

FROM LEGISLATIVE INTENT TO HOSPICE PRACTICE: EXPLORING THE GENEALOGY OF THE MENTAL CAPACITY ACT 2005

Author: Dr Caroline. A. B. Redhead

Affiliation: School of Law, Centre for Social Ethics and Policy, The University of Manchester, Oxford Rd, Manchester, M13 9PL, UK

Acknowledgements: The authors is grateful to Professor Sara Fovargue, Dr Lucy Frith and Professor Marie Fox for providing comments on a draft of this paper, and to the anonymous reviewers of the submitted draft for their helpful suggestions.

ABSTRACT

The Mental Capacity Act 2005 (MCA) regulates decision-making for people without capacity. Post-legislative scrutiny of the Act in 2014 by a House of Lords Select Committee concluded that the MCA was neither well understood nor working well in practice. The aim of the research discussed in this article was to consider how the Act's principles are understood and interpreted in hospice practice, specifically considering the patient's role in the decision-making process.

The research proceeded through four distinct, but linked, phases which, together, offered a 'life story' of the MCA from legislative intent to current hospice practice (in 2019). The research was informed by relational theory and legal consciousness theory and the methods described are underpinned by a narrative approach to analysis. Phase one was an innovative genealogical analysis of policy and legislative documents (n=24) influencing the 'coming to be' of the MCA. In phase two, a systematic review of Court of Protection judgments (n=63) 'historicises' the empirical research, which was the focus of phases three and four (group interviews and individual interviews, respectively). Staff from two participating hospices participated in two group interviews and six individual interviews (13 participants), providing empirical data. Template analysis was used in all four phases of the study, and adapted to facilitate a synthesis of the findings across the study as a whole.

FROM LEGISLATIVE INTENT TO HOSPICE PRACTICE: EXPLORING THE GENEALOGY OF THE MENTAL CAPACITY ACT 2005

INTRODUCTION

The way we care for people approaching the end of life, and how we manage death, are continuing conversations that the hospice community in the UK wants to encourage.¹ These conversations often take place as hospice patients lose their ability to make decisions for themselves as the end of their life approaches, creating a unique decision-making context. An understanding of how patients' decision-making should be properly supported (both legally and as part of their care) is thus particularly important for hospice staff. In England and Wales, the Mental Capacity Act 2005 (MCA) sets out what constitutes capacity to make a decision, how to assess whether someone has capacity, and how decisions can be made for individuals who lack the capacity to make them for themselves. The Act came into force in 2007 and was intended to catalyse and lead societal change.² 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'.³ Yet, post-legislative scrutiny of the MCA by a House of Lords Select Committee in 2014 concluded that the Act was not working well in practice, that its implementation had not delivered the empowerment it promised, and that cultures of paternalism (in health) and risk aversion (in

¹ Hospice UK <www.hospiceuk.org/our-campaigns/dying-matters> accessed 16 May 2022.

² Select Committee on the Mental Capacity Act 2005, *Mental Capacity Act 2005: post-legislative scrutiny* (HL 2013-14, HL 39); Department for Constitutional Affairs, *Mental Capacity Act 2005 Code of Practice* (The Stationary Office, 2007). Available at <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/921428/Mental-capacity-act-code-of-practice.pdf> accessed 16 May 2022.

³ Select Committee on the Mental Capacity Act 2005 (n 2) 6.

social care) continued to prevail.⁴ The Select Committee considered that, in the context of health and social care, the MCA was not widely understood and embedded in practice.⁵

I explored whether these conclusions were accurate for the understanding and implementation of the MCA in English hospices, by investigating how hospice staff cared for patients whose ability to make decisions for themselves had been compromised by the progression of their disease. In this article I describe the qualitative methods I developed and used in my research to map the key ideas of the policy-makers and legislators who were engaged in the development of the MCA and then trace them through decisions in the Court of Protection, and into policy and practice in hospices. My aim was to construct a genealogy of the MCA from legislative intent to (then) current hospice practice, to chart the dynamic relationship between law and practice in the area of decision-making for people without capacity, and, ultimately, to compare the decision-making approach of hospice staff to the intentions of the original legislators. My conclusion, challenging the findings of the Select Committee in the particular context of hospices, was that hospice staff *did* understand the MCA and were implementing it in hospice practice to the benefit of those whose decision-making capacity had been compromised by the progression of their disease.

In this article I present both the methodology and the methods I adopted to guide my enquiry. In section 1, I introduce my research and set out the context for it, I note the theoretical framing in section 2, and describe and discuss the methods and the methodological approach in sections 3-6. In the concluding section of the article, I reflect on the methodological choices,

⁴ Select Committee on the Mental Capacity Act 2005 (n 2) 7

⁵ Select Committee on the Mental Capacity Act 2005 (n 2) 8

how they supported my investigation, and whether this combination of methods has broader application to empirical socio-legal analysis.

SECTION 1. SETTING THE SCENE: AN OVERVIEW OF THE STUDY AND THE LANDSCAPE OF THE ARTICLE

My methodological approach evolved iteratively, in tandem with the design of my empirical study, as I began to engage with literatures of interest. I wanted to present an interpretation of the 'life story' of the MCA from conception to practice in the hospice context, aiming to offer a critical exploration of *how* the Act was working in practice to (re)assess the Select Committee's conclusions. I used four phases of enquiry to facilitate the exploration of different, but complementary, data sources. In this way, I constructed a layered and comprehensive socio-legal account of the MCA's approach to decision-making for people who lack the capacity to make decisions for themselves.

In the first phase, my focus was on documentary sources that illuminated the social and policy context within which the concepts underpinning the MCA were debated, and its principled approach to decision-making established.⁶ Examining this contemporary discourse gave me a window into the legal and ethical context from which the MCA emerged. In phase two, I designed and carried out a systematic review of decisions in the Court of Protection (CoP), to underpin an analysis of the way in which the courts had interpreted the key concepts of the MCA since its entry into effect. In phases three and four, I undertook empirical research,

⁶ Noting that the 'principled' approach had not been drafted into any piece of legislation in England and Wales before the MCA. See Joint Committee on the Draft Mental Incapacity Bill, *Draft Mental Incapacity Bill* (HL Paper 198-II, HC 1083-II, TSO 2003), particularly Vol I Recommendations 4 and 5

narrowing my focus to the hospice context and investigating organisational practice (phase three), and staff members' individual experiences of decision-making with patients (in phase four).

In designing this phased approach, I was conscious that, for the successful completion of the research as a whole, a coherent transition between each phase would be essential. The theoretical framing and methodological approach had to 'hold' all four phases of the study which, albeit all qualitative in nature, would draw data from a variety of documentary and empirical sources. My objective was to analyse data from each distinct phase using a method that could identify and preserve any themes flowing between them; thus allowing the research to reflect the developing story of the MCA. I considered a number of analytic methods which would both enable this flow and allow me to achieve a coherent synthesis without losing the granularity of the data from each phase. Common to each phase, and supporting the coherence of the research as a whole, was the embedding of the data in the language and concepts that describe and situate the MCA. For this reason, I will now briefly describe the contours of the MCA decision-making landscape and introduce the key principles and concepts (capacity and best interests) which both guide and constrain decision-makers. Equally important is the context of the hospice 'movement' in the UK, and I next explain its salient features, so that the key themes which link the phases of the research and the methodological relationships between them in the (arguably) unique context of hospice care are situated.

1. The MCA, 'capacity' and 'best interests'

The MCA provides the legal framework for decision-making on behalf of individuals who lack the capacity to make decisions for themselves. The Act aims to protect people who lacked the capacity to make a decision, while empowering them by maximising their ability to decide or to participate in the decision-making as far as they were able.⁷ The MCA is underpinned by five key principles:

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)).

Capacity may fluctuate and an individual may have capacity to make some decisions but not others, the key is whether 'at the material time' (MCA s2(1)) someone can make *and* communicate the decision, whether by talking, using sign language or any other means (MCA s3(1)). To have capacity to make a decision, an individual must be capable of understanding

⁷ Department for Constitutional Affairs (n 2).

what is proposed, of retaining, using and weighing information in the process of making the decision, and of communicating that decision (MCA s3). If they cannot make (or communicate) a decision because of an impairment of, or a disturbance in the functioning of, the mind or brain, capacity will not be established (MCA, s2(1)).

In the event that someone is considered *not* to have capacity to make the decision for themselves, the MCA permits a decision to be made on their behalf, in their best interests (MCA s1(5)). A range of factors must be considered in establishing someone's best interests, including their past and present wishes and feelings, the beliefs and values likely to influence their decision and any other factors they would consider if they were able to (MCA s4(6)). The MCA does not prioritise a person's wishes and feelings above any other of the relevant factors. The lack of priority given to someone's wishes and feelings in the MCA framework has been the subject of academic criticism,⁸ and goes against the approach set out in the United Nations Convention on the Rights of Persons with Disabilities.⁹ Indeed the Law Commission, in its recent review of the MCA, recommended that particular weight *should* be accorded to someone's wishes and feelings in making a decision for or about them.¹⁰ Despite the Government's decision not to legislate to reflect this, it is clear that the wishes and feelings of the person about whom a decision is being made are an increasingly important factor in a 'best interest' decision about them¹¹. Hospices also espouse and promote a

⁸ See, for example, Emily Jackson, 'From 'Doctor Knows Best' to Dignity: Placing Adults Who Lack Capacity at the Centre of Decisions About Their Medical Treatment' (2018) 81 *The Modern Law Review* 2 247.

⁹ Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD) art 3.

¹⁰ Law Commission *Mental Capacity and Deprivation of Liberty; A Consultation Paper* (Law Com No 222 2015). Available at <www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/> accessed 16 May 2022. Note that, while 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.

¹¹ *Wye Valley NHS Trust v B* [2015] EWCOP 60.

‘patient-centred’ approach in their provision of palliative care,¹² and I wanted to investigate whether attention to patients’ wishes and feelings was a characteristic of this approach in the context of MCA decision-making by hospice staff. I therefore paid particular attention to exploring the ways in which patients were supported to make decisions, and the extent to which their wishes and feelings were reflected in hospice decision-making.

2. The ‘hospice movement’ in the UK

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’, which was created to prioritise care for patients with a terminal diagnosis and to promote an holistic approach to their care.¹³ Saunders’ concept of ‘total pain’ underpins hospice philosophy, which is that, in providing palliative care, hospices must acknowledge and address not only patients’ physical pain, but also their emotional and social pain, and their spiritual need for security, meaning and self-worth.

The notion of person-centred care, described by hospices as fundamental to their approach, is undergirded by the concept of ‘total pain.’ These two key concepts come together in the over-arching aim of the hospice movement to tailor palliative care around the needs of *that* particular patient and *their* particular condition.¹⁴ I suggest that this approach, together with the distinctive evolution of UK hospices outside the NHS¹⁵ and their aim to support (but not

¹² Hospice UK <www.hospiceuk.org/information-and-support/your-guide-hospice-and-end-life-care/im-looking-hospice-care/what-hospice#content-menu-1780> accessed 16 May 2022.

¹³ Cecily Saunders, ‘The evolution of palliative care’ (2000) 41 Patient Education and Counselling 7; David Clark *Cicely Saunders: A Life and Legacy* (Oxford University Press, 2018).

¹⁴ Hospice UK (n 12).

¹⁵ Hospices in the UK are typically constituted as independent charities, see Hospice UK <<https://professionals.hospiceuk.org/about-us/membership>> accessed 2 September 2022.

to cure) patients at the end of life, means that hospices interpret the MCA in a unique decision-making context. In situating my empirical work in hospices, I was interested in exploring how this unique context was reflected in, or translated into, hospice staff members' interpretation of the key principles of the MCA, particularly the concepts of 'capacity' and 'best interests'.

What I found was that the empirical data, grounded in the hospice as a particular decision-making context, encouraged a focus on the importance of thinking relationally. Interview participants suggested that relationships become more widely relevant at the end of life, so that, for example, their patients' relationships with past selves, with their current disease, and with an imagined future all influenced decision-making. Decisions were taken within the context of a multi-disciplinary team, of which the patient and carers or family members were an integral part. This encouraged a methodological approach, particularly to the synthesis of the four phases, that was similarly attentive to the workings of relational entanglements.

SECTION 2: A NOTE ON THEORETICAL FRAMING AND METHODOLOGY

Acknowledging the centrality of relationships to MCA decision-making in hospices, my research investigated relational theories in the context of the MCA framework. In my exploration of the 'constellation of ideas, practices and institutions'¹⁶ relevant to the notions of self and autonomy that inform legal ideas about capacity and decision-making, I was influenced by the ideas of relational theorists, whose convictions I share. Relational theory posits that, 'existence is not an individual affair,¹⁷' but, rather, that we are embedded in, and

¹⁶ Jennifer Nedelsky, *Law's Relations A Relational Theory of Self, Autonomy, and Law* (OUP 2011) 3.

¹⁷ Karen Barad, *Meeting the Universe Halfway: quantum physics and the entanglement of matter and meaning* (Duke University Press 2007) ix.

constituted by, our relationships.¹⁸ This theoretical framing, in the context of hospice care, allowed for an exploration of the law's approach to care and compassion as relational concepts,¹⁹ and, as part of that, an engagement with ethic of care literature. I found Carol Gilligan's understanding of an ethic of care as 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 particularly relevant to MCA decision-making.²⁰ My data indicated that an approach akin to this guides hospice staff in their interpretation of the MCA for patients approaching the end of life. I also drew on legal consciousness theory²¹ to explore the way in which the MCA is experienced by hospice staff members as they make decisions in the context of caring for patients.

Interlinked with my relational approach to the law, 'story' was another key feature of my research. I thought about stories in my genealogical consideration of the 'life story' of the MCA and my characterisation of judgments as legal stories linking the 'law in books' to the law in ordinary people's everyday narratives of life and circumstances. My empirical work engaged with stories in the more traditional sense, attending to the stories told by hospice staff members to illustrate their understanding and interpretation of the MCA in practice. A narrative approach is particularly relevant to hospice decision-making, because stories have

¹⁸ Carol Gilligan, 'In a Different Voice: Women's Conception of the Self and of Morality' (1977) 47 *Harvard Educational Review* 4 481; Barad, (n 17); Jonathan Herring, 'Caring and the law' (Hart 2013); Nedelsky (n 16).

¹⁹ Maksymilian Del Mar, 'Imagining by feeling: a case for compassion in legal reasoning' (2017) 13 *International Journal of Law in Context* 2 143.

²⁰ Carol Gilligan, 'Moral Injury and the Ethic of Care: Reframing the Conversation about Differences' (2014) 45 *Journal of Social Philosophy* 1 89. I was also influenced by Gilligan's earlier work (see n 18), the work of Jonathan Herring, see n 18 and 'Compassion, ethics of care and legal rights' (2018) 13 *International Journal of Law in Context* 2 158; and the work of Joan Tronto, see, for example, 'Beyond gender difference to a theory of care' (1987) 12 *Signs: Journal of Women in Culture and Society* 4 644.

²¹ Patricia Ewick and Susan Silbey, *The Common Place of Law: stories from everyday life* (University of Chicago Press 1998).

long been 'given time and space' in hospice and palliative care.²² Furthermore, 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.²³

A narrative approach also suited the non-linear view of time that underpinned my research. Stories contract time, wander back and forth in time, are inextricably part of time and yet remain timeless as they are re-made each time they are (re)told and actively reconfigure the past within the context of their telling.²⁴ Narrative research can, therefore, use storied tellings to investigate how the past is brought to bear, 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.²⁵ Adopting a storied approach to thinking about data in each of the four phases also created conceptual and analytic coherence. I followed Reissman's approach, treating archival documents, judgments and interviews as analytic units (thus keeping the narrative intact) rather than fragmenting them into coding units for analysis.²⁶ This allowed me not only to achieve a more nuanced analysis of the content of each *individual* document, but also to identify patterns (themes) chronologically across each *phase* of the research and, ultimately, across the study as a whole. I was also persuaded by Reissman's theoretical conviction that narrative is an important approach to investigative enquiry because a close analysis of stories can reveal truths about human experience.²⁷

²² Amanda Bingley et al, 'Developing narrative research in supportive and palliative care: the focus on illness narratives' (2008) 22 *Palliative Medicine* 653.

²³ See, for example, Warren Brookbanks, *Narrative Medical Competence and Therapeutic Jurisprudence: Moving towards a synthesis* (in McMahon, M. & Wexler, D. (eds) *Therapeutic Jurisprudence*, The Federation Press 2003).

²⁴ Mona Livholts and Maria Tamboukou *Discourse and narrative methods* (Sage 2015).

²⁵ Ewick and Silbey (n 21).

²⁶ Cathy Reissman, *Narrative methods for the human sciences* (Sage 2008).

²⁷ Reissman *ibid*.

My contention is that law is part of this narrative connection between people and society.²⁸ 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.²⁹ This theoretical and methodological approach underpinned and informed the methods I developed and will discuss in this article, starting with my exploration of the social and policy context within which the concepts underpinning the MCA were debated.

SECTION 3. FOUCAULDIAN GENEALOGY AS METHOD: ANALYSIS OF THE DESCENT AND EMERGENCE OF THE MCA

Foucauldian genealogy focuses on the descent of the subject; descent in the sense of a lineage, a family tree or a network of relationships.³⁰ Foucault did not consider that anything was traceable back to a single point of origin; rather, he looked at heterogeneous and diverse historical sources and explored the links between them in order to understand how they worked together to set the scene for something new to come about.³¹ Foucault was interested in relationships with the power to effect change and to establish new ways of thinking, and in the ways in which the interplay of these relationships promoted new possibilities and ways of being in the world.³² In Foucauldian genealogical analysis, the aim is

²⁸ For a discussion of the idea of law as a biography, see Sally Sheldon and others, 'The Abortion Act (1967): a Biography (2019) 39 *Legal Studies* 18.

²⁹ Ewick and Silbey (n 21); Nedelsky (n 16).

³⁰ C G Prado, *Starting with Foucault: an introduction to genealogy* (Westview Press 2000).

³¹ *Ibid.*

³² *Ibid.*

to trace the antecedents of the subject of interest, to look for factors that might have come together to set the scene (to create the conditions of possibility) the start of something new.³³

In designing a method informed by Foucauldian thinking, my aim was 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.³⁴ In looking to trace the descent of the MCA, I sought a broad understanding of the direction of *social* policy travel, in order to investigate its relevance to *legal* change. I aimed to create a data archive that ‘took the temperature’ of society immediately prior to the emergence of the MCA, and to use that archive as a tool with which to bring Foucault’s genealogical approach to bear in the socio-legal context. In the absence of any established Foucauldian method for undertaking a socio-legal genealogical analysis,³⁵ I designed and implemented a two-stage approach. In the first stage (*Descent*), I constructed a data archive. In the second stage (*Emergence*), after reading and re-reading the data in the archive, I looked for patterns (themes³⁶), insights into the changes in societal thinking, that became influential in the changed societal and legislative approach to mental incapacity.

It was in the first stage, ‘descent’ that the key challenge of this genealogical approach lay. In compiling the data archive, I was creating an imaginary of the ‘descent’ of the MCA’s approach and key concepts, the first chapter in the ‘life story’ I wanted to write. I was conscious that an insufficiently broad-ranging archive might omit aspects of the story, limiting the patterns and

³³ Michel Foucault, ‘Nietzsche, genealogy and history’. (Paul Rainbow (ed) *The Foucault Reader* Penguin 1975).

³⁴ See Lucy Series, *Deprivation of Liberty in the Shadows of the Institution*, (Bristol University Press 2022) for a similar ‘critical genealogical’ approach to investigate problems associated with social care.

³⁵ Prado (n 30).

³⁶ These informed my use of template analysis to explore the data, see Section 6 below.

insights I was hoping to reveal. To guard against this, I looked for threads and connections widely in a diverse collection of documentary materials. I continued building the archive until I felt that I had achieved a level of data saturation, that my continued reading was confirming similarities in the data rather than new 'lines of flight,' thus creating a productive symbiotic relationship between the 'descent' stage and the 'emergence' stage.

My exploration of the historical material to map the descent of the MCA started with the documents cited in the explanatory note to the Act.³⁷ I adopted a 'snowballing' approach and selected additional documents for review as I identified connections and tessellations. This approach generated a heterogeneous archive of historical documents which would have been difficult to access by way of a traditional review of a particular body of literature. The 'snowballing' approach, by contrast, allowed me to search across a broad variety of documents, and to create an archive comprising legal case reports, consultation documents, policy documents, judicial opinion, parliamentary reports, UN documents, press reports and political manifestos. My construction of the archive was deliberately neither linear nor chronological. I followed the references and connections backwards and forwards in time, identifying the factors that came together to set the scene for a legislative change and created the 'conditions of possibility' for the emergence of the MCA; in particular, the key principles (in s1 of the MCA) and the central concepts of capacity and best interests, which were intended (and continue) to direct the Act's use in practice.

³⁷ Available at < www.legislation.gov.uk/ukpga/2005/9/notes/contents> accessed 16 May 2022.

These concepts and principles became visible as far back as 1991³⁸, and the philosophy underlying them was visible throughout the archive as a whole. Immersing myself in the documents, I reflected on whether, and how, they influenced the development of the MCA's principles and central concepts. By interrogating those reflections, I identified three threads running through the archive: an increasing societal acceptance (and celebration) of difference, a movement towards inclusion and empowerment, and an intolerance of discrimination or misuse of power. I drew three key over-arching themes from these threads; *emergence of the individual*, *a person of value*, and *role of law*. There was support across the archive for legislation which enabled rather than restricting, and which accorded rights to a person without capacity (the *emergence of the individual*). The *person of value* theme references the philosophical idea that human beings are valuable in and of themselves.³⁹ This underpins the human rights instruments that appeared in my data archive, and, in particular, the importance of their emphasis on the dignity and worth of each human being.⁴⁰ 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 reflects the influence of a human rights discourse on policy during this period. The *role of law* theme, central to my overall interest in the relationship between law and society, developed throughout the study (leading to my use of legal consciousness theory in understanding the experience of hospice staff members in applying the MCA framework). In the context of my Foucauldian method, the *role of law* recognizes Foucault's characterisation of legal (and medical) practices and processes of 'legality' as powerful.⁴¹ His conception of power as a complex network, within which people

³⁸ Law Commission, *Mentally Incapacitated Adults and Decision-Making: An Overview* (Law Com No 119 1991).

³⁹ Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn, OUP 2009).

⁴⁰ See, for example, United Nations *Declaration on the Rights of Mentally Retarded Persons*, <ohchr.org/EN/ProfessionalInterest/Pages/RightsOfMentallyRetardedPersons.aspx> accessed 16 May 2022.

⁴¹ Michel Foucault, *Discipline and punish: The birth of the prison* (A. Sheridan tr, Penguin 1975).

act to condition the options and actions of others, also has particular resonance in the context of medical decision-making for people without capacity.⁴²

Working together through the phases of the research, then, these three themes encapsulate the social change that took place in the decade prior to the enactment of the MCA. They became my key themes, and, linking the four phases of the research, they underpinned my detailed investigation of the development of the law concerning mental capacity from the intentions of those debating law reform in the 1990s to the interpretation of the MCA in English hospices in the present day. The next stage in that investigative journey was my review of Supreme Court and CoP judgments from 2007, when the MCA came into force, until 2018.

SECTION 4. A REVIEW OF THE JUDICIAL LITERATURE: THE EMBEDDING OF THE MCA INTO 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.⁴³ 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.⁴⁴ Judicial decisions have direct consequences on the individuals involved in the cases, and indirect, longer-term consequences as those decisions are applied and (re)interpreted in subsequent cases heard by the courts. I used Supreme Court and CoP

⁴² Ibid.

⁴³ Ewick and Silby (n 21); C. Smulavitz, *Law and Courts' Impact on Democratization* (in Cane, P. and Kurzner, H. (eds) *Oxford Handbook of Empirical Legal Research*, OUP 2010).

⁴⁴ Ronald Dworkin, *A Matter of principle* (Harvard University Press 1985).

judgments as lenses through which to review how the MCA had been, and was being, embedded in practice.

I adapted the requirements for a systematic literature review in the social science tradition to my search of case law interpreting and applying the MCA, designing and using a systematic strategy to ensure that I completed a comprehensive search for relevant judgments. Case law applying the MCA is, unsurprisingly, extensive, and so I applied specific inclusion and exclusion criteria to enable the identification of an appropriately focused body of judgments for detailed analysis. My search was directed by this question:

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?

I included or excluded cases by applying the following criteria:

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).

I searched two legal databases: Westlaw UK and LexisLibrary (UK). The searches were restricted to cases heard in the English Supreme Court and the CoP, the court with jurisdiction in England and Wales to make decisions under the MCA. The search retrieved a large number of cases (n = 1,596), and the PRISMA flow diagram (Figure 1 below) depicts the process and reasons for exclusion at each stage. The final corpus of cases selected for analysis (n=16) was created by applying reasoned purposive inclusion criteria (see Table 1).

Table 1: Reasoned purposive inclusion criteria for selection of the final corpus of cases

Inclusion criterion	Reasons
Decisions of the Supreme Court	The decision-maker of last resort: sets precedent
Cases 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 of judgments was not influenced by the likelihood of the care or treatment considered being offered by a hospice (such cases appeared rarely to come before the CoP), although the provision of palliative care was relevant in several instances. Whilst I had hoped to be able to review cases with a direct correlation to the hospice context, I felt, on reflection, that reviewing a broader range of decision-making places and spaces allowed a more nuanced understanding of judicial development of the MCA, as well as allowing the empirical phases to offer a distinct perspective on the hospice context.

Having identified the final corpus of cases, I took a two-stage approach to analysis. I looked first at the application of the MCA, reviewing how the key legal concepts of capacity and best interests had been interpreted and applied in the judgments (the doctrinal lens). I looked at the rationale for the judge's application of the MCA framework to the facts and recorded my findings in a detailed data extraction table. I then went back to the judgments and read them again, this time approaching them as narratives in which the judge re-told the story of the events leading to the court's involvement (the narrative lens). By combining a doctrinal and a narrative engagement with the content of each judgment, I wanted to develop a deeper understanding of how the MCA was being embedded into practice. Reading through the judgments-as-narratives, I coded each by reference both to the three key themes from the genealogical analysis, (*emergence of the individual, a person of value, and role of law*) and to note different ideas. This allowed me to identify patterns in the judges' reasoning that reflected the aims of the legislators, as identified by the genealogical work, and to capture any departures, or differences. The identification of additional patterns as part of the

narrative stage facilitated the development of richer theoretical ideas as the study progressed.⁴⁵

Applying this two-stage doctrinal / narrative analytic approach to the final corpus of cases, I found that the three key themes from the archive underpinning the Foucauldian review, *emergence of the individual*, *a person of value*, and *role of law*, continued to be relevant to the way in which the legislation was judicially interpreted in the CoP. The genealogical analysis had captured the themes broadly, and the judgments were the lens which, over time, afforded a closer view of *how* CoP judges considered the person at the centre of the decision-making process (*emergence of the individual*), accorded value to their wishes and feelings (*a person of value*), and brought the MCA to bear in so doing (*role of law*).

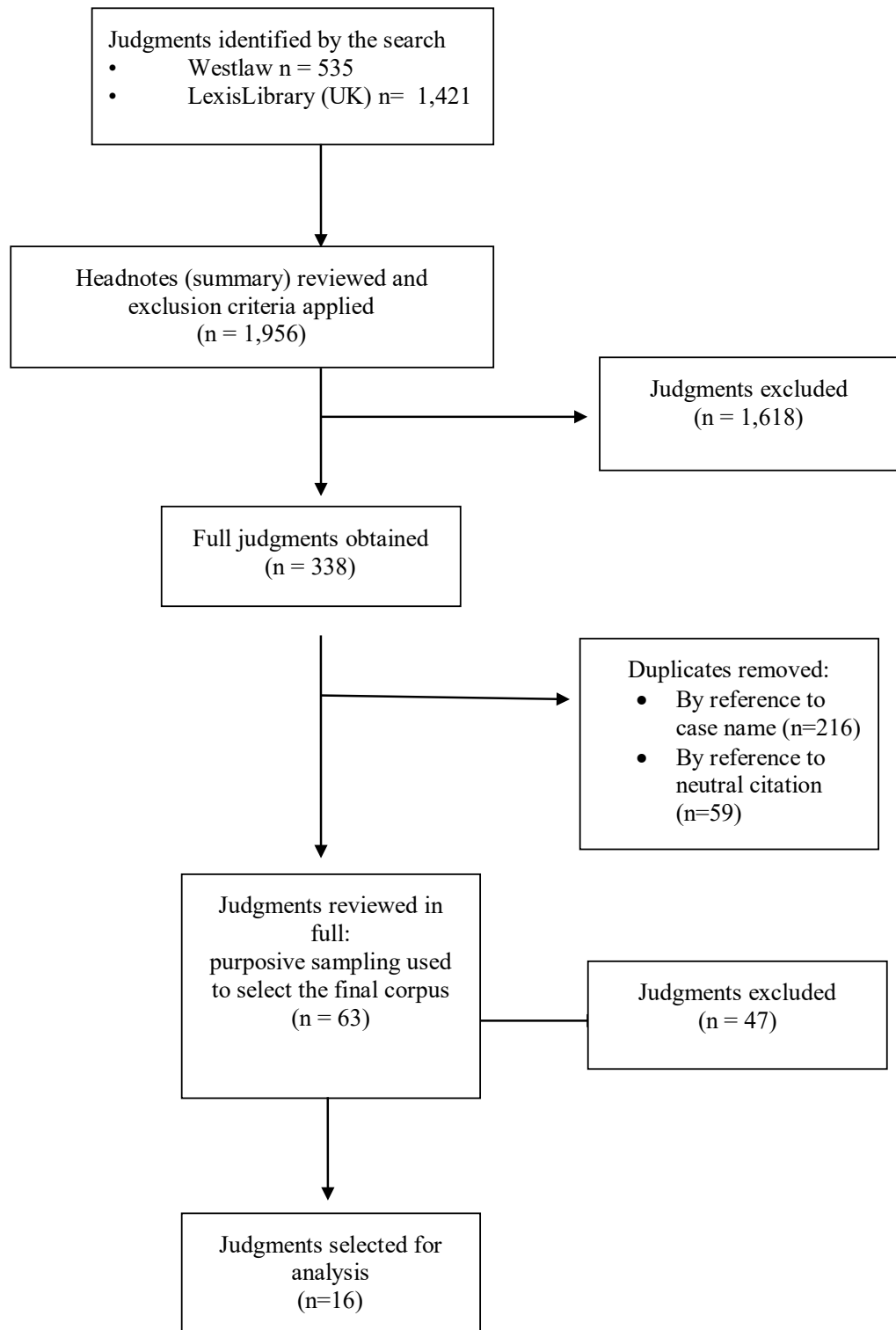
Interestingly, the review of judgments revealed a change in judicial engagement with the person whose story was being told (P). Where direct engagement was possible, judges increasingly chose to meet P. This suggested a shift in judicial practice in the CoP, a correlation with the intentions of the legislators (*emergence of the individual, a person of value*) and enabled a theoretical consideration about the constitutive nature of relational engagement in legal practice (*role of law*).⁴⁶ This was reflected in the findings of the empirical research in the final phases of the study, where participants' described a consciously relational

⁴⁵ While a detailed discussion of these findings is without the scope of this article, the point can be illustrated by reference to a theme of time and space in the context of relatives' memories of the former wishes and feelings of someone existing now in a minimally conscious state. In *Briggs v Briggs* (No.2) [2016] EWCOP 53, Charles, J. (at [58]) accepted the views of others as evidence of Mr Briggs' wishes and feelings, allowing me to suggest that, in so doing, the judge was acknowledging importance of an idea of *relational* autonomy in MCA decision-making.

⁴⁶ For discussion of the theoretical underpinnings see Nedelsky (n 16) particularly Chapter 1.

engagement with patients in their care as an important aspect of their interpretation of the MCA framework.

Figure 1: stages of the case law review



SECTION 5. DISCUSSIONS WITH HOSPICE STAFF

In phase three of my research, I explored how senior staff (decision-makers from across the multi-disciplinary team) worked together to interpret and apply the MCA, finding that the policy and practices they implemented set an important organisational dynamic. Again, I employed a staged approach, reviewing the organisational policy documents for the hospice and then discussing their development and application in practice with a group of senior staff with responsibility for ensuring compliance with the MCA. Two group interviews were held at the participating hospices (see demographic information in Table 2). The group interviews were semi-structured and followed a discussion guide provided to participants in advance. The focus was on the key concepts of capacity and best interests within the broad legal framework of the MCA and the narrower framework of particular hospices' policies and procedures.

Table 2: 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
<u>Nature of role:</u>		
Clinical care	4	3
Social care	1	
Education	1	1

In phase three, I was interested in exploring both the bigger picture (the development of the law and the regulatory environment in the hospice sector) and trying to uncover any specific influences on policy and implementation of the MCA in the context of each participating hospice (such as, for example, whether learning from a particular patient's journey, or a staff

member's experience was reflected in guidance or training). I thus conceived the organisational 'policy' as being something which was subject to change while remaining part of the ongoing culture and organisational context of the hospice. I investigated this at an organisational level and, in phase four, in conversation with individual staff members.

Phase four was the final phase of the study. I recruited and interviewed hospice staff from the two participating hospices. Recruitment was by purposive sampling of 3-4 staff members from each participating hospice. I endeavoured to capture a broad range of perspectives, recruiting from across the range of clinical, social care, bereavement and spiritual care professionals represented on the staff, my central inclusion criterion being that all participants had responsibility for supporting patient treatment and/or care decision-making.

Inclusion criteria for the sample were:

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 research was publicised within each participating hospice and interested staff members were invited to email me. In the event, only three participants were recruited in each participating hospice (see Table 3 for participant information).⁴⁷

⁴⁷ Recruitment to the study was challenging. Recruitment information was circulated by an organisational contact and Initial expressions of interest were followed up once, in accordance with ethical approval for the study.

Table 3: Individual Interviews: Demographic information

	Hospice 1	Hospice 2
No. of participants	3	3
Gender:		
• M	1	0
• F	2	3
Age range (years)	23-53	34-57
Nature of role:		
Clinical care	2	2
Clinical care/education	1	
Social care		1

In my semi-structured interviews with these staff members, I explored their personal experiences of decision-making under the MCA. Participants were asked to narrate memorable experiences of decision-making for patients, but were not asked to situate their stories in a discussion of the legal or policy context. Rather, I encouraged them to present and discuss their experiences by reference to the principles that guided *their* engagement with care and treatment decision-making for patients. Participants explored the experiences chosen in depth, concentrating on the way those involved (such as the hospice staff, the patient, and their family) took part in the decision-making process. The aim of this final phase was to understand the professional perspective of MCA decision-making, particularly as regards the patient's role in the process. As with Ewick and Silbey's work in investigating legal consciousness, it was in individuals' *perceptions* of the law and not the law itself that I was interested.⁴⁸

Having collected the range of data I hoped would illuminate whether, and, if so, how, the intentions of the legislators had become woven into the present understanding by hospices

⁴⁸ Ewick and Silbey (n 21). Legal consciousness became a key feature of my research and a significant aspect of the discussion about the distinctiveness of the hospice movement.

of the MCA in practice,⁴⁹ I drew the threads of the research together in a synthesis of the findings across the study as a whole. In the section that follows, I describe how I used template analysis in each phase of the study, and to synthesise the findings across all four phases.

SECTION 6. USING TEMPLATE ANALYSIS TO ANALYSE AND SYNTHESISE

Template analysis, a type of thematic analysis, uses hierarchical coding 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.⁵⁰ In each phase of the study, I developed an initial template from my inductive coding of the first document, judgment, or interview transcript, which then formed the basis for coding the second, and so on, facilitating the iterative development of more complex codes and, ultimately, themes from the documents, judgments or interviews being analysed. In developing my initial coding template for each phase of the research, I worked through a process, based on that described by Brooks et al.:⁵¹

1. I familiarised myself with the data by reading and re-reading the documents, judgments or interview transcripts. I preliminarily coded the data by highlighting aspects which seemed to me to be interesting in terms of facilitating my understanding of the data, or to suggest a pattern or trend.
2. Having identified my initial codes, I organised them into clusters around the patterns (themes) they suggested. In phases two to four, during this process of organisation, I

⁴⁹ For a discussion about historicising the present, see Penny Tinkler & Carolyn Jackson, 'The past in the present: historicising contemporary debates about gender and education' (2014) 26 *Gender and Education* 170 available at < doi.org/10.1080/09540253.2013.875131 > accessed 16 May 2022. See also Series (n 34).

⁵⁰ Brooks, J., McCluskey, S., Turley, E. & King, N., 'The Utility of Template Analysis in Qualitative Psychology Research' (2015) 12 *Qualitative Research in Psychology* 202.

⁵¹ Ibid.

considered the relevance of the broad conceptual ideas represented by the key themes from the genealogical analysis (*emergence of the individual, a person of value, and role of law*).

3. The resulting conceptual themes, arranged hierarchically, comprised the initial template for each phase, which was then iteratively developed as the rest of the data was analysed.

Template analysis was a useful method for this research, facilitating the identification of patterns and common threads over time and across the heterogeneous narrative sources explored. The method also allowed similarities between themes from earlier phases of the research and the later phases to be made visible. This was achieved by using the three key themes from the genealogical analysis, *emergence of the individual, a person of value, and role of law*, as 'organising themes' for the analysis of the judgments and the interview data. I did not characterise or use these three themes as 'a priori' themes, in the sense that they represented some pre-determined theory or structure, because to have done so would have created a sense of conflict with the 'bottom up' approach that underpinned my research. However, I reflected on the relationship between these key themes and the data I was analysing at each phase of the project. In this way, analysis of the judgments and the interview data continued the process of 'historicising the present',⁵² which my genealogical approach to constructing the life story of the MCA had started. The challenge, from the perspective of the research as a whole, was to bring the analysis together coherently, to make sense of the

⁵² Livholts and Tamboukou (n 24) 64.

relationship between the four phases, and to bring the life story of the MCA up to date (or, at least, to the date of the data collection).

I considered a variety of methods to achieve this. Noblit and Hare's approach to synthesis, based on identifying key concepts from one study and 'translating' them into another to take an argument beyond the content of the original studies, appeared the best 'fit'.⁵³ However, their notion of 'translation' of related concepts into each other felt too static for my purposes, suggesting simply a different means of expression of the same idea. I looked to the work of the relational and narrative theorists, whose ideas had influenced my situation of this research, for a more dynamic approach to synthesis. Barad's ideas about diffraction as an analytic tool were immediately appealing.⁵⁴ Initially a quantum physicist, Barad has grounded her concept of diffraction on the behaviour of waves when they overlap, and the apparent bending and spreading of waves when they encounter an obstruction.⁵⁵ She uses diffraction as a metaphor for describing an approach to analysis that attends to the effects of difference, suggesting that diffraction makes visible the relational nature of change.⁵⁶ Barad's ideas about diffraction underpinned the way I had visualised the themes from the (phase one) genealogical research moving into the legislative process and, from there, into the MCA itself. Thinking about synthesis, and Noblit and Hare's use of 'translation' to pull related concepts together, I decided to create a 'synthesising template'. I based my synthesis on Barad's notion of diffraction to examine how the themes from the four phases were related (characterising each phase of the research as a slit through which the themes were passing and looking at

⁵³ Noblit GW and Hare RD, *Meta-Ethnography: Synthesizing qualitative studies* (Sage 1988)

⁵⁴ Barad (n 17).

⁵⁵ Barad (n 17), see discussion in Chapter 2.

⁵⁶ Barad (n 17), see particularly Chapter 2 at 71.

the diffraction patterns created), and, in so doing, to make visible any (lack of) change in interpretation of the MCA over time.

In order to develop this synthesising template, I reviewed the analytic templates from each of the phases, looking for over-arching links and patterns across the datasets. As I had done in approaching the analysis of each phase, I again considered the relevance of the *emergence of the individual*, *a person of value*, and *role of law* to the data as a whole. This exercise generated four broad themes, within which the themes of each phase nested (see Table 5). The synthesis clearly makes visible the effects of change over time in the interpretation of the MCA, suggesting, for example, that the notions of care, compassion and therapeutic jurisprudence, have become increasingly relevant to law and legal thinking, and making visible the role of legal consciousness in hospice staff's interpretation of the MCA. Interestingly, for the aims of the research (to consider how the MCA's principles have been understood and interpreted in hospice practice, and to compare this understanding to the legislators' intentions), the three key themes from the genealogical analysis, *emergence of the individual*, *a person of value*, and *role of law*, remain visible in the final template, albeit patterned differently after their passage through time and place.

Table 5: The synthesising template: 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

SECTION 7. REFLECTION AND CONCLUSION

The story of my research started with negatives. 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.⁵⁷ The conclusion of my research, however, was positive. My findings suggested that the MCA *is* well understood in hospices, that its implementation *does* empower patients who lack or are losing capacity, as it allows their wishes and feelings to be heard and reflected in decisions concerning their care and treatment at the end of life. Furthermore, I found that hospices (as organisations) and their members of staff were *keenly* aware of their responsibilities to work within the requirements of the MCA.

In this article, I have described how my phased approach to the research enabled the collection and interrogation of varied narrative datasets. My approach was the cumulation of varied readings, discussions, and excursions into methodological dead ends that looked interesting from the entry point. This was both a benefit and a challenge, for obvious reasons. My research design facilitated a coherent approach to a potentially complex combination of methods in a relatively small-scale piece of research. Template analysis worked well in this context, but my use of it was not unusual and need not figure in this reflective conclusion, save to acknowledge its important role in allowing the 'flow' of the themes from one phase

⁵⁷ Select Committee on the Mental Capacity Act 2005 (n 2).

to another, and its role in facilitating a synthesis which led to an interesting theoretical discussion.

In terms of the wider application of the methods to socio-legal scholarship, I suggest that there is a place for an adaptation of the systematic review, and for the genealogical approach, underpinned by Foucauldian thinking, that I developed to investigate the 'becoming' of statute law. While the former, in the form I used for my exploration of the phase two data, would not satisfy a systematic reviewer from a social science background, it does allow for a focused and defensible collection and analysis of a body of case law. As to the latter, a genealogical approach has, from a socio-legal perspective, continuing merit for researchers.⁵⁸

In my research, its purpose was to facilitate a detailed exploration of the reasons for which the time was right for the MCA to come about, but it has broader application than this.⁵⁹ A Foucauldian genealogical approach could accommodate the collection of a larger documentary archive than I was able to navigate, and, combined with a transparent and replicable search strategy, could defend itself against claims of researcher bias. Such an approach also has the potential to draw out and uncover more complex themes rooted in power dynamics, which were a key fascination of Foucault's.⁶⁰ A genealogical approach might be of most value, though, in an investigation that seeks to understand how a *change* in the law came about, as my study did or, as Series' recent work has done, to explore why the law

⁵⁸ I note Series' use of a similar approach for the research into post-carceral social care, described in her recent book (n 34).

⁵⁹ See for example Series' recent book, *ibid*.

⁶⁰ See, for example, Foucault (n 31); Foucault, M. *The Confession of the Flesh* in Gordon, C. (ed) *Power/Knowledge Selected Interviews and Other Writings* (The Harvester Press Limited 1977)

in some areas has changed *less* than we might hope or expect.⁶¹ My current research on the use of direct-to-consumer genetic testing by donor-conceived people,⁶² includes a comparative analysis of laws removing gamete donor anonymity in several jurisdictions. I am exploring the ways in which a Foucauldian genealogical analysis of notions related to the importance of genetic heritage in each society prior to, and post, the legislative change might support a comparative socio-legal study. Laws with contested normative framing (assisted dying might be an example) would also offer fertile ground for a genealogical analysis based on Foucault's ideas.

Thus, I think that my genealogical approach is generalisable to laws and legislative change both in England and Wales and in other jurisdictions.⁶³ The same is true of the phased combination of documentary and empirical enquiry, linked and synthesised by template analysis, which I used to investigate the development of the MCA's key concepts over time. My research focused on a particular legal framework in what I have characterised as a unique (decision-making) context. However, my methodological approach would serve equally well as a means of investigating the 'life story' of another statute in a different context.

Looking closer to home for my final reflections, my exploration and development of the research methods I have described above has facilitated a richer engagement with the

⁶¹ Series (n 34).

⁶² See the ConnecteDNA research project website: <<https://sites.manchester.ac.uk/connecte-d-n-a/>> Accessed 31 August 2022.

⁶³ Interestingly, in Sweden, before the Government can draw up a proposal for legislation, or legislative change, analysis and evaluation of the matter in question is required. The resulting Official Reports (Statens Offentliga Utredningar, or SOU) offer a readily available and comprehensive archive of information to the socio-legal researcher interested in a genealogical enquiry.

relationship between law and society, and between people (including judges) and 'the law', particularly in the context of laws that support caring relationships, and specifically where decision-making capacity is in issue.