information. That's been really useful. Unless anybody has anything that they...they think it would be good to talk about in addition? Any other comments that you think would be....

Thank you.

[Thank you...thank you..]

Example Individual Interview template with comments and initial coding

Individual 1 Hospice 1

PARTICIPANT:

Commented [CR130]: Inpatient – collegiate decision-making. GP – individual decision-making. It's comparable to individual autonomy and relational autonomy. Maybe there is a link here with "old school" and new school approaches: the involvement of others in the process??

So I'm an advanced nurse practitioner, so what that means is I work as part of the medical team, so cover admissions, discharges and review people on the unit, but I also have a role beyond that which is my colleague and I run the respite service so admitting people in and out of the unit for respite, we have two respite beds. And I'm also very closely linked with the motor-neurone disease clinic, the specialist nurses come up once every three months and I'm involved in that clinic but then I support the patients that are maybe moving more rapidly towards end of life, I support them very specifically in this area, 'cos the MND nurse, if they come from Preston, so it's a long way for them, so I'm just sort of on hand and a bit closer to hand supporting the people with MND in this area and try to link them in with some of the hospice services and make sure that their palliative care comes in along with their day to day care so it becomes seamless which is really important for them. I work a bit in education as well, but I, before I did this role, I worked as a Deciding Right facilitator, so I was out training district nurses and GPs, social workers, about advanced care planning and one of the first things we realised was that you had to start by going back to basics about Mental Capacity Act because most people thought they knew about it but didn't actually know the principles or how properly to assess someone so. So I've got sort of like a background in a bit of education as well.

Commented [CR131]: This relates to what care and treatment means

Commented [CR132]: This relates to the nature of care

Commented [CR133]: MCA journey

INTERVIEWER:

And do you think that people's understanding of it has generally moved on?

PARTICIPANT:

I think it has, I think involving patients, it does vary from doctor to doctor, from place to place, but I think generally it has, somebody said to me recently that you can really tell that they felt that the younger consultants, 'cos we've got sort of consultants in

now that have been brought up with the Mental Capacity Act if you know what I mean?

INTERVIEWER:

I know exactly what you mean.

PARTICIPANT:

And they felt that at the hospital, this was one of the medical students, she said you could really tell who lived in the current culture as opposed to who hadn't and who used to think that a patient's best interest was what I thought was in their best interest and she feels that that is changing, and we definitely got a sense of that in the community as I was going round, that it's on the turn but it's a massive culture to change I think.

INTERVIEWER:

And why do you think that is? Why do you think it's a massive culture to change?

PARTICIPANT:

I think because it was just so inherent in the medical profession, I think in the NHS but I think probably generally in the medical profession that the doctor knew best and the doctor made the decisions and it was almost like the doctor was God, and you didn't question the doctor, the doctor just made the decisions, and so if there was a best interest decision to be made, the doctor would know best, and you know people of an older generation, a few of them still believe that, they believe that and they want the doctor to make the decision 'cos they know best. They have no concept of the fact that they might have some input into that themselves. So I think there was a very parent child relationship, you know between the doctor and the patient and I think it is changing but I think it's changing slowly.

INTERVIEWER:

Commented [CR134]: Old school/new school. Everyone sees the world through different eyes

Commented [CR135]: Old school/new school "the current culture" – consider what this means in the context of care and treatment. The current culture is about questioning, challenging, engaging with your care. The old school is "the doctor was God" cf the role of the judge in the court system

Commented [CR136]: Paternalism – old school

Commented [CR137]: Old school and new school/habitus/MCA journey

Commented [CR138]: Old school – "the doctor was God"

Commented [CR139]: Relational power

Commented [CR140]: Patients wishes and feelings – so what is paternalism then? Patients wishes and feelings play into it.

Commented [CR141]: Condition of possibility for a re-balancing of power: requires doctor to enable

Commented [CR142]: Paternalism in a nutshell. Habitus. But also relational power and societal acceptance. And the 'current culture' is to question, to explore, to Google ones symptoms

Commented [CR143]: Paternalism!

And so do you think it's led by, you're a trainer that goes from the hospice into the community, do you feel as if that's the way the learning is flowing, that's it's that people are more accepting of it within the context of a hospice set of services or palliative care?

PARTICIPANT:

I don't know. I've been in nursing for 30 years but I've only been in specifically palliative care for the last seven years. So I think in palliative care, a patient's view is just naturally more important or seen as being more important, when you've only got a few days, weeks, months to live then what that patient wants for the time, so I think it probably is a place where there's more subjective decisions to be made almost, you know if you go in for surgery and it's a straight in and out, it's done as a process isn't it and maybe there's not quite so much patient, maybe, you know it's easier just to follow a process, whereas you can't do that in palliative care 'cos every patient is different, every situation is different, so you can't have that same structured process. I don't know whether it's just that in palliative care we have more time to talk to people, we get to know people and understand people in a way that maybe you don't have time for in general practice. But well for me it's certainly different to being in the hospice setting, but it does still depend on doctor to doctor, and some doctors have got a much clearer grasp of mental capacity, what the Mental Capacity Act really means than others.

INTERVIEWER:

And do you think there's an element in that of the doctor having to give up a little bit of power in that relationship, to move towards you know allowing the patient to be as involved in the process as they can be or they should be?

PARTICIPANT:

Commented [CR144]: Time as a resource and a constraint – the power of time as part of the shaping of the decision-making process

Commented [CR145]: Nature of care is a factor of the way in which the MCA is interpreted. Palliative care is subjective care

Commented [CR146]: In other specialities there's not so much patient, more process

Commented [CR147]: Palliative care is distinctly different

Commented [CR148]: Significance of time. Time as a resource. Time as a factor of patient-centred care. Consider though the inherent contradiction here: the fact that a patient's condition is life-limiting also concentrates the time left in a way which magnifies it – the care is not urgent; rather the care is considered and subjective. Palliative care is relational care rather than a curative process. The direction of travel is different. "more patient less process"

Commented [CR149]: Everyone sees the world through different eyes

Yeah I think the training very much in the past was you know if this happens you do this, this is what you do for this condition. And so I think they just yeah that's part of them being in control of these life and death situations and they just feel that I think some doctors just feel that that's there's a set way of doing things really, why would you not choose to do it that way. But I don't yeah.

Commented [CR150]: Old school is about process not patient??

Commented [CR151]: Old school: habitus

Commented [CR152]: Othering of 'old school' approach. MCA journey

INTERVIEWER:

So for you supporting the patients that you support, how do you approach that decision making process?

PARTICIPANT:

I think for me, most important thing is listening to the patient, and I think that, I mean I did some work, as part of my Master's and I did some looking into about conversations and you know studies have shown that if you go into a consultation the consultant speaks for 80% of the time and the patient speaks for 20, and yet if you ask the patient what they would prefer, what the patient wants is to be listened to, and so for me it's about listening to the patient and not, you know yes I maybe have an agenda in my head, I might be going in to do an admission so there are certain things that I need to tick off to get done, but if I launch into my certain things that I need to get done, by the end of the it the patient's too tired to really communicate with me, so what I want to know is you know what how that person sees and feels about what's happening to them and what their preferences and priorities about their care are. Because the other things are general things that I can pick up and can often find from other places, so it's trying to listen at least as much if not more than I speak. And yeah so that's definitely I feel a way that you know I am maybe slightly different than the way that other people approach things, and actually then working with that person to work out how best to meet the priorities that are their priorities not my priorities. I

Commented [CR153]: Relational power – recognising the patient's power to be involved in the process.

Commented [CR154]: Active listening/patient narrative

Commented [CR155]: Compassion/hospice as expert??

Commented [CR156]: Patient narrative

Commented [CR157]: Does this feed into compassion? Or into the patient's narrative?

Commented [CR158]: Patient-centred care

went to it was a gentleman with MND actually and he decided that he didn't want a peg feed, and it's one of the things that gets thrown up to people with MND almost as soon as they're diagnosed, will you want, something you might consider in the future is whether you want to be artificially fed through a gastrostomy tube or whether you want non-invasive ventilation. And he decided right from the beginning that there was no way he wanted to be peg fed, and he was very clear about that and I went to see him and one of the first things he wanted to do was complete an advance decision to refuse treatment, to refuse this peg feed, so we talked about it and I went away and I said look I'll come back, I'll write it all out, we'll come back and talk about it again and then I'll bring back the form with the right wording on it and you can sign it and get your witness to sign it. And when I arrived back with this advanced decision to refuse treatment, I happened to be there at the same time as the speech and language therapist that had come to assess him. And she did like a really good assessment and watched his swallow and all that sort of thing, and then she sat there and one of the things he said to me before is that he said he just feels people are constantly asking him and bombarding him about this peg feed and he just didn't want it, he was quite strong about it. And she did her assessment and then she said to him of course there'll always be the option for you to have a peg feed and be artificially fed, and he said yes but no, and she said what do you mean yes but no, and he said yes I know about peg feed but no I don't want it. And she then went and spent ten minutes talking to him about what a peg feed was, what the advantages were, what the you know and she got to the end and he was like looking at me and I was looking at him across the room, and he was having trouble with his language and speech at the moment so he couldn't, he just let her carry on, and then when she got to the end she sort of looked at him and he said yes, but no. And I just thought he so clearly said

Commented [CR159]: "yes but no" – this theme is about active listening. About understanding the "yes" and hearing the "no" and proceeding with the process accordingly

that at the beginning but she wasn't, she had to go through her thing of I've told him about this, but if everybody does that, people feel like almost bullied into treatment that they don't want.

INTERVIEWER:

So do you think that she felt that she had to do that because of the MCA?

PARTICIPANT:

Yeah I think it's part of their, you know you've got to make sure people know the you know what the risks and the benefits are, and I think people almost feel like that's my job so I should do that, but if a patient clearly has capacity and they have got, he said he already had that conversation you know they'd at the MND clinic down in Preston, you know people had already had that conversation with him. And he almost needed his advanced decision to refuse treatment to stop people keep asking him the same questions again and 'cos he did he felt like he was being, he felt like he'd made that decision, he didn't want to keep revisiting it but everybody that came had got their role to play and part of their role to play was to ask that question. And he was just getting really sick of, he said I've got a drawer over there full of information and leaflets that people have given me and he said I haven't read any of them he said because it's all too much information. There's a danger that we try and bombard people with information because we're worried that you know they've got to have the right information at the right time haven't they, and they should be allowed to make a decision and be accepted that they can make that decision. Yeah. And it's just for me it's about listening, you know is this person, you didn't need to be with this guy for very long to work out that he completely had capacity and he knew what he was talking about, he knew what he wanted and what he didn't want, he'd obviously had and all she needed to have said is have you had a conversation with someone then

Commented [CR160]: The MCA as risk avoidance. Legal consciousness. Law as a shield: LCP approach

Commented [CR161]: Patient story to copy

Commented [CR162]: Consider if this is a downside of the MDT. Multi perspectival approach assumes multi-perspectival engagement – which, in the absence of proper communication and active listening from across the team becomes a multi-perspectival repetition of an assessment which doesn't hear the “yes but no”

Commented [CR163]: Legal consciousness – lacking discretion and lacking expertise?

Commented [CR164]: MDT downside

Commented [CR165]: Legal consciousness: before the law?

about? You know when he said yes but no, yes I know about it but no I don't, who have you had a conversation, well I've had a conversation with the MND team, they've talked to me about it, that's all she needed to know, she didn't need to go through it all over again.

Commented [CR166]: Unconscious competence

INTERVIEWER:

So do you think that's something to do with her interaction with the legal requirements in a sense that maybe you understand them so well that they inform the way you deal with patients without you really consciously thinking about it, and that if people are not quite at that same level.

PARTICIPANT:

Yeah maybe.

INTERVIEWER:

They feel that they have to go through the process to make sure that their records.

PARTICIPANT:

Yes their records, sometimes I think it is partly to do with that sort of tick box, and it's about using guidelines and procedures and things, it's about understanding those but then using your professional judgement and I suppose that's what you're talking about isn't it. That I've got a level of professional judgement that somebody that's maybe not been not had the experience that I have had wouldn't have, and so you know I would look at a guideline and say yeah that's a guideline and there's some really good information I can take from that, can use from that, but actually there are some things that I think for this patient aren't appropriate and therefore would do differently but could justify why I was doing it differently. And so maybe it is a bit of you don't realise I don't think of myself as being someone who has got more

Commented [CR167]: Hospice as expert/person centred care/compassion/active listening

Commented [CR168]: Role of law/legal consciousness. LCP approach contrasting with the use of professional judgment – which assumes an understanding of the process and the power/confidence both in your relationship with the patient and also with the employer to understand the “yes but no” and to accept it.

knowledge than the next person if you know what I mean, but I suppose I have had 30 years of nursing experience.

INTERVIEWER:

But then I suppose within that there's something else in that you know when you were talking about old school and new school, so the old school doctors have probably got that same amount of experience but there's something about them accepting the change isn't there and embracing that change, so I'm wondering if it's something about your willingness maybe to engage either not maybe so much in a relationship but in a, the listening I suppose is where it starts from, maybe it's your willingness to listen and use your experience in a different way.

PARTICIPANT:

I think it's yeah I think it's about seeing that patient as a person isn't it, you know I had very good basic training. And I'm a very people person, I'm interested in who people are, so yeah I think you know doctors have to make a lot of certainly on the acute they have to make life and death decisions, you almost need to be a certain sort of mentality to take the pressure of being a doctor I think sometimes, and especially in certain areas, in A&E or whatever, and I think GPs, that's something I felt with GPs, was that a lot of GPs can come across as almost sort of like arrogant and that they know best, but then they're out there making life and death decisions on their own without the support of a hospital team of doctors around them and they almost have to have that sort of confidence in themselves if you know what I mean?

INTERVIEWER:

Yeah I know what you mean.

PARTICIPANT:

Commented [CR169]: Legal consciousness/hospice as expert/significance of time/releasing power to the patient. NB the 30 years of experience may be a barrier to understanding the MCA (old school/habitus). Experience is a condition of possibility for change – MCA journey. Not a guarantee.

Commented [CR170]: Seeing the world through different eyes...

Commented [CR171]: Significance of MDT support. But also MDT needs to be cohesive and focused on the patient rather than the tick box/LCP approach. So organisational/leadership culture is also crucial in setting the relational context

Commented [CR172]: Seeing the world through different professional eyes too

In order to do the job they're doing and not you know and I think they need to have that confidence but it's just balancing that with actually being able to say well I can make a decision but actually I have to look at how that affects how that decision affects the patient, and how that decision affects one patient will be very different to how it affects another. And even how that decision affects this patient might be different to how the same decision affects this patient in two weeks' or three weeks' or a months' time, and it's that complexity that I think sometimes gets missed.

Commented [CR173]: Relational care?

Commented [CR174]: Seeing the world through different eyes

Commented [CR175]: Significance of time. Decision is time and situation specific.

INTERVIEWER:

And is there something about the amount of time that you get to spend with patients in the environment of the hospice?

PARTICIPANT:

Yeah, I definitely think that helps, I definitely think having time to listen to people helps. I think when, even when you know even when the MND nurses come for the clinic, they've got like a set thing that they go, almost like certain information that they need to update themselves on, and that by the time you've spent your time, if you get a long enough list, you've got an hour with someone, there is and then you get to have you got any questions, it's almost like the have you got any questions at the end is enough for somebody to say how they're really feeling about something.

Commented [CR176]: Significance of time

Commented [CR177]: Significance of time – limitations of 'care and treatment' as a package

INTERVIEWER:

So that's more or a last tick box rather than setting the context.

PARTICIPANT:

Rather than actually setting the context of all the questions yeah. And actually you know, are there some questions that actually I don't need to ask today because that's going to be too distressing for someone and I can work out from what they've said, do you know what I mean, what's going on. But we have become very I think worried

Commented [CR178]: Relational approach: active listening

Commented [CR179]: Patient's narrative supports relational engagement. Stepping outside the strictures of the 'process' to make it patient centred.

about like you say doctors are worried about being sued or things not being done in the right way, I think there is an element where people feel like they've got to do things in a certain way and have them written in a certain way so that they can cover themselves almost. But I wonder whether in covering ourselves we actually lose some of the personal relationship and the interaction that needs to happen.

Commented [CR180]: MCA as a shield. This removes the patient from the process: it makes the process all about the legal safety of the decision-maker/organisation and not about the patient. Does this also affect the nature of care?

Commented [CR181]: Legal consciousness: law as a shield

Commented [CR182]: Losing the person in the process.

INTERVIEWER:

Do you think that the feeling within the hospice is more supportive and protective to allow that to allow the attitude that you've just described to be ok?

PARTICIPANT:

Yeah I think it is, I think certainly we all try to support each other, in allowing people to have more of a or have the right to say how they want their care to be or whatever and what options we put forward and I think yeah it's a very supportive team and I think that does make a difference. Yeah definitely I think that makes a difference, and it's the first place where I've worked where I've felt that my experience has been valued, has sort of been recognised and valued, and I didn't feel that really, I've never felt that in 30 years of nursing. So I haven't had to just stick to a set rule almost or a set pattern and I can come out and say I've done the admission on that patient but we haven't talked about this and we haven't talked about this and we haven't talked about this because they just weren't up for it today, and that's ok you know and actually somebody will say well that's ok, we'll get to that tomorrow, you know or we'll ask when we can but you've done the important bits are covered, so yeah I think it is much more of a supportive environment that allows it. Definitely yeah.

Commented [CR183]: Relational process – team and patient. Collegiate approach. Organisation-specific – so the group interview analysis is important at setting the context for the individual to take hold of the conditions of possibility.

Commented [CR184]: Value of experience? Does this feed into the culture of expertise in the hospice?? Or does it grow out of the ability (and the willingness) to see each person as an individual?? This is patient and team members

Commented [CR185]: Significance of time, the luxury of time

Commented [CR186]: Importance of the organisational culture. The mediation of power is enabled by the organisational context.

INTERVIEWER:

So do you think that that's something that other medical professionals could grow into if they came into the hospice environment from the acute?

PARTICIPANT:

Yes, yeah I think it is partly a personality thing, I think it's partly who you are as a person yourself, I don't think everyone can. I mean we talked about some of the nurses, some of the nurses get the whole active listening, communication stuff, they're naturals at it and others don't get it at all and some sort of understand it but need to learn rather than they're just naturally good at it, and so they need to learn a few techniques. So I think you can learn but I do think that there's a lot about the culture, and I think even the culture of the hospice, since I've been here has changed interestingly, I think there is much more we're much more fluid than we were before about things, and so you know things like the respite service is much more based on individual need rather than oh you get three individual weeks a year and they have to be three months apart, do you know what I mean, whereas now Helen and I run it much more on an individual basis of saying well this patient's got MND, their chances are for survival over the next six months are very limited, what's the point giving them one week every, their family actually need one week in or their family actually need two weeks because the family are lambing, one year we had a farmer and his family were lambing so he had two weeks respite here because that was the time that the family were out all doing the lambing and couldn't look after him, what's the point of giving him two weeks in six months' time when he was dead? He needed that time then so it's run on a much more individual basis and I think we have, I think the medical team that we have at the moment, [X] is very patient centred and I think and [Y] and I are, and I think [Z's] come into that and [Z's] developing that same thing, and I think that does mean that the culture is changing even here to be more individual, looking at the individual, valuing the individuals input into what's happening to them. Which makes it a very, for me it makes it a very good team to

Commented [CR187]: Seeing the world through different eyes. MCA journey.

Commented [CR188]: Patient centred/ El/

Commented [CR189]: Circle of care/ patient narrative/ hospice as expert – understanding the progression of the disease

work with, 'cos I would struggle to do the job I do in an environment where I felt that as a professional I couldn't make those calls.

INTERVIEWER:

So is the family, you mentioned about the lambing, so is the family generally a really important part, assuming that the patient has?

PARTICIPANT:

As long as the patient's got family and they have a good relationship with them and they're happy for us to involve the family, I mean that's one of the first things we try to work out is whether they're happy for us to, who in the family they're happy for us to discuss their care with, because obviously if they're in a condition where they are unconscious or can't make decisions for themselves, it's important to know who they would trust us to be able to have conversations with. And when people come in here the family need support and so it's really important, 'cos giving information is one of the biggest ways you can support the family, in whatever way the family can cope with that information, you've got to give it in the right way, but for the right people, but that's one of the biggest ways you can support the family. Families who don't know what's going on, don't feel supported, so yeah family it's vital that we have that, it's always difficult if there's family that people don't want you to talk to, but that's very rare, usually people are happy for you to talk to their family.

INTERVIEWER:

How do you balance that communication if the family, you know the guy that you mentioned who didn't want the peg feed, if his family hadn't, if his family had just wanted him to be sustained for as long as possible, how do you manage that, is that something that you think is done differently in hospice from elsewhere?

PARTICIPANT:

Commented [CR190]: Patient at the centre/ collegiate approach/seeing the word through different eyes – so P might not choose to work here if the environment were different

Commented [CR191]: Circle of care/patient narrative/hospice as expert – understanding the likely progression of the disease within the context of the care required and the legislative framework

Commented [CR192]: Compassion? Relational approach, certainly. Importance of information and understanding the relational implications.

Commented [CR193]: Circle of care: information as a critical component of care and appropriate delivery of the information as a key factor of the provision of care

I probably only in time, I think we have time to spend talking with the patient and the family and trying to marry those two things up, you can't always do it, even amongst family members you can't, they can have differences of opinion, but usually with a bit of diplomacy you can get people to see and people often respond in a stress or shock situation, people often respond in a very emotional top of their head sort of way, and actually you need to give them a bit of space and then they'll come round to what someone's saying. So if you can stay calm and explain why a patient might be making the choices they're making, and helping them to understand what maybe the pressures that they're putting on their loved one. I mean food is a great one where family insist that you have to eat and drink because otherwise you're going to die, you know which obviously you can understand where the logic of that comes from, but equally for people who are right at the end of their life, the last thing they want to do usually is to eat or drink and actually part of the body's closing down and dying is not wanting to eat and drink, and so then you end up with this battle between the family and the poor patient over what they're eating and they're not eating, and I went out to see a lady in the community who I went, I'd never met her before, but I went in to change a syringe driver and she wasn't supposed to be necessarily days to weeks but maybe months, and she was obviously when I went in I could tell there was an atmosphere in the house, and so I sat and talked to her and asked her what was going on and she'd felt under pressure from her family to eat and drink and yet she was really struggling. And so I spoke to the son on the doorstep and said you know you need to be really careful about how you approach this, you can offer your mum things and let her eat what she wants but don't make her feel that she's got to eat, and he was saying oh you're making it sound like she's approaching the end of her life and she might be dead, and the GP who obviously knows her well has been in yesterday and

Commented [CR194]: Significance of time and understanding the context of the progression of the illness

Commented [CR195]: Compassion – understanding the situation and being able to imagine from the family's perspective why it is so hard. Hospice as expert. Care as broader than medical care: circle of care

the GP said that they think she might have three or four months left to live and now you're making it sound like she might die quite quickly. And so I said to him look nobody knows, nobody knows how long your mum's got left, I said but do you want the last few days of your mum's life to have been you battling it out about whether she was going to eat or not? And anyway I went back to work, that was on a weekend, 'cos that's why I had gone to her and I didn't know her, and I went back to work and she died two days later and her son came over to me when I went to visit someone in the house over opposite, I just happened to see the son came out and he just said to me thank goodness you had that conversation with me because they'd got to the stage where they were not even wanting to be in the same room as each other over a battle about food, which she was obviously clearly dying and you know.

INTERVIEWER:

But he just wanted to help.

PARTICIPANT:

He just wanted to help and do the right thing, and so it's about trying to get them to understand from the patient's perspective, you know and it's like the fight, everyone talks about fighting cancer, you know but some people have fought cancer for so long, they just haven't got any fight left in them, and it's not that they're giving up, they just haven't got anything else left to give. And you know and I think it's trying to get families to understand it from the patient's perspective really. And that's like you know the doctors or anyone involved in their care, we have to try and see it from their perspective, 'cos at the end of the day they're the key person aren't they, they're the person that you're trying to support and actually how they are dealing with and living with their condition or dying with their condition, for me that's the most

Commented [CR196]: Relational approach: perspectival imagination

important thing, so decision making has to be based as much as you can around what how that person is responding to their condition and what's happening to them.

Commented [CR197]: Compassion/Hospice as expert

INTERVIEWER:

Which presumably changes over time as well.

PARTICIPANT:

Absolutely.

INTERVIEWER:

So something that they might have wanted at a certain stage, might be something that they don't want as they....

PARTICIPANT:

It's one of the things I used to talk about in my education sessions, was I had a friend who was dying of cancer and she actually had stomach cancer and was physically well apart from having a few odd symptoms stomach wise, but was then diagnosed with terminal cancer and they thought she'd got about six months to live, and they said that they could extend her life potentially by three months with some chemotherapy, it makes me laugh that they talk about these times like they're realistic times, but and they could and she didn't really want the chemotherapy but she felt that she ought to do it for her family, but she was worried about then the chemotherapy making her not well, which is exactly what happened, and actually she died a lot quicker and had to spend some time in hospital because she was poorly from the chemotherapy. But I was having that sort of conversation with my husband about chemotherapy and stuff like that and he was saying I know what I'd decide in that situation, so I said oh what would you decide? And he said for me it's about quality of life not quantity of life so if I was well at the time I wouldn't want the chemotherapy and I would definitely say no to the chemotherapy and took whatever

Commented [CR198]: Time as a measure but also as a tool to manage expectation? Also "them and us" – who is 'they' here? The acute??

was coming to me. And I say I understand that I said but what if our eldest daughter was three months pregnant and you may or may not have missed the chance of seeing your grandchild? He said oh yeah that would make it different wouldn't it. And I said that's exactly, you can't expect people to make these decisions as one off decisions, because they do change, our families' situations change, how we feel about our own health changes, how we feel about life changes.

INTERVIEWER:

So that's an interesting conversation around advanced decisions to refuse treatment, because I suppose depending on what stage in your life you make that decision, you know you might make it when you're well and you have full capacity and then when you're if you become ill, you know and the treatment that you're refused is offered, is indicated and then is offered to you, do you often see people changing their view in those situations?

PARTICIPANT:

I think the whole thing about advanced care planning is that it's really, 'cos people don't understand that advanced care planning only comes into place when people have lost capacity, so you know I always make it really clear when I'm doing an advanced decision to refuse treatment for example with someone, I make it very clear that this means nothing until you can't say for yourself. And so we're saying if you're unconscious or incapacitated and you can't make a decision for yourself, this is what you would choose, but actually until that time, you will be making the decision and that you can change the decision, you can throw this bit of paper away, you can tear it up and it doesn't become relevant anymore. It's only relevant really, I mean I think, I've obviously done a lot of thinking about advance care planning, there are some really good things about advance care planning and some not so good things

Commented [CR199]: Significance of time – change over time, length of 'time left', patient narrative as it relates to the 'time left' / quality of life v quantity

Commented [CR200]: Hospice as expert. The role of information – and time. Change over time.

Commented [CR201]: Decision-making as a liberator and not as a limiter

about advance care planning. So like advance care planning done really well is always a positive thing, I think advance care planning done badly can be a very negative thing, and I think that's the danger, is that you train up people who don't know what they're doing, you know if they don't know what they're doing, you do a bit of training and they have a bit of an idea of what they're doing, and then it all goes a bit pear shaped because they don't really understand the complexities of it. Because people do change their mind and advance care planning should be about looking at what people's options are for them, you know not looking at what their options are, so the options for advance care planning for MND, you might be able to think well they would be whether someone wants a peg, whether they want to be resuscitated, whether they want, well those are sort of straightforward things that you can have in your head when you're talking to someone, but actually what I want to know when I do advance care planning with someone is what's really important to you. Because if I know what's really important to you, that might that will automatically help me work out what you need to have on your advance care planning, because if what's really important to you is to live as long as you can because you've got a young son and you want to see, then that would change what I would be talking to you about and how I would, do you know what I mean?

Commented [CR202]: Hospice as expert. Care includes understanding the context for the decisions – patient narrative and the legalities

INTERVIEWER:

Yeah. What about things like I don't know religious preferences or something that might mean a lot to you when you have capacity but then if you lose capacity and you maybe there was a discussion recently about a Muslim guy who the ritual washing and the ritual shaving was very important for his family but when he lost capacity, because he couldn't any longer make the connection between why it was happening

Commented [CR203]: Hospice as expert/patient narrative/information as a key component of care

and the religious side of things it became quite distressing for him, but it was very distressing for the family to think of him not receiving.

PARTICIPANT:

Not having that yeah.

INTERVIEWER:

So in that circumstance, the person who he was before, arguably isn't there, when they've lost capacity, you know so I suppose I'm interested in how the decision works when it has to be mediated between two essentially different people who happen to be in the same body.

PARTICIPANT:

I mean that's pretty unusual isn't it that sort of scenario, but I guess, it makes me think of a patient that I used to know about, it wasn't my patient, but we used to know about that was in a EMI unit, who'd got dementia, and they had been a vegetarian, and so they would be given vegetarian meals, but when they were sitting eating their vegetarian meals they would be nicking sausages and things off other people's plates, so it's a similar sort of thing isn't it, and you know I guess you can only look at those situations at the time and try and balance what you know that person's wishes were and what they would want, but I think if something's distressing someone, so you know so the only way to stop this person nicking meat off people's plates was to isolate them and sit them on their own, they didn't do that, they just let him carry on, so they didn't necessarily feed him sausages but they wouldn't make a big issue if he took a sausage off someone else's plate if you know what I mean. And I guess it's just trying to balance the distress of the patient and the distress of the family and work out how you can best meet that patient's needs.

Commented [CR204]: Significance of time and the progression of the disease. Change over time both of the condition but also in what the patient's points of reference are. So the basics of eating overtake the principles of what it is right to eat when the ability to process information at that level is lost

Commented [CR205]: Circle of care. Balance.

INTERVIEWER:

Because then their best interests I suppose, you know if their wishes and feelings as part of any best interests assessment if his wishes and feelings, the vegetarian guy were to eat sausages then you know what I mean that's a change in what you can understand about him.

PARTICIPANT:

Best interest is always, you know it's like best interests is a moment by moment thing as well isn't it. Because I might say to you that I'm a well I am, I don't eat meat, I eat fish, so I don't eat meat, so if you put me in a home I would be very distressed to think that someone was going to, and I couldn't say what I wanted, I would be very distressed to think that someone is going to start feeding me meat after being a vegetarian for over 20 years. But equally if I was in a situation where I was in a home and I was doing what that guy was doing and my family were becoming distressed about it, I would want them to, I would then want them to let me eat meat if it was going to be less distressful for my family, because if it didn't bother me, do you know what I mean, the most important thing to me at that point would be the distress of my family. And so then my decision might change again because actually as a person it would be much more important to me that my family weren't distressed about it, that someone supported them and talked to them than what was happening with me, 'cos I wouldn't have capacity so it wouldn't bother me would it. So it's very complicated isn't it to know what to say 'cos you could say my best interests would be that I didn't want to eat meat, 'cos that's what I'd said and therefore I should be, but actually that's only my decision, like you say, at that time isn't it. And so you can only, I think best interests you can only you have to work on what evidence you've got and then you've got to make some assumptions, because in different situations we'd all say different things, and how do I know whether, you know I might say no I would never

Commented [CR206]: Significance of time across the piece. MCA journey – change over time. Sensitivity to the progression of the disease and the patient narrative as it moves forward with the disease is part of the hospice expertise. Nature of care – palliative care must embrace change.

have chemotherapy but how do I know whether I was in that situation I would or I wouldn't, you can't know that. So you can only, that's why I try to understand who someone is rather than just look at specific decisions, because are they the sort of person that wants to explore all new things and find a new potential cure that they would want, anything that prolongs their life, or are they the sort of person that says actually do you know what, I've had a really fulfilled life, I really am happy with the way my life has gone, and yeah this is a terrible thing that's happening to me but actually I accept that that's where I'm at. In which case how I would perceive their best interests would be different, and I think that helps you, should help us, make decisions with people much better if we understand who they are as people rather than just looking at a specific decision as a specific time if that makes sense, and you can only do that by listening to people. And you know I'm not saying that I always get it right, but I do try to always listen and I think that's where we sometimes fall down is that we don't listen enough, we talk too much and don't listen enough.

Commented [CR207]: Person centred and time-specific. Centrality of patient narrative. Relies on a relational approach.

Commented [CR208]: We talk too much and don't listen enough. That in itself is a commentary on power in the relationship.

INTERVIEWER:

So sometimes then, if somebody comes into your care and actually they're in a process of accepting what's happening to them, your relationship with them in that moment or in those series of days or whatever, is probably more allows you to be more accepting of what they want at that point than potentially what their family thinks they might want, based on the person they were before, so that makes your role really difficult, because you then have to bridge that.

PARTICIPANT:

Again you're the bridge, absolutely yeah.

Commented [CR209]: You're the bridge: between patient and family, between patient as person and patient as patient, between 'official power' and 'personal power'

INTERVIEWER:

And is that something that happens quite a lot in your experience?

PARTICIPANT:

Yeah I think it does happen quite a bit yeah, I think sort of in a sort of informal, you know it just happens, but I think we do, we spend a lot of time talking with families about and trying to almost advocate for the patient, I think we do quite a lot of that yeah. I mean some families are just there, they have it already, and the patient's agenda is their agenda, but some families just don't, and it's not because they love them any less, they just don't understand what's happening to them, they don't understand the processes in the same way. And I think also some people, the more experience you have of having someone die, I think that must help. You know some people are just so, it's such an alien environment for them, and I'm very fortunate, I've not got you know all my mum and dad are still alive, my brother and my sister are still alive, not actually had, apart from grandparents I've not had a lot of death in my family, and so I still think to myself I have no idea what will happen if someone really close to me dies, you know I'm very close to my sister and I've got a very good relationship with my mum and my dad and I have no idea how I'm going to respond when something happens to them, because I just think, I might think in my head how I might like to behave, but how I behave and how I feel about things, who's to say?

Commented [CR210]: Importance of communication

Commented [CR211]: Importance of information. The right information at the right time in the right way.

Commented [CR212]: Hospice as expert – as the bridge between the process and the patient: circle of care

Commented [CR213]: Alien – unfamiliar, disturbing, distasteful – even extraterrestrial. Terminal illness/death is alien. Role of the hospice as a bridge.

INTERVIEWER:

But in a way the very fact that you recognise that comes out of all the experience you've had supporting other people as they've been through those times where everybody's in a situation of change maybe or trying to come to terms with a situation of change.

PARTICIPANT:

Yeah.

INTERVIEWER:

That's really interesting and I kind of don't want to stop talking to you but yet we are up, it's up to you, we can carry on talking if you want to?

PARTICIPANT:

Yeah I'm alright for a little while if you want to but I don't know if we're answering any of your questions, I feel like we might have gone off track?

INTERVIEWER:

No.

PARTICIPANT:

Are we on track?

INTERVIEWER:

My interest really is in how you deal with things, you know and so all the work I've done in the previous bits of the study have been about where the law came from, where the MCA came from, and then how it's interpreted at an organisational level, so this stage is really about how people specifically within the hospice context, how people work with it in their and not so much work with it but how they live, how they make decisions on a personal level and obviously it's within the overall framework of what the law sets out but it's more about how you individually respond, so the ideas about listening and active listening and it's exactly that kind of thing that's interesting for me at this level, yeah no that's great.

PARTICIPANT:

I think it has its challenges, I think active listening and relating to people on that level I think has its challenges, personally, I think you get very involved, you know you get involved in, if you have a slightly deeper level of understanding someone I think that can make it challenging in terms of you know we're always dealing with people who are approaching the end of their life and you want to make that the best it

can and it's great when it goes the best it can, it's just really hard when it doesn't, sometimes end of life is messy, and that is really personally challenging.

INTERVIEWER:

When you're very close to it.

PARTICIPANT:

When you're yeah when you're opening yourself up to that level of communication.

'Cos you do have to open yourself up to that, you can't be a closed book and have that level of communication with someone I don't think, they need a bit of you to know who they're dealing with.

INTERVIEWER:

And to give you trust presumably.

PARTICIPANT:

And trust and to build up that relationship, yeah absolutely.

INTERVIEWER:

So something that I've also felt from some of the other conversations I've had is that when people are in the community that the approach is a little bit different, you know the approach maybe to the risk involved is a little bit different and I'm wondering whether distance in all sorts of different ways makes a difference. So you were talking about GPs making decisions by themselves and you know in all of this there's a sense that the closer you are to an individual who's in that messy stage, that more is required of you if you see what I mean.

PARTICIPANT:

Definitely yeah.

INTERVIEWER:

Commented [CR214]: Personal cost: which is why the staff support network in the hospice is valuable – and this isn't replicated so much in the community

Commented [CR215]: A relational process. Compassion. Compassion requires emotional engagement "They need a bit of you"

So when things end up in court, the Judge is a really long way away from the kind of messiness of the situation and in a way that makes the decision easier but potentially less personal, what do you think about that?

PARTICIPANT:

I think that's right, I think you know a Judge is looking, I mean a Judge is only really being fed information and I think there's so much more than just information that you obtain from people, and I don't, that sounds a bit sort of airy fairy.

INTERVIEWER:

No I know what you mean.

PARTICIPANT:

There's like you know you get an intuition or a sense of who someone is by being with them, you can't get that by, I could say to you you know this patient's been a real rogue in his life, that might give you a bit of an interpretation of who that person is, but actually when you get to meet that person, there's something about them, maybe a little spark or the way they look at people, there's something that just makes you think oh yeah, there's something about, and like yeah a Judge in that situation is not, but then in the really complicated and the difficult situations like you know with this thing with [paediatric patient in the news] Alfie at the moment, you know at some point, someone's got to make a decision that says this is enough haven't they, and when there's two people that have equal in a way equal weight in that decision, and they're in conflict, there's got to be someone that is away from it, but you almost think it's a shame that the Judge can't, 'cos the one person he doesn't see in all this is Alfie.

INTERVIEWER:

Although I think some Judges have changed that.

Commented [CR216]: Personal narrative as a factor in good care: what is it that you need other than 'just information'? Is this the role of compassion in facilitating an interpersonal engagement – person to person rather than medic to patient. Requires 'a bit of you': requires imagination and emotion =compassion.

Commented [CR217]: Patient narrative/relational engagement/care includes giving and receiving: 'a little bit of you'

PARTICIPANT:

They've gone to go and visit the patient.

INTERVIEWER:

Yeah, I mean interestingly when you talk about old style and new style, I think that's the same with Judges as well.

PARTICIPANT:

Yeah that's interesting.

INTERVIEWER:

When you look back at the old cases, even the language that the case reporter's written in is difficult and you know legalistic and you know what I mean, and the much more recent ones are much less like that and Judges have gone to see people, and also some of the judgements that are read they Judge has said I feel as if the person's in the court room, you know and they've either been represented I mean I imagine by somebody like you came, or the relatives have represented that person, so the Judge feels as if the person is part of the decision, even though physically.

PARTICIPANT:

They've not yeah.

INTERVIEWER:

So maybe the decision is more difficult if there's closeness, but maybe it's more likely to be right if there's closeness as well.

PARTICIPANT:

Yeah, and there was a thing on Breakfast News yesterday, a lady whose child had been in intensive care, and the child was old enough to have a say, not old enough to make the decision but old enough to have a say, and they didn't want their life prolonged, but as a parent she did want their life prolonged, and she they did go for a

while down the prolonging of life route, whatever that was, and she says you know one of the things she regretted most was not going along with what, but it was just like the child had accepted where they were quicker than her and her husband had, and it was interesting listening to her from her perspective about you know the sort of cloud that she was living in at the time and the only thing that made rational sense to her was keeping her son alive, and you can see that in Alfie's parents, that the only rational thing for them, for them that's the only thing they have focused on, they couldn't move from that focus, and you know and she says you can't then try and rationalise into that because they won't see it. And it was really interesting listening to her talking from a sort of parent's perspective because it's very easy to make judgements isn't it about other people's decisions or other people's judgements, and I try, I try, we're human, we all make judgements, we all make assumptions, but it's just really for me it was just really interesting to hear her talk about you know about the sort of mental state that they would be in, which I think hadn't really, I hadn't really thought about it like that, do you know what I mean, I hadn't thought about the way as a parent that would be your focus and then coming out of the other side of it, she now realised that that's what had happened and actually she had prolonged her son's life for longer than it needed to have been for the wrong reasons, do you know what I mean, that's sort of what she was saying really, and that actually you know the people around that were trying to say that he should just be for comfort measures and palliative care, you know that that and her perception of what palliative care meant, she said her perception of palliative care was they just stop everything and leave him, and she said and it was only when they got into the palliative care bit that she realised that palliative care was so much more than that, and so people all the time are making decisions only on the information they know, and you can't know everything can you.

Commented [CR218]: Implication is that there is a distance between rationality and the right thing to do in a palliative care situation

Commented [CR219]: Role of information – and limits of information. 'You can't know everything'

Even I as a palliative care nurse don't know everything about a particular condition or a particular person, so you can only make those decisions on the knowledge you have at the time. And so listening and communication have got to be key to all of this.

INTERVIEWER:

That's what I think, absolutely, as with almost everything in life.

PARTICIPANT:

And you can only communicate what you can communicate at the time, 'cos you go down the tick box route and you try and communicate, you know you can't always, well you can't ever probably you know fully communicate all of the advantages and all of the disadvantages of a treatment, you can only go on the ones that are the most likely. And I've always said that it doesn't matter to me whether it's a one in ten chance of something happening or a one in a million chance of something happening. If you're the one that it happens to, it's catastrophic isn't it, and so the statistics go out the window, it doesn't matter if somebody with your condition lives for you know the average is six months, because for you it might be tomorrow.

INTERVIEWER:

Like the lady whose son you bumped into.

PARTICIPANT:

Yeah, so you know so what do those statistics, how do those statistics actually help you make decisions? They sort of help you make decisions but in some ways they get in the way of you making decisions.

INTERVIEWER:

So actually where they might help is for you to think about them and then communicate something that comes out of your experience and your knowledge of the person to put I mean not even maybe to mention the statistics but to put that in the

Commented [CR220]: Listening and communication supplement the care when you don't know what the answer is

Commented [CR221]: Compassion – imagining the perspective of the patient

Commented [CR222]: What is knowledge? Is knowledge actually al in the relationship then – what is important to that patient in the context of that condition, at that time and as shared in that relationship. Consider the influence of moral luck as well. Statistics – generalizable knowledge – needs to be personalised in the context of the patient as person.

context of that individual person at that individual time, which is really the story that you told me about the lady who was refusing food, who the statistics had said might have another three months to live but actually she only had two days so. So the communication, the relationship and the communication.

PARTICIPANT:

Because if you talk to somebody you know for that son, he was desperately trying to keep his mum alive, and his battle with her was about trying to keep her alive but what he was doing was actually she was already dying I think now, I understand from how quickly she died after, she was already in the dying process, that's why she wasn't wanting to eat and drink. And if he you know if he could look at that and think well we might have six months but equally she might die tomorrow, then how you behave to someone might change and it's those sorts of things that I think I try and portray to people, don't go thinking that someone's told you you've got six months, therefore I've only got six months and I need to almost like stop planning after that, but equally don't think you've got six months and assume that you've got six months 'cos you might only have a week. And we all need to have flexibility I suppose, it's about having that flexibility and that understanding isn't it to make decisions that are right for me now but can be changed in the future. And I mean in terms of advanced care planning, I always try and have, I never try and stick with a plan A, I like to have a plan B and a plan C, and I like to make sure that people understand that plan A might only happen if the family can cope with it, 'cos if someone wants to die at home, that might be great in terms of what everyone wants because I'm going to go home and die and I'm going to be dead in a couple of days and the family are all going to rally round and that's going to be wonderful and I'm going to have all these carers and a night sitter and all this, but then when I go on for

Commented [CR223]: Importance of time.

Commented [CR224]: Change over time.

three weeks and my family are exhausted and my son's got to go back to work or whatever, then it doesn't look so rosy and it's not so possible. So then I say well if that's not going to happen, and is somebody's decision, I had a conversation with a lady and her brother who's looking after her, last week, and she wanted me to talk, she said can we just have a conversation about what the future might hold? I said yeah ok, so she said I want to stay here and she's got two homes, she said I want to stay here in [Place], but she lives on the other side of the lake to [place], so her poor brother is like a rabbit in headlights you know, he's never done anything like this before, and I said well I understand that but the you might not be able to get the care provided here, if you get pain it could be a long time before anyone gets out to give you an injection or anything like that, if you need it at the time. I said great if everything goes smoothly and things carry on and it all goes then absolutely you should be able to get your wish and we'll work as well as we can to get your wish, but what would we do if we couldn't do that or if your brother was really struggling. She said well then we'd do this and we'd go to our other home which is more central, and so I said oh right ok, that's good, and what if that wasn't going to be manageable, where would we go then, thinking to myself this brother is not potentially going to cope, we need, and I don't want him to then feel that he's let her down because she's not got what she wanted, and that's another big issue for families. So I always try and make sure, 'cos I was saying to her but do you understand if you're not able to make this decision for yourself, we might move you from one place to another, not because it's what you want, because we know what you want is to be here, but because it's the only thing that her brother can cope with. And she said oh yeah I understand that, she said but it would need to be so that he could manage, and I said that's fine, but because we talked it through and. I talk about creating pictures for people, what does

Commented [CR225]: Change over time: MCA journey

Commented [CR226]: Circle of care

Commented [CR227]: Creating pictures for people – continuing the patient narrative into a future which they are not properly equipped to understand. Hospice as expert in the context of the condition – and compassionate in the context of the patient's journey towards 'messy' end of life. It's not paternalism – much more supported decision-making. Where they have capacity – 'active listening'. Maybe the difference between paternalism and compassionate paternalism is active listening – engagement in the decision person to person, whether through the narrative wormhole or not.

it look like to be at home, what does it look like to be in the hospice, what does it look like to be you know in the hospital, how does that look for your end of life care? Because otherwise people are making decisions on things that are completely unrealistic pictures. I want to go home means I want to go home to my lovely home where I sit in the chair and watch telly and somebody makes me a cup of tea, it doesn't mean I go home sitting on a perching stool in the middle of the lounge because I can't sit on the sofa because it's too low and if I get down there I can't get back up again, do you know what I mean, you have to create what ... what the realistic picture of that looks like. People want to go home, because they don't want to be in the place that they are, and they want to go home because home is familiar, but it's not familiar when you're on your own gasping for breath and your family can't be with you, do you know what I mean, it's not a familiar situation to you. And so I try and use the experience I have to create a bit of a picture of what that might look like and what the problems might be for that person in that home with that family with that situation, but you can't do that, I can't do that for you, your situation would be different to my situation, because we've all got different family, different situations, different homes. So you can't make that as a blanket decision or you can't say well look, it's not a quick decision is it, but we want in hospital and particularly I think, sometimes these decisions are expected to be made too quickly without enough information, without enough listening. So, but in the hospice the advantage we have is time, and I think that's why I work here, 'cos I don't know how these days I don't know how I would cope in an acute setting, 'cos I'd have to do too much compromising.

INTERVIEWER:

Yeah and compromise is pretty difficult in these kind of decisions isn't it.

Commented [CR228]: What is 'home'. Care must extend to understanding the relevance of home and the accessibility of 'home' as it is understood by each patient. Role of time in the concept of home – and role of patient narrative in understanding what home means...

Commented [CR229]: Patient narrative and illness narrative come together in compassionate care; mediated decision-making brings together various perspectives to get to the best interpretation of the situation as a multi-faceted condition of possibilities

Commented [CR230]: Compromising here implies a reduction in care. So is palliative care also about having the resources – time, compassion and financial/material resources – not to compromise the patient's choices??

Commented [CR231]: Significance of time/ I need to be able to sleep at night

PARTICIPANT:

It is yeah, well then you go down the we've done the best we could for someone, with what we've got. I got told on the district that I wanted to provide platinum care and we could only afford silver, and that I had to pare down my platinum and that's why I'm here. I love the community, but I didn't want to provide silver care, when I knew what platinum looked like.

Commented [CR232]: I need to be able to sleep at night. No compromise. Patient not process.

INTERVIEWER:

Yeah that's interesting, somebody else I spoke to said that in that situation she had to make decisions that would allow her to sleep at night, which is essentially what you're saying as well isn't it.

PARTICIPANT:

And that's about who you are as a person, and I got to the stage where I couldn't do it anymore, I was being asked to compromise so much that I couldn't, I felt that I was compromising who I was as a nurse and I wasn't willing to do it anymore and I left, 'cos I just felt that I couldn't pare it down any further, and they put me into a situation where I couldn't, they got me into a situation where I would be willing to stay, say I worked from 8.30 'til 5.30, and I would be willing if I'd got say a terminally ill patient or someone that I knew was in a bit of a crisis, I would be willing more than willing to work through my lunch, to stay 'til 7.30, eight o'clock at night, not put those hours down, just because I cared about the people I was nursing, I would be willing to do all those things for those patients, but they wouldn't let me do that either, because then they were saying you've got to come back here for lunch, so I had half an hour away from base, and another visit that was just near it, because they insisted that I had to be shown to be having my lunch, and I would have my lunch in my car is how I used to do it but they told me I wasn't allowed to do that. I had half

Commented [CR233]: EI - the medic as person

an hour back to base and then half an hour back out to another visit, so they just made it impossible for me to do my job. And then if I went on, I wasn't allowed to work into the evening, I had to be finished because they had to know I was back safe, which were all good reasons for my own, they're all to do with my own protection and I understood all that, but equally it meant that I couldn't do the job that I wanted, I couldn't do it at the level I wanted to do it at. Because how do you listen to someone?

I was going in, even me, and I think I'm very proactive about active listening, I was going in to take bloods from someone, and on the one hand you're being told you don't ever just go in and take bloods, that's part of your assessment, you should be assessing what their home's like and what situation, how they're feeling and all that, but then when you've got 16 visits to do in a day, with half hour journeys between some of them, including terminally ill patients that you might be doing personal cares for, how are you supposed to fit that in? So I'd be going in to take blood from someone thinking to myself please don't say anything to me today because I can't cope with anything else, I have no time in my, I have more than enough things to be dealing with already and I can't cope with what you're going to tell me. So almost like praying that someone doesn't have a problem before you even go in.

INTERVIEWER:

Which is a really distressing way to provide care.

PARTICIPANT:

Which is a really distressing way to provide care, and it's very damaging to who you are, it's very damaging to who I was as a nurse and as a person, to feel that I, and I thought to myself I can't keep up at this level anymore because I'm you can compromise, I can compromise in my care, I compromise in my care here all the time in the sense that you might think I've got maybe eight patients to see and I might want

Commented [CR234]: Legal consciousness in the community – risk averse mentality. Compliance led approach ('I had to be shown to be having my lunch'). 'Package of care' is a commodity which is delivered. Care as a concept in this model is different from caring of the kind that 'needs a piece of you'

to spend two hours with everyone, well I can't, that's not possible, so I have to compromise what I do, but there's a level of compromise where you just know you've gone too far.

INTERVIEWER:

Yeah. And that's the sleeping at night point.

PARTICIPANT:

And that's the sleeping at night bit yeah, so it's being able to know that you've done your best for someone in the situation, that you've at least been able to feel like you've done your best, and to also accept end of life care that it's sometimes messy and you're not going to make everybody's death a perfect death, but I think that's hard for people who aren't in a supportive team, 'cos I think when it's messy and when you don't make someone's death you know a good experience, whatever that expression means, then I think that's really hard on the team, and if you're in a supportive team that works 'cos you can support each other, but if you're not in a supportive team it must be very difficult.

INTERVIEWER:

Yeah. Thank you very much that was a really useful conversation, really interesting.

Commented [CR235]: I have to be able to sleep at night. NB the distress at the level of your personhood – ie deeper than your professional self. Patient as patient/patient as person requires nurse as nurse/person as nurse

Commented [CR236]: Importance of MDT support