LEGAL DECISION MAKING AND DEMENTIA: A DISCOURSE AND CONVERSATION ANALYSIS STUDY

by

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Abstract

This thesis adopts a socio-legal approach to investigating mental capacity law and legal decision making for people with dementia and their carers. I use the empirical research methods of semi-structured interviews and observations to answer my research questions. I conducted 20 interviews with people with dementia and their carers, and four observations of solicitor-client meetings where a will was being discussed. I used this data to answer three main questions. Firstly, how do people living with dementia and their informal carers access and interpret legal advice, what is the content of this legal advice, specifically how does this rhetoric form the construct of 'capacity law', and what impact does this have on their understanding of their legal rights and their mental capacity? Secondly, how do legal actors assess capacity and how does this impact the legally relevant decisions made in the lives of people with dementia? And finally, what is the contribution of observational methods, such as Conversation Analysis (hereafter CA), to understanding legal decision making in action? My data is analysed using thematic discourse analysis and Conversation Analysis. This enables a rigorous exploration of the rhetoric which constructs what capacity law is in the everyday lives of people with dementia and their carers, as well as in the everyday legal setting of a solicitor’s office. In my analysis, I demonstrate how capacity law in England and Wales currently restricts people with dementia and their carers as it does not properly reflect the reality of their relational lives. I contribute to several theories in this thesis, drawing from sociological, psychological and legal theories. I argue that if capacity law practice adopted a relational approach to personhood and sought a more inclusive, contextual understanding of the impact of people's relationships and experiences when decision-making, then people with dementia and their carers could be empowered. People

with dementia and their carers' voices are at the centre of this thesis and my proposals, therefore I can conclude that to properly reflect and respond to their needs law and policy must adapt, allowing for the complexity of everyday life.

Dedication and Acknowledgements

This thesis is dedicated to my family and to Alice.

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List of definitions

Capacity law

When referring to capacity law, unless explicitly stated otherwise, I refer to the capacity law in England and Wales. The mental capacity Act governs England and Wales, as does law pertaining to wills. This thesis concerns only to these countries, as Scotland and Northern Ireland have different governing laws

People with dementia

I refer to people with dementia, however my participant's specific diagnoses differed (as can be seen in the method section). Broadly people with dementia can also include but is not limited to, people with Alzheimer's, or mild cognitive impairment. People may also have other diagnoses as well as memory impairment (such as stroke or depression).

Introduction: legal and psychological definitions of capacity, the impact on people with dementia and their carers.

The context and aims of this research

This research is interested in how law exists in the everyday lives of people with dementia and their informal carers. My research aims are threefold;

> Firstly, understand how decisions about wills and power of attorney are made in the everyday lives of individuals with dementia and their families/carers. Secondly, to investigate when, and how, mental capacity is understood in the everyday lives of people with dementia and the everyday legal settings. Finally, I aim to add to the theoretical development of the concept of relationality through empirical investigation and highlight how it might be integrated into capacity law to empower people with dementia and their carers.

To achieve these aims I conduct empirical research involving people with a diagnosis of dementia and their carers, as well as a solicitor and their trainee solicitor, and their clients who are making wills. I detail the methodology of my research later in this introduction, it is important to ground this research in the sociological field, and in the everyday lives of legal actors. My attention to society and law and the symbiotic relationship between the two will be discussed in this chapter after I first introduce what capacity law is, what it has been, and why this is important for people with dementia and their carers. I also pay attention to how my research relates to disability studies, and law as language, making a unique contribution to both fields by adopting a socio-legal discourse analytic approach to answering my research questions. I examine capacity law through the discourses evident in the three main laws used for Lasting Power of Attorneys (hereafter LPAs) and wills in England and Wales. All references to capacity law in this thesis pertain to that which governs England and Wales, as both Scotland and Northern Ireland have different governance. These laws are the Mental Capacity Act (2005) (hereafter MCA), which governs LPAs, the *Banks v Goodfellow* (1870) common law case which is used for assessing testamentary capacity for wills making, and the United Nations Convention on the Rights of Persons with Disabilities (2006) (hereafter UN CRPD), which the UK ratified in 2009.[1],[2]

Following this discussion of the legal discourses of capacity and how these may impact people with dementia, I widen my gaze to examine how the symbiotic relationship law has with the society in which it exists may explain perceptions of capacities. I pay close attention to the consumption of psychological and scientific information regarding capacity, and how this is evident in legal interpretations of capacity. This exploration of legal and societal discourses of capacity inform my statement of research and the problems which I aim to address. I state my research questions and follow this by explaining how I will answer these in this thesis. I explain the theories (summarising chapter 2) and methods (summarising chapter 3) I have used to answer my research questions, and why these are suitable for this research. I point to the novelty of my approach, as these everyday legal discourses have not been examined in this way before (to my knowledge). I then give a chapter-by-chapter overview detailing the analytical findings from my research (chapters 4 – 7), before drawing conclusions about this thesis and the approaches I take.

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[1] *Banks v Goodfellow* [1870] 5 LR 549 (QBD) (Cockburn CJ)

[2] I give a full reference for each doctrine when first citing said document, and thereafter use the abbreviated form with no reference.

Capacity law discourses

When stating the changes in discourse in this chapter, I refer to how writing in legal documents is not a passive process but one of active engagement with social beliefs, where word choice is conscious and purposeful. This is reflective of new rhetoricist values (Berger, 1999). The debates and sociological exploration of the relationship between law reform and social change is too significant to be fully addressed in this chapter, however I align to the stance that there is a generally symbiotic relationship between the two, and this is sufficient for this thesis. Levett and Thompson (2015) offer a summary of the interactions of law and society whereby the law is both reliant on and incites social change, which can be through direct or indirect impact. This simplifies the complexity of the relationship but demonstrates the plurality of discourse's influence(s) and effect. Legal rhetoric investigation is essential due to the authority given to legal discourse and its potential to change public opinion (for positive or negative outcomes) (Mccann, 2017). I have tracked the discourse shifts of capacity law, observing the changes in written law that link to societal views of capacity. I explore the implications of discourse further first by examining how culture can affect perceptions of capacity, then how interviewees form their own constructs of capacity.[3]

I will now outline the terminology used, firstly in the common law of wills*, Banks v Goodfellow*[4], secondly in the MCA and finally in the UN CRPD. I will discuss each of these, examining the discourse, how they interact and how this presents in practice.

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[3] See page 23-32 of this chapter for explanation of potential cultural influences, and chapter 4 for my analysis of how interviewees construct capacity.

The common law: *Banks v Goodfellow* and 'the golden rule'.

Banks v *Goodfellow* provides the common law test for testamentary capacity from 1870. It sets the precedent for assessing if a will is valid. Importantly, despite proposed reforms by the law commission, currently it remains the guiding law for will making (Law Commission, 2017). It states that for a will to be valid:

> 'No disorder of the mind shall poison his affections, pervert his sense of right, or prevent the exercise of his natural faculties—that no insane delusion shall influence his will in disposing of his property and bring about a disposal of it which, if the mind had been sound, would not have been made.' (p. 29)[5]

The use of this archaic language is problematic, as has been acknowledged by the law commissions review (2017). However, *Banks v Goodfellow* establishes that the presence of a mental disorder is not grounds to dismiss the testator's will, and that the disorder must affect the ability to understand the consequences of the will. If we interrogate the language used, we observe the discriminatory intonations; a difference is identified between those who possess a sound mind and those who do not, and whether they will be subject to an assessment of legal ability.

This discourse of questionable testamentary capacity is consistent with the ageist and medical implications of the golden rule (Cartwright, 1994; Matthews, 1994). The best practice guideline of the golden rule used for testamentary capacity states:

> 'That the making of a will by an aged or seriously ill testator ought to be witnessed or approved by a medical practitioner who has satisfied himself of the capacity and

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[5] *Ibid*

> understanding of the testator, and records and preserves his examination or findings.'[6]

This advises legal professionals to obtain a medical opinion when capacity is in doubt when making a will and conflates ageing with capacity loss. This encourages an over-reliance on a medical diagnosis to determine legal rights, and ageist rhetoric. It oversimplifies and constructs capacity as preferably medically assessable (Areheart, 2008). The discourse of *Banks v Goodfellow* and the golden rule shapes how testamentary capacity is defined in legal practice, despite progress in understandings of decision making using newer psychological knowledge. Furthermore, a person who is not deemed to have testamentary capacity can apply to the Court of Protection for a statutory will (Gov.Uk, 2018; Hardinng 2015). The implications of the discriminatory language of the common law are evident; a person with a mental disability is treated differently because they must apply to a state actor to make their wishes after death valid and legal (Harding, 2015). This othering is exacerbated by the prevailing outdated discriminatory discourse and exclusionary practices. I will examine how this discourse affects testamentary capacity assessments in practice in chapter 6.

The Mental Capacity Act

The MCA is the governing law for LPAs and was created in 2005 with the aims at enabling people to have more control over their decision-making if they lack capacity at the time they need to make a decisions. The MCA defines a person as lacking capacity if:

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[6] Re Simpson [1977] 121 SJ 224

> *'At the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.*[7]

The MCA attempts to enable and protect persons with disabilities, emphasising that capacity is decision specific and time sensitive. The MCA also specifies non-discrimination conditions[8] and emphasises that functional ability is integral to a person's capacity (*Mental Capacity Act 2005 Code of Practice*, 2007). Though the law and the MCA demonstrate progression, Bartlett states that 'express discrimination has merely become implied discrimination' (2012, p.763). Whilst the MCA marks an improvement on previous discourse of medicalised competency, it remains discriminatory because it relates the presence of impairment to increased likelihood that a capacity assessment is needed. Initially, in the code of practice, the MCA compounded this idea of implied discrimination. They did this by ordering the stages of a capacity assessment as establishing if a person has a disorder first, and carrying out a functional assessment of capacity second. This has been somewhat revised in case law, whereby it is established that there are, given the principles of the MCA, 3 stages to assessing capacity. Firstly, can the person make the decision? (encouraging the assumption that all persons have capacity unless proved otherwise)Secondly, does the person have an impairment? (a diagnostic assessment), Finally, how does this impairment affect the person’s ability to make the decision required? (a functional assessment).[9],[10] These cases mark the continued shifting of capacity rhetoric. However, I would still argue,

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[7] Mental Capacity Act, 2005, section 2, 1-4

[8] Mental Capacity Act, 2005, preliminary, 3 (a, b)

[9] PC & NC v City of York Council [2013] EWCA Civ 478, [2014] Med LR 213 (Richards LJ, McFarlane LJ, Lewison LJ)

[10] A Local Authority v JB (Rev1) [2021] UKSC 52

the MCA is the guiding statute, and still we have the inclusion of diagnostic criteria making those people with a disorder more vulnerable to having their decisions and actions restricted by legal processes.

The MCA does not replace common law tests such as the *Banks v Goodfellow*, but it dominates conversations regarding dementia decision making and directly influences LPAs (Butler-Cole, 2015).[11]

The MCA itself dictates that for a person to be capable of making a decision they must demonstrate they can:

> '(a) understand the information relevant to the decision;
>
> (b) retain that information;
>
> (c) use or weigh that information as part of the process of making the decision; or
>
> (d) communicate the decision (whether by talking, using sign language or any other means).'[12]

The act sets a benchmark for capacity, whereby each criterion must be met to be deemed legally capable. The law also establishes that capacity is decision and time specific. This threshold criteria reflects discourse in cognitive psychology, where the processing of information and executive brain functions, such as reasoning and working memory are instrumental in decision making.[13] The MCA discourse is a more nuanced practical psychological examination of decision making than *Bank v Goodfellow*. Though we have not abandoned this language entirely as *Banks v Goodfellow* is still used. The historical

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[12] Mental Capacity Act, 2005, section 3, 1

[13] See chapter two for an in-depth discussion of capacity tests in psychology

progression is evident, especially given the continual reinterpretations of the MCA in courts. The ongoing (and now delayed) wills reform aims to modernise the language used in the common law test (Law Commission, 2017).[14] The discourse and understanding of capacity have changed, but the inclusion of diagnosis within the capacity assessment means those with a disability are still placed under greater scrutiny than a person without a disability/diagnosis. The MCA still fails somewhat to fully relinquish the previous ideals of medical competency-based measures as the law commission aimed to do when drafting the MCA (Hoggett, 1994). This is where the progress of the UN CRPD is most needed, and how current prevailing MCA rhetoric falls short of the equality principles that underpin the UN CPRD.

The UN CRPD

I will first lay out the convention as it is written and highlight key areas regarding current laws in England and Wales. I will then discuss the arguments proposed by those who advocate full adoption of the values in the UN CRPD. I will then present the potential issues of implementing the UN CRPD, and how the theory of relationality may shed light on overcoming these issues. The UN CRPD aims to enable and empower individuals with a disability as persons before the law, enjoying all freedoms offered by the social contract (Arstein-Kerslake & Flynn, 2017). The state of mental capacity in law and the implications for those with disabilities must be improved, and the UN CRPD change in discourse offers one way to do so.

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[14] In light of a government request the wills review is now on hold whilst the law commission undertakes a review into laws pertaining to weddings, see https://www.lawcom.gov.uk/project/wills/

The UN CRPD produced a new discourse of capacity. England and Wales were one of the first countries to ratify the convention, but it is yet to be fully adopted. The UN CRPD Article 12 states that:

> '1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
>
> 2. States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.'[15]

Neither the MCA nor the b*anks v goodfellow*[16] test act within these principles because both assert that a person can be denied legal capacity based on mental capacity.

Article 2 strengthens this statement as the UN CRPD defines discrimination based on disability as:

> 'Any distinction, exclusion or restriction based on disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field'[17].

The current laws in England and Wales that should support people with disabilities actually restrict their ability to carry out legal actions on an equal basis with non-disabled individuals. The common law of wills and the MCA fit this description of discrimination, hence the assembly's dissatisfaction with how the UN CRPD has been implemented. Under

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[15] UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution, Article 12 / adopted by the General Assembly*, 24 January 2007, A/RES/61/106

[17] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution, Article 2 / adopted by the General Assembly, 24 January 2007, A/RES/61/106

these laws, persons with disabilities do not enjoy all rights on an equal basis with others and having a disability means legal capacity can be questioned. Conversely, the UN CRPD UK initial report (H.M. Government, 2011a) does not identify any issues of capacity in regard to disability. The favourable report neglects to state the outcomes for a person who is not deemed to have capacity and the fact that they are then denied equal enjoyment of legal rights (H.M. Government, 2011b). The UN CRPD committee were not satisfied with the implementation of the convention, particularly given social care reforms in 2012 and the increase in complaints to the CRPD committee about implementation (U.N. Committee on the Rights of Persons with Disabilities, 2016). The UN CRPD convention frames capacity as a human right, to refute that a person has legal capacity is to deny their human right (Dhanda & Narayan, 2007).

The UN CRPD as an international convention can change the discourse of disability and transform legal capacity. The rhetoric of the convention and Shakespeare et al (2017) state 'from semantic, epidemiological and legal perspectives, dementia is a disability.' People with dementia can use the UN CRPD to protect their rights. My empirical work investigates how people with dementia perceive themselves, and adds to the debate of the UN CRPD's impact, particularly as the dementia as disability rhetoric is recent (DEEP, 2016). The impact of the UN CRPD's inclusion of dementia as a disability can be seen at a policy level, but it will be vital for my research to understand how this might impact people making everyday decisions who could access the rights described in this convention. The UN CRPD values proposed need to filter to all levels of law and society. As I discuss in chapter two, society's neuroculture acts as a barrier for all people to be valued equally. Those with any abnormalities in neurology, or those who cannot achieve the unrealistic hypercognitive ideals will be (and are) penalised in this society (Dhanda & Narayan, 2007; Stephen G Post, 2000). Additionally as is evident through my participants self-identification of disability, it is not consistent that people with dementia recognise their diagnosis as a disability.[18] This discourse of disadvantage is also reflected in disability studies research, examining how people with disabilities are placed at a marked disadvantage by society, and the laws that govern society (Shakespeare, Zeilig et al. 2017). The principles of the UN CRPD have incited much debate about how to change the law in England and Wales, but we have yet to see significant action to meet article 12. In 2014 a roundtable of legal experts reached the consensus that although the general principles of the MCA worked well with the UN CRPD, overall and importantly in practice, the MCA was not compliant with the UN CRPD (Martin, 2014). Progress could be construed as the Liberty Protection Safeguards amendment to the MCA which has been passed but implementation is delayed.[19] With regards to assessing capacity, fundamentally capacity to make a legal decision can still be denied a person by the state. I add to debates on how equal access to legal decision-making can be achieved by adopting more relational legal practice, based on my observational and interview empirical research.[20] As Bartlett (2020) surmises, the MCA does not stray so far from those principles in the CRPD that it cannot change to become compliant, the issue is how we move forward (Bartlett, 2020). We can only do that by examining how decision making occurs in practice, to better understand if and how the UN CRPD values can be met. I will now examine literature which largely concerns the full adoption of UN CRPD values, and the difficulties of practically implementing the UN CRPD.

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[18] See table of participants, chapter 3, Table 3.5

[19] https://www.gov.uk/government/collections/mental-capacity-amendment-act-2019-liberty-protection-safeguards-lps

[20] See chapter 3 for a full explanation of my methods, and chapter 4-7 for my analysis.

In 2014 the UN committee released a General Comment specifically on article 12 to clarify its position on capacity. It states that:

> 'The right to equal recognition before the law implies that legal capacity is a universal attribute inherent in all persons by their humanity and must be upheld for persons with disabilities on an equal basis with others'. [21]

This reiterates the UN CRPD's statement that legal capacity is to be enjoyed by all persons regardless of disability. It also confirms that both testamentary capacity and the MCA are not UN CRPD compliant, as both can deny a person the capacity to make (or have made) a legal decision.

Arstein-Kerslake (2014) praises the UN CRPD's social approach to capacity, arguing that to deny legal capacity is to deny personhood and fundamental human rights. Arstein-Kerslake (2014) points out that despite the law's current insistence on drawing some causation between cognitive functioning, and decision making ability (and hence capacity), little is known about the extent of such links. Our reliance on cognitive testing in law may be unfounded, causing unnecessary barriers to those with disabilities. Though we can draw information from cognitive psychology, the internal debates in the field weaken the causal argument. For example, as I discuss in the following chapter, the number of different approaches taken to testing the same phenomena demonstrates the inconsistent approaches of how to assess cognition correctly.[22] Law has oversimplified the relationship between cognitive functioning and decision making capacity and is reductionist in its account of cognition and capacity. Overall, although we have a wealth of information about

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[21] CRPD, General Comment No. 1, Equal Recognition before the Law, UN Doc. CRPD/C/GC/1, 11 April 2014, 1 (8)

[22] See appendix D for a full list of the different cognitive psychology tests available for testing capacity.

cognition and decision making ability from cognitive psychology, we cannot draw a simple causative link, as Arstein-Kerslake (2014) argue. Mental capacity and legal capacity are not the same. However, in the MCA legal capacity is dependent on mental capacity, which is assumed to be reliant on good cognitive functioning due to lack of impairment; this is reflective of neuroculture and hypercognitive idealism which I discuss next in this chapter, reflecting on how social and cultural values shape perceptions of personhood and capacity. The UN CRPD committee in general comment 1 state that although mental capacity will differ, legal capacity is inherent and does not fluctuate depending on mental capacity. The state must provide sufficient support to enable a mentally incapacitated person to enjoy full legal capacity (Arstein-Kerslake & Flynn, 2014). This has been supported by work demonstrating how supported decision making can ensure the principles of article 12 of the UN CRPD are met (Harding and Taşcıoğlu, 2018). Arstein-Kersake and Flynn (2014) make the argument for a clearer division between mental capacity and legal capacity, and I add to this literature, seeking to disentangle the symbiosis of cognitive function and capacity that is apparent in mental capacity law. Additionally, I add to discussions of supported decision making by observing practice and discussing decision making processes with people with dementia and their informal carers.

The practical action of ensuring full legal capacity for all persons is absent from the UN CRPD, and as Dawson (2015) argues, this lack of clarity has opened the UN CRPD to so-called radical interpretations. This is where a state is expected to provide beyond its ability. In futile pursuit of a capacity which is not present (though this would be in extreme cases only, for example a person who has never had or I was never ascertained to have capacity), I mention Dawson's argument to acknowledge the critics of the UN CRPD. Dawson (2015) perhaps misunderstands that the UN CRPD is not a strict directive document, but instead it may be used to encourage states to adopt more enabling laws. The principles of the UN CRPD are idealistic, and each state which ratifies it can create or adapt its own laws to ensure it remains UN CRPD compliant. Economic arguments are not moot, but the UN CRPD is a malleable document that each state can interpret and strive to achieve using their varied strengths and capacities. Dhanda and Narayan (2007) argue that the purpose of the UN CRPD is to incite reform for states given the evolving discourse, not provide instruction. Furthermore, General Comment 1 does lay out explicit obligations for states. Even more explicitly, a section on implementation at national levels is included, where statutory language change is suggested to protect legal capacity for all, demonstrating the importance of legal discourse, and the further exploration of such discourse outside of the statutes and courtrooms.

This insinuates that the committee somewhat aligns to the arguments put forth about law as a language (Endicott, 2002; Bittar, 2020). The importance of language is singled out as potentially influencing meaning and implementation, perhaps constitutive of how a law is applied. Again, this is where my research offers novel insight into how capacity law occurs in everyday practice, where most people experience and interact with capacity law. I discuss this concept further in the next section.

The UN CRPD has, in a sense, been put on a pedestal by its supporters. It is hailed as the convention which could change disability discourse in law, encouraging a paradigm shift. However, the UN CRPD only belongs on this pedestal if it is influencing change (Kayess & French, 2008). Discourse change and progression have begun, but it remains to be seen how the UN CRPD will influence law in England and Wales. This is especially prudent now, given the glowing (biased) review of its current implementation status (H.M. Government, 2011b), and the avoidance of drawing on the UN CRPD in domestic case law.[23]

Legal discourse has progressed historically and there is a clear attempt to ensure capacity law is more enabling in the MCA. However, as demonstrated, capacity law in England and Wales still acts in a discriminatory manner and outside of the principles of the UN CPRD. Though legal capacity rhetoric has progressed, the UN CRPD demonstrates how much still needs to change if laws are to become enabling rather than restrictive. Relationality and person-centred practice (and acknowledging the contextual factors of personhood) offer solutions to implementation issues. UK law seems hesitant to recognise a capacity not solely reliant on cognition, but to ratify the UN CRPD's principles fully and recognise all persons as legal actors, we must seek to redefine legal capacity as being reliant on context, relationships, and cognition. Therefore, though legal discourse change is imperative, it is also essential to examine legal practice, and as I explore next, the society and culture in which law exists. To best understand legal interpretations of capacity we must examine all its contexts. My empirical research examines legal context at the person-person everyday level. Prior to this empirical research I draw on theories of culture and society to examine how these may interact, shape and contribute to legal discourses of capacity and personhood, contributing to my conceptual framework for this thesis. This conceptual framework ensures my thesis works to contribute to various fields of knowledge including: socio-linguistics, socio-legal theory, law as language and disability studies. I acknowledge that a purist discourse or conversation analytical approach promotes lack of theorising prior

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[23] For example, the supreme court case A Local Authority v JB (Rev1) [2021] UKSC 52, a high-profile recent case that noticeably avoids referring to the UN CRPD.

to analysis.[24] However given my socio-legal research questions, I require some conceptual framing to ensure my questions are answered, and I can reflect upon how my research fits within the socio-legal field of study. My research questions are not purely linguistic and my thesis is more reflective of applied Conversation Analysis practice, as well as thematic analysis. I use both inductive and deductive approaches to answer my research questions, the following sociological theory contributes to my inductive findings.[25]

Societal and cultural values, the importance of rhetoric.

Capacity transcends disciplines, though my focus is concerning legal decision making, this does not confine my study to law. In this thesis I advocate for the acknowledgement of relational personhood by law (informed by psychological and sociological knowledge) and the need for a more contextually sensitive and accessible legal framework. To understand why we have the framework we currently do; I examine different cultural and social theories which may contribute to capacity rhetoric evident in England and Wales. Firstly, I will examine how the cognitive psychological language of the MCA could stem from neurocultural values, and then how these values can influence the ideals of legal personhood. The psychological theory where cognitive function is heralded as the defining and imperative skill for all persons in society is what encourages the use of defunct and outdated language in capacity law. Grounding my research in the cultural and social values in which law exists allows me to examine how the problematic discourses I have discussed prevail. Next, I set out my research questions and my approach to answering these pertinent questions. I also evidence how my thesis contributes to the debate of how

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[24] See chapter 3 for a detailed description of my analytical framework and method.

[25] Further discussion of my conceptual framework can be found in chapter 2.

language is constituted by law, and therefore legal meaning is inextricable from the language, interpretation and actors who enable and enact laws (both the everyday legal actor as well as professional interactions).

Neuroculture

Neuroculture is an emerging term as neuroscience advances and is increasingly used daily in society (Katz, 2012; Williams et al., 2012). Neuroculture is defined as the culmination of expectations that as neuroscience progresses, this knowledge is being used to influence and identity health, wellbeing practices, general understandings of the brain, cultural practices and cultural interests (Idvall, 2018; Rose & Abi-Rached, 2014; Vidal, 2009). One extreme advocate for the appropriation of neuroculture states that all 'objections appeal to folk psychology — the common-sense means, at our disposal, to explain behaviour regarding beliefs, desires, expectations, goals and so on' (Moreno, 2003, p. 150). Moreno is stating that neuroscientific insights will be able to explain every social phenomenon and that eventually neuroscientific understandings will surpass and replace so-called 'folk' psychology. This extreme example highlights the potential dangers of neuroculture, of which I do not have space to thoroughly discuss the potential (and currently hypothetical) issues with control and neuroculture. Neuroscience has produced few theories of the mind and brain. Primarily, it has sought to identify and describe brain function and is less concerned with whom the brain belongs to and how the person functions (Uttal, 2001). Yet, we find ourselves in a neuroculture, encumbered with a sense of neuromania. This is a term adopted by Tallis (2016) (who was a practising neurologist in his own right) to describe society's obsession with explanations of human behaviour and emotion provided by neuroscience. In short, neuroscience although valid within its own right, does not concern itself with enabling an individual to decide. Instead, neuroscience focuses on what parts of the brain are involved in making a certain type of decision, and how it can be located in the neural structures of the brain.

Neuroscience and modern neuroculture can be traced to the 1980s, but fascination and belief in the biological excavations of behaviour stem from the fixation with the nervous system in the 1800s (Casper, 2014; Cooter, 2014). Uttal (2001) warns of the dangers of modern neuroculture, likening it to methods used by phrenologists to explain and justify the segregation of African Americans into the 1960s and preluding slave trade (Uttal, 2001). This is much like the comparisons between brainhood and phrenology. Uttal (2001) warns that we may be experiencing a neo-phrenological fad because neuroscientific research receives little critical analysis. The complexity of cognition is reduced to searching for the location of a form of cognition in the brain and external factors affecting cognition are given less weight, if any attention at all (Uttal, 2011; 2013). Phrenology is an extreme example of how scientific progression influences cultural norms, but it is important to remember phrenology's apparent 'validity' in the period in which it was popular. Phrenology demonstrates how science can be, and has been, used to popularise discriminatory rhetoric and disable individuals. Neuroscience is at risk and capable of doing the same, creating an ethical dilemma and practical harm to people with disabilities. Furthermore, neuroculture has emerged due to the media reporting and hype surrounding the field (Thornton, 2011). We must interrogate how this research is being communicated and why this is harmful to society and influences and reflects the law.

The validity of neuroscience, like all science, must be questioned and interrogated. Notably, the rigour of so-called 'ground-breaking' studies must be cross-examined further before reaching the general population. The validity of neuroscientific knowledge is not of great importance for this discussion, what is important is its influence. I am not condoning a complete disregard for neuroscientific knowledge due to predominantly general scientific faults (for example, psychology has been in a replicability crisis since around 2011). We cannot discount all knowledge due to a realisation that rigour must be improved (Open Science Collaboration, 2015). An issue unique to neuroscience is that the layperson is more likely to be satisfied with a neuro-scientific explanation of a psychological phenomenon even when that information is logically irrelevant, even when presented with another 'good' explanation without neuro-scientific information (Weisberg, Keil, Goodstein, Rawson, & Gray, 2008). This is concerning particularly when considering that neuroscientific knowledge can be used to restrict a person's actions in legal contexts. Weisberg et al (2008) shows that whether relevant or not, neuroscience is treated as respectable information and its effect is, therefore, greater than non-neuroscientific knowledge (for example, personal testimonies of P's capacities). Neuroscience has a dominant influence when used in general media, to the extent that it does not matter whether the neuroscience used is relevant.[26] Weisberg et al. (2008) found that people are less likely to critically engage with neuroscientific explanations because the specialised language satisfies the reader that the information must be accurate and true. Essentially, neuroscience is praised highly and interrogated little in a culture that is all too eager to accept and consume such information. Neuroscience has become embedded in culture through neuro-realism (Neuroimaging is used to show physical evidence of subjective emotions), neuro-essentialism (the brain has become the

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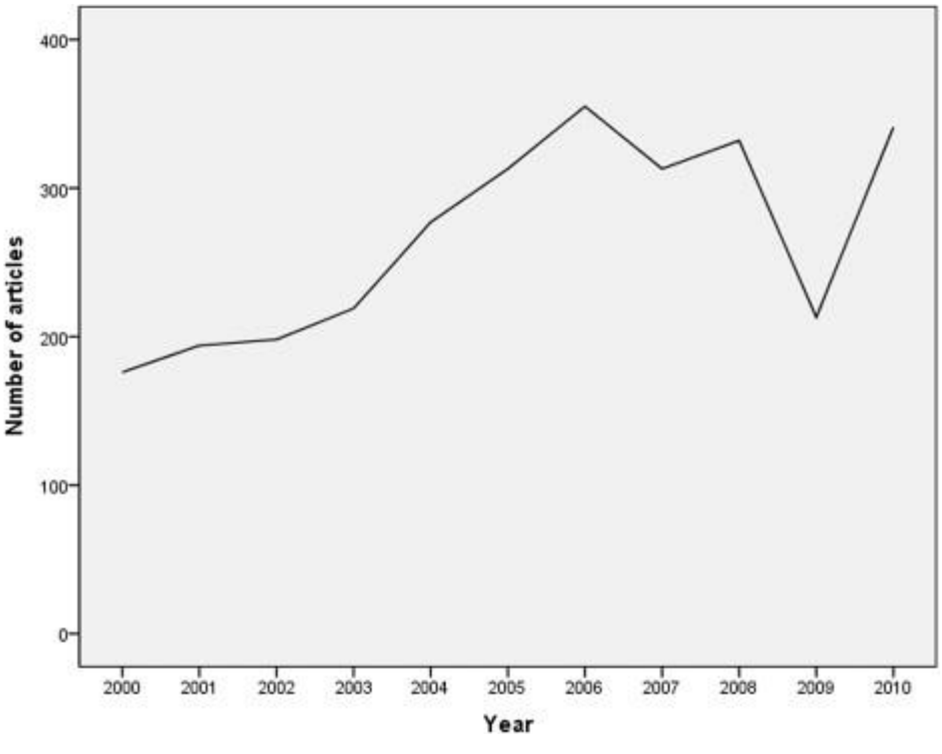
[26] For example see these two conflicting articles in mainstream scientific magazines: https://www.psychologytoday.com/us/blog/hope-relationships/201402/brain-differences-between-genders; https://www.newscientist.com/article/dn28582-scans-prove-theres-no-such-thing-as-a-male-or-female-brain/ ; as well as wider reports; https://www.independent.co.uk/voices/comment/differences-between-male-and-female-brains-time-reconsider-value-stereotypes-8981037.html ; https://www.dailymail.co.uk/femail/article-9706483/Brain-fog-busters-bottle-Smart-oil-raise-IQ-pills-claim-sharpen-wits.html.

self) and neuro-policy (neuroscientific evidence is used to support a political agenda) (Racine, Waldman, Rosenberg, & Illes, 2010). These three phenomena are present in society today because of the popularisation and media fascination with neuroscience. Since the so-called 'neuro-turn' of the 1990s (Vidal, 2005) media and public interest in neuroscientific explanations has meant an increase in the number of articles referencing neuro-information. O'Connor, Rees and Joff (2012) carried out a content analysis on the LexisNexis news media database from 2001-2010, their results can be seen in the graph below (O'Connor, Rees, & Joffe, 2012, p. 224). The number of neuroscience-related articles published in the six newspapers increased across the decade, almost doubling between 2000 and 2006. 2010 saw article volumes return to their earlier heights.[27]



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[27] No explanation is given in this article as to why there is a dramatic decrease, or any related articles by the same authors. We can postulate that the impact of the REF meant fewer research outputs were being pushed during this time period. Additionally, the governments 'living well with dementia' campaign was released, encouraging a social perspective of dementia rather than neurological deficits.

Figure 2.1. *Number of Neuroscience-Related Articles Published per Year in the Popular Press*

This graph refers to newspaper articles, not academic journals. This is not a demonstration of the increased research in neuroscience but rather increased visibility of neuroscientific research and increased neuro-rhetoric in general media. This increasing trend on the graph is worrying as it indicates that neuroscience is continually pushing essentialist rhetoric of capacity. Neuroscientists 'should be aware of how their papers will be read by the legal community and should play a more active role in educating and engaging with that community' (Garland & Glimcher, 2006, p. 130). I would further add that neuroscience is one of the most dominant ways we seek to understand the human brain. We (lawyers *and* neuroscientists) must critically analyse how this rhetoric affects society's views of personhood, and if neuroscience has created the negative neuroculture space, how this affects policy. A study by O'Connor and Joffe (2013) found that neuroscience perpetuates and encourages a lay perspective of traditional, individual notions of personhood and the self. The self and its location within a whole person, existing in a complex contextually-influenced world is vital for enabling people with disabilities. Neuroculture acts as a confounding factor in this pursuit of enablement.

Hypercognitive values

Hypercognitive values are a result of neuroculture. These values essentially mean that the more cognitive skill a person is deemed to have, the more successful they will be in society, because these skills will be recognised and praised (Post, 2000). Hypercognitive expectations are defined by neuroculture's focus on the healthy and endlessly improvable brain as the location of the valued self. Hypercognitive expectations in capacity law are evident through the narrow focus on individual cognitive function when assessing capacity to make decisions. Post's hypercognitive theory is one way to understand this phenomenon. Hyper-cognition originates as a theory of mind development. It states that people understand that everyone can only access their own mind, but understand that others also possess a mind, this is a developmental milestone. Humans must understand that others possess a mind like their own, without having direct access to it. The theory of mind development contributes to understanding how humans acquire the neuro-typical skills such as language and socialisation. An example of where this theory is used in practice is when assessing people on the autism spectrum (Baron-Cohen, Leslie & Frith, 1985; Milligan, Astington & Dack, 2007).

Neuroculture originates in the 1980s (Vidal, 2005), hyper-cognition was theorised by Andreas Demetriou 10 years later in the 1990s. Incidentally, this is when neuroculture started the so called ‘neuro-turn’, with neurological explanation increasing in popularity (Tallis, 2016). Demetriou posited that hyper-cognition was a self-governing system in the mind which acted as an interface between individual cognitive systems and reality (Demetriou, 1993; Demetriou, Efklides, Platsidou & Campbell, 1993). One of the most significant flaws of the theory is that Demetriou claimed that the hypercognitive system could influence and control micro-level cognitive systems and the eventual decisions made: 'this system must necessarily involve two distinct sets of skills and strategies. The first is a set of online strategies for handling mental resources, general cognitive functions, and representations. The second is a "theory of mind" that functions to guide the task-SSS affiliation processes' (Demetriou et al., 1993, p. 125). An SSS is a 'specialised structural system'. This is a macro-level structure that attends to specific functional tasks, such as dealing with numerical information. In other words, the hypercognitive system provides an incomplete theory of cognition, with no explanation of how the structures differ and interact. It is the product of self-reports from participants about their cognitive function (other studies have not been supported or replicated using rigorous methodology) (Pascual-

Leone, 1998). Furthermore, a less mentioned criticism is that Demetriou states that the resultant decision relies primarily on how 'clever or stupid' a person is in a particular situation. This is an outdated assessment of cognition and language which is largely dismissed in psychological practice.[28] The theory of hyper-cognition is now largely discredited, given the ever-expanding field of cognitive psychology providing newer and more complex theories. However, we must pay attention to the origins of hyper-cognition as its values influence society (Post, 2000). In neuroculture, hypercognitive theory continues to exert influence because it also values the functional brain above all else. The idea of cognition being largely reliant on intelligence are culturally appropriated and potentially influence policy, law and discourses of personhood.[29]

Hyper-cognition describes the phenomena where cognition and intelligence equal human worth. The more intelligent and cognitively able a person is and can be, the more they are worth and the more they will succeed in a hyper-cognitive society (Post, 1995; 2000). Conceding that society is influenced by hypercognitive ideals, those with Alzheimer's disease (or any other condition or impairment affecting cognition) are the most vulnerable and will enjoy the least success. This is evident, as in O'Connor et al.'s (2012) study (see p.7) of the newspaper articles included in the content analysis, 43% discussed how to enhance the brain and potential threats to brain enhancement. Public interest in the brain is most prevalent when hypercognitive values are being discussed, showing that the public is aware of the superiority of an "intelligent" and un-impaired brain. The law explicitly encourages this rhetoric by singling out those with an impairment as being potentially legally

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[28] Theories of intelligence generally include multiple intelligences, using the standardised tool, The Wechsler Adult Intelligence Scale most commonly used by clinicians classifies a person’s IQ level as either: Very Superior, Superior, High Average, Average, Low Average, Borderline and Intellectual Disability (Benson et al., 2010).

[29] See chapter 2 for an in-depth discussion of how neuroculture and hypercognition result in the theory of brainhood, and whether we can see this evidenced in law.

incapacitated using the two-stage test.[30] Post (2000) argues that in western society we herald ideals of self-control, independence, economic productivity and cognitive enhancement. These values dominate the norms of the human image and human fulfilment and to be without them is to be less than human. This is a dangerous and sobering thought. The MCA capacity test stipulates a two-stage test where a diagnosis is identified, and the person is then subjected to a capacity assessment (MCA Code of Practice, 2007). Even with the recent reinterpretations of the MCA guidance prioritising the presumption of capacity, the continued presence of the diagnostic aspect of a capacity assessment means people with a mental disability are disadvantaged.[31] Those without a disorder are not subjected to such scrutiny. Additionally, the code of practice has yet to be amended, and one must question how much impact such cases have for the everyday scenarios where a person's capacity is relevant to making a legal decision.[32] This is the clearest case of discrimination related to hyper-cognitive values within the act, even though its purpose is to support and enable the vulnerable. Hypercognitive values are present in the MCA despite its purpose as a tool to enable. Arstein-Kerslake & Flynn (2014) state that finding someone

without capacity to make a decision is equal to denying them the human right to make a legal decision. This may seem an extreme conclusion, and I acknowledge that the MCA does stress adjustments enabling people to make decisions. However the evidence of hyper-cognitive values is clear, and the rhetoric within capacity law easily translates.

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[30] Mental Capacity Act, 2005, section 2, 1

[31] As previously stated, the JB case stipulates a three-stage approach to capacity assessing, firstly establishing if a person can make a decision, then if they cannot is there a diagnosis, and is this inability due to the diagnosis. These are the amended grounds on which capacity should now be assessed.

[32] For example, neither wills or LPAs need to be made with a legal professional, both can be made at home with witnesses attesting to a person's capacity.

The right to make a legal decision is denied to those who do not possess sufficient cognitive ability. Restrictive and essentialist values disable individuals in society, and particularly those subjected to mental capacity assessments. As Hughes (2014) suggests 'the humane response, however, should be to nurture the possibility to such potential' thereby enabling people with disabilities(p. 148). By using a different set of values, rather than the restrictive hyper-cognition, we might combat restrictive cultural and societal influences and continue to improve upon the progress in rhetoric which I have traced in capacity. The history of capacity rhetoric and cultural and societal values contribute to the issues faced by people with dementia and their carers. These issues are most prevalent when they wish to make a legal decision, such as a will or an LPA. This thesis aims to explore, using a grounded methodology, how people with dementia are affected, why, and what this impact looks like for people with dementia, their carers the practice of law, and examine wider implications for mental capacity law.

Law as language

In my socio-legal, empirical approach to understanding law in action, I subscribe to the notion that, at least for the purpose of my thesis and research questions, law is language. Law is constituted of, enacted, and interpreted through institutional and individual uses of language. The legal acts with which this thesis is concerned, LPAs and wills, consist almost entirely of language which performs a legally binding action. As I discuss in chapter 3, the pragmatics and study of language beyond assumed semantic meaning is relevant for this thesis. I subscribe to Endicott's (2002) assertion that

> 'lawmakers characteristically use language to make law, and law must provide for the authoritative resolution of disputes over the effects of that use of

> language...legal philosophers are political philosophers with a specialization that gives language (and philosophy of language) a special importance' (p.1).

To understand how legal language is used, and given its authority in action, we must use pragmatics (and in this thesis, discourse and Conversation Analysis) to understand what the legal language is doing in a certain context. This thesis adds to the body of literature supporting this theory of law as language, and evidences how legal language operates in the everyday lives of people with dementia and their carers. Similar to Zodi (2019) I seek to understand how legal language can be used by lay-people, and legal professionals, to reach mutual understanding (a common goal I explore through the interrogation of epistemics in interaction, which I discuss in chapter 3, and notably in chapter 6). As Zodi (2019) evidences 'comprehensibility is not a purely linguistic or stylistic problem. Even in the case of traditional comprehensibility situations… it is clear that it is not solely complicated language that hinders understanding' (p.246). By exploring the impact of legal language, context, and pragmatics, I work to refute ideas by opposing theorists that recognise law as only a system of rules, whereby moral understandings of legal concepts and words are somewhat inarguable if universally understood (Dworkin, 1967). I situate my thesis in the realm of everyday legal decision making, where the co-operative task of making a legal decision is bound within the co-operative task of communication. The theory of law as language and arguments made by Endicott (2002), Bittar (2020), and Zodi (2019) among others align with my socio-legal approach to answering my research questions, my conceptual framework, and my epistemological and ontological methodologies which I explain in chapter 3. There is not space within this thesis to fully explore the breadth of the debates around law as language. However, it is worth noting here how I contribute to this literature, and why my thesis adds a uniquely empirical perspective on the theoretical debate.

My research

Capacity transcends disciplines and although my focus is concerning legal decision making, this does not confine my study to law. In this thesis, I advocate for the acknowledgement of relational personhood by law (informed by psychological and sociological knowledge) and the need for more contextually-sensitive and accessible legal practices for mental capacity. Though the UN CRPD has been ratified, the MCA and *Banks v Goodfellow* deny the human right to exercise legal capacity as they require a threshold to be reached for legal acts to be legitimate. My research adds to the literature, expanding upon how we can meet these ideals, and why it is important that capacity law is more reflective of people's relational lives in which they make such decisions. Though my research does not directly sit within disability studies or the theoretical research of law as language, it contributes to both fields on the periphery. I focus on enabling capacity law, people with dementia (which is inconsistently referred to as a disability in discourses), and language and its importance for people's experiences of law.

Firstly, I must note my research was granted ethical approval from the University of Birmingham's ethics committee and adhered to all rules stipulated. Next I introduce the purpose of my research, and how I have answered my research questions whilst adhering to the ethical research governance of the university of Birmingham.[33] Importantly, this research aims to draw attention to and give voice to people who experience law on an everyday level, taking the focus away from the statutes and major court cases. Instead, I pursue answers from a socio-legal perspective, prioritising the people who experience law and their interpretations.

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[33] See appendix A for the full ethics form submitted to and approved by the University of Birmingham

Statement of my research questions

As I have identified previously in this chapter, capacity law in England and Wales potentially impedes and negatively impacts the lives of people with dementia and their carers. People with dementia are a growing proportion of society, with which law will have to interact (Alzheimer's Society, 2022). Therefore, given the aims of this research, I have produced a number of research questions. These questions are embedded in the legal, cultural, and social context I have highlighted, and will examine what this context means for people in their daily lives. They'll also examine how discourse can enable a better understanding and potentially improve the lives of people with dementia and their carers. My research questions are:

1. How do people living with dementia and their informal carers access and interpret legal advice?
    i) What is the content of this legal advice, and how does this rhetoric form the construct of 'capacity law'?
    ii) What impact does this have on their understanding of their legal rights and their mental capacity?
2. How do legal actors assess capacity, and how does this impact the legally-relevant decisions made in the lives of people with dementia?
3. What is the contribution of observational methods, such as Conversation Analysis (hereafter CA) to understanding legal decision making in action?

In this introduction I have examined the discourse of doctrine and case law of testamentary capacity (*Banks v Goodfellow*), the MCA, and the UN CRPD. Now, I will detail how I will answer these questions in this thesis.

To answer my research questions, I have conducted empirical research. My research included 20 interviews with people with dementia and their informal carers (usually a spouse), and four observations of a solicitor with clients making a will (all clients over the age of 50). I use these data to answer my three research questions in chapters four, five, six, and seven. I take a social-constructionist approach to answering my research questions, using an inductive methodology to guide my analysis and produce findings which are grounded in the experiences and observations of the day-day lives of people interacting with capacity law.

Theories

In chapter two of this thesis, I lay out my conceptual framework and explore how cultural and social theories are evidenced when examining mental capacity law. Through the compartmentalisation of the self due to neuroculture and hypercognitive values, I examine different theories of personhood. Firstly, I examine how individualistic autonomy and neurocultural values result in the theory of brainhood. I pay attention to different types of capacity assessment described in psychology and how these have been adopted (or ignored) through rhetoric and cases in law. I examine how the mental capacity act has been used since its inception, and how this has influenced disability studies. I then offer relational theory as an alternative theory of personhood that can enable people with dementia and is potentially more reflective of people's everyday decision making. Throughout my analytical chapters I also draw on other sociological theories to expand upon the findings evidenced through my discourse and Conversation Analysis. I outline these briefly in my chapter-by-chapter breakdown.

Relationality's role in law

Current law recognises capacity as an individual's ability to make an autonomous decision. This mirrors the cognition-centric approach to capacity where it is individually assessed and influencing factors like relationships or emotions are either not considered or controlled. Relationality is a feminist theory that purports that any individual's decisions must be influenced by moral, social and cultural relationships (Harding, 2017). We cannot isolate an individual from their whole life experience when establishing how they make a decision; their relationships with others will undoubtedly influence their decisions (Peel & Harding, 2015). Relationality can recognise that 'the individualised notion of autonomy, that a person is in a position to 'make up their own mind' is arguably a fallacy. We need to recognise that agency, making choices, requires relationality' (Peel & Harding, 2015, p. 140). We cannot deny any person of their relational context and doing so means we cannot achieve the values of the UN CRPD.

Clough (2014) argues that the UN CRPD enables context to become a contributing factor and demands a more responsive legal framework to enable individuals to access the support needed. Relationality coincides with this view as it focuses on enabling personal contexts. A person who is disabled may have a social structure that cannot accommodate all their needs, but also be supported and influenced (negatively or positively) by personal relationships. A person cannot be isolated from their institutional or personal context. Capacity assessments, (namely the Mini-Mental State Exam, or the Mental Capacity Act) that are used in clinical and legal contexts, despite the different purpose of such environments neglect to consider either landscape and fail to account for the person's full ability and capacity. There is a lack of empirical evidence to examine this theory. Through conducting innovative research such as this,), I can give insight into how to make legal practice accessible, giving voice to the people affected by capacity law, and reflect their actual experience and understandings of capacity and legal decision making. As research observing everyday legal practice within this area is novel, I draw upon psychological and institutional-based observational research to draw comparisons between practices used. As I outline next, this includes the popularised approach of person-centred practice which is widespread in care environments.

Psychology's contributions to law

Psychological definitions of capacity are as diverse as legal definitions, and all capacity discourse must be considered in law. Currently capacity law in England and Wales incorporates cognitive psychology's language and allows for some person-centred considerations, as I demonstrate in the next chapter. However, what is consistently absent is the individual's context and an acknowledgement of neuro-centric definitions of capacity in the application of capacity law. An example of this is the debates leading to the creation of the MCA and, as I discuss in the following chapter, the use of capacity law and cognitive-centric information in court. Contextual factors allow us to consider the theoretical reasoning of relationality and previous cognitive strengths and skills (if known, or from self/carer reports). This will encourage inclusivity promoted by the UN CRPD, without denying the positive knowledge of medicine (and cognitive-based diagnostic tests) which is too often afforded deciding status (Mckenzie & Macleod, 2012).

Hillman et al. (2012) advocate a person-centred approach to capacity assessments, facilitating a supportive environment and enhancing rights recognition. This Australian ethnographic study aimed to understand if and how the UN CRPD is enacted in Australian capacity contexts. They found that through using a person-centred framework, a deeper understanding of the individual's wishes was achieved, and this encouraged their active participation in planning supportive actions. This demonstrates that person-centred care enables and aligns with how the UN CRPD views capacity as universally supportable and an inherent human right. I would also argue that given that the enabling factor is a deep understanding of the individual, close relationships would have the same effect. In short, a clinician or lawyer meeting the client for the first time will not enable the client’s capacity to make decisions to the level requested by the UN CRPD because they lack the deep understanding and knowledge of that person. A capacity assessment may gather an understanding of that person's mental capability, but it will not enable them to exercise their legal rights because the individual's desired outcome is unlikely to be known. Hillman et al. (2012) offers a brief glimpse at how relationality and person-centred care incorporate the ideals of the UN CRPD, and how capacity can become an enabling concept, instead of a restricting one. In chapter two I expand upon this and examine which psychological theories have influenced legal capacity rhetoric, and why this currently falls short of the proposals of the UN CPRD. This examination of the meaning of capacity and personhood are central to my empirical analysis, which I will now outline.

Methodology

In **chapter three,** I report my method for my research and methodological reasoning. This includes exploring the practicalities and challenges of conducting my semi-structured interviews and naturalistic observations. This chapter contributes to answering research question 3.

Given my research questions’ focus, I take a social constructionist approach.. Briefly, I use Thematic Discourse Analysis (hereafter TDA) and CA to analyse the findings from my empirical research. I carried out 20 semi-structured interviews with people with dementia and their informal carer (commonly a partner). I conducted these interviews to answer research question 1 (i and ii). This dataset exceeded the observational data set in quantity, and therefore chapter 4, 5, and 7 report the rich findings of the TDA carried out. Summarily, all interviews followed the themes, diagnosis, daily life, legal actions, information sources and legal position. A TDA was carried out on all interview data. TDA allowed themes to become identified and focused the following Discourse Analysis, in keeping with the social constructionist approach, and ensured the findings would answer the research questions.

Observational data was difficult to obtain in the legal space of a solicitor’s office. I expand on this, and the issues created by this hesitancy to participate in research, in chapter 3, 6, and 8. I observed one solicitor while they were making wills with clients (who had also agreed to participate in the research). This data provided a unique insight into the conversational practices between solicitor and client. These data were collected to answer research question 2 and 3. Furthermore, though small, this dataset is invaluable in understanding capacity assessments, as it was collected through conversation between the solicitor and the client. I conducted CA to understand the micro-level conversational practices which occur in this legally-important interaction. Conversation Analysis is a common practice used to understand institutional interaction. To my knowledge, this analysis has yet to be applied to data of more mundane legal settings. To understand capacity, it is imperative that the conversation where assessment occurs is understood and deconstructed. Through this deconstruction I explain how this solicitor does (and does not) explicitly assess capacity within the meeting. This observational data also adds to my findings about the importance of relationships for people with dementia when making a legal decision.

My analysis, a chapter-by-chapter overview

Due to the inductive approach of TDA and CA, my analysis's focus is shaped by my data. I adapt my research focus on the themes which emerge as important to the interviewees.

In chapter four I analyse my interview data and focus on the discourse in the two themes: ‘definitions of dementia’ and ‘capacity.’ In the former I have two subthemes. Firstly, the ‘anonymous subject of dementia’. Secondly ‘emotional reactions and experiences’. In the latter theme, capacity, I examine the two subthemes: ‘implicit discussions of capacity’, and ‘explicit discussions of capacity’. This chapter contributes to answering research question 1.

Through examining these two themes I can draw distinctions between how law defines a person with dementia and their potential capacity, and how people with dementia and their carers define dementia and capacity. The interaction between dementia and capacity to make a legal decision has not been examined in this way before. As a result, it could contribute novel knowledge to legal scholarship and inform any future amendments to capacity law, even if this is simply making citizens aware of the nature of legal capacity and what the definition is. I contribute to literature focusing on the discourses of disease and particularly dementia. I add to this body of knowledge by reflecting on how the disease is othered, but also how this protects a person’s sense of self. I contribute to socio-linguistic literature by looking at metaphor use, and contextualising this within the theory of neuroculture to which I subscribe (drawing links between neuro-language and metaphor use).

People with dementia and their carers other the illness to protect themselves against the negative impact of dementia in neurocultured society. By othering the dementia, the individual brainhood is protected, and they can exist within the so called ‘healthy aging’ rhetoric popular in society. Capacity, as understood by people with dementia and their carers, (the majority of whom have made a legal decision) is different to that dictated in capacity law. Indeed, interviewees can point to the other without capacity, but find it difficult to relate this official capacity to themselves. This is an interesting point if we are to better understand how capacity law is enacted in these everyday scenarios.

This chapter builds on the ideas put forward in chapter two, examining how personhood is and isn’t affected by the presence of dementia, and what this means for legal decision making. The following chapter examines how people use these understandings to plan for their future. Given that the decisions governed by capacity law are future-oriented, it is important to examine how ideas of capacity and future capacity within relationships are oriented and accounted for.

In **chapter five** I use TDA of my interviews to answer research question one, paying attention to how legal decisions are made relevant (or not) to interviewees’ constructions of planning for the future. Both wills and LPAs are future-oriented decisions, so it is pertinent to understand how they form (or are absent from) the construct of planning for the future. The themes identified are relational and moral future plans, anticipatory and protective future places, delayed and disrupted future plans, and desired rights and control in the future. In relation to these themes and the discourse analysed I discuss different constructs of time, and the different components of time (for example, legal time and the moral ‘right’ time). I also highlight how some interviewees expressed a desire to complete suicide (often referencing assisted suicide) due to dementia's impact on the end of their life. I discuss the implications of this in the context of social and legal issues. In the last theme, I discuss the absence of rights talk in interviews, and the issue of legalese regarding rights. This chapter contributes to answering research question 1.

My finding that future-oriented legal decisions are not integral to the construction of people with dementia and their carers futures is a novel and interesting one. It highlights the issue that law is not seen as relevant for everyday life and plans, even where LPAs might be used for such purposes. This raises questions about how legal decisions are used, and if LPAs, wills, as well as Advanced Decisions to Refuse Treatment (hereafter ADRTs) are suitable for giving people the desired control at the end of their lives. Time is a recurring theme across this chapter. I contribute to the literature regarding temporality and law, and the ideas of multiple selves (past, present, and future). I relate this to the constructions of personhood and how legal construct of linear temporality is problematic. My arguments in this chapter concern the need for a re-framing of the current tools available to help people with dementia plan for their future with the disease. I propose that LPAs and ADRTs might offer people with dementia the control desired at the end of their lives. Additionally, I use my data to show that people with dementia must be included in the ongoing debates around assisted suicide and euthanasia legalisation in the UK.

I add to the findings in chapter four concerning personhood, and how this personhood is interpreted in past, present, and future contexts. I also add to my observation that interviewee constructs of law differ from that in doctrine, a fissure that needs addressing. In the following chapter, I report the findings of my observational data, noting the overwhelming financial focus of the decisions being made and assessed.

In **chapter 6** I discuss the findings from my observational data which I analyse using CA. I discuss how the solicitor and client co-produce the construct of the legal decision. In this chapter I evidence two collections: clients presenting information as knowledge and 'statements of legal obligation'. These collections of data address research questions 2 and 3. I analyse my data by paying attention to solicitor and client epistemological rights, and how this impacts and informs how the task of making a legal decision is constructed through the conversation.

These data are unique and therefore gives valuable insight into a legal space that is under-researched. I offer unique insight into how the solicitor observed references capacity in discussions with clients, and what the capacity discussion might look like in action. This is a new insight into how the law is being enacted in everyday settings.

I contribute to literature regarding epistemological stances in institutional conversations. I must draw on research in other institutional settings throughout this chapter (namely medical and counselling settings) as these are the closest comparison points. I add to legal discourse regarding what capacity is and how it is enacted, particularly that occurring outside of the courts.

I demonstrate how solicitors may benefit from using conversational techniques adopted by counsellors and medical professionals to assess capacity through conversation. Additionally, I argue that solicitors, and by proxy law, needs to create more inclusive spaces allowing for different definitions of family and valued relationships.

This chapter gives insight into how future-oriented decisions are discussed and made within the legal space of a solicitor's office. This adds to my findings outlined in chapters 4 and 5.

The attention to familial and personal knowledge links with my next chapter where both data sets are examined to understand how relationships influence legal decision making.

In **chapter 7** I analyse both datasets (interviews and observations), looking at how relationships inform legal decisions. Within this, I refer to how relationships are integral to constructs of identity, personhood, and life with dementia. I use both datasets to demonstrate the importance of relationships when making a legal decision, and how law restricts or supports the inclusion of these relationships. This chapter answers research questions 1,2 and 3.

I argue that, by using both interview and observational data, I can gain a better perspective of how people make legal decisions. Contrary to some positivist CA researchers, I argue that the addition of interview data gives further insight into the history of the decision making, and how this history is integral to the decision making process. I give insight into how law can be moulded to suit the relational needs of a person when making decisions outside of the legal space, and then compare this with how legal decisions are potentially constricted within the legal space.

In this chapter I use my data to evidence the theory of relationality regarding legal decision making. I add to the legal literature arguing for the adoption of relational personhood within law. Through my observational data I am also able to comment on relational evaluation in this setting, drawing on kinship theory to explain how some types of relationships are validated or devalued by the solicitor.

I argue that decision making is a relational act. Legal practice must adapt to recognise this more fully and allow people to access the support available from their relationship and the history of couplehood. I argue that law disallows people to be their authentic relational self, and by doing so negatively effects people with dementia whose relationships become integral to their lives.

These findings link to discussions of personhood made prior to this thesis, and in chapter 6, by expanding upon the observation that the solicitor values certain types of relationships. This chapter serves as evidence for my theoretical reasoning in chapter 2. It is also conducive to answering all research questions and is a precursor to my conclusion.

Finally, I bring all my findings from across the thesis together and conclude in **chapter 8**. I make recommendations for future practice in solicitors' offices and changes needed for people with dementia and their carers to access and fully make use of their legal rights.

Conclusion

Capacity has been defined in various ways. We need to understand how these various definitions are being actioned on a day-to-day basis in legal settings, which is what I endeavour to do in the proceeding chapters of this thesis. Using an empirical social constructionist approach, investigating everyday legal decision making, I will interrogate if and how the MCA restricts and discriminates against people with dementia and their carers. Subsequently, through understanding multiple constructions of capacity (through theory, psychological inquiry, observations of capacity in practice, and the perspective of those people subject to capacity law's restrictions), I can begin to homogenise different definitions to understand what capacity is, and how it is used and understood. To incorporate the UN CRPD values, we must use psychological knowledge, relational theory, and the lived experiences of persons with dementia and their carers to understand what is utilised for decision making processes and how this can be incorporated into a definition of legal capacity.

Having introduced the background theory, context, and setting up the main issues of this research, I have shown why capacity law requires further research and investigation and why my approach is unique and will add valuable insight to this field of study. Additionally, I have demonstrated why it is important we address the issues identified, given the potentially harmful impact on a growing population of people subject to capacity assessments. In my outline of each chapter, I have detailed how I answer my research questions and why my empirical approach and inductive method have led to some novel points of inquiry. I will now outline my theoretical approach in-depth in the following chapter, focusing on theories of personhood which are relevant for capacity law, including brainhood, Kantian autonomy and individualistic personhood, and relational personhood. I will also interrogate the contribution of psychology to the legal discourses of capacity, and how this contributes to our current understandings of capacity.

Chapter 2: Personhood and capacity, the theory and practice of implementing the MCA

Introduction

In this chapter, I outline some theories which I find relevant for the examination of capacity law in England and Wales. I draw upon the ideas of brainhood, a theory built upon the established hypercognitive ideals of a neurocultured society, to examine why we locate the autonomous self in the brain. I analyse Kantian theories of autonomy and rationality, and cognitive psychology's explanations of the mind, to understand current mental capacity law in England and Wales. I argue that individualistic Kantian autonomy restricts the legal system's concept of autonomous legal actors. I use the relational theory of personhood to critique this individualistic approach to personhood and mental capacity law. Following this theoretical analysis, I discuss how capacity is interpreted in both health and social care practice, as well as clinical and legal settings. Through this analysis I show how capacity definitions and interpretations vary considerably, and why this is problematic. I discuss how this misuse of differing capacity concepts in legal settings reflect and align to different ideals of personhood. Specifically, I interrogate how cognitive psychology has influenced the construction of mental capacity and decision making. I examine practice reviews of how the MCA has been used, and what this says about the implementation of capacity testing in health and social care settings (Hinsliff-Smith et al, 2017; Williams et al, 2014). Next, I look at how cognitive psychology has progressed legal thinking, but is used inappropriately, particularly when considering the different purposes of cognitive psychological tests of capacity. These tests are often used for diagnostic purposes in legal cases to indicate capacity to make a legal decision. For this reason, we need to understand the potential negative effects of adopting this cognitive approach.. The nuances between capacity assessments created for diagnostic purposes and capacity assessments to make a legal decision are misinterpreted across the respective fields. To evidence this, I present findings from a review of capacity cases brought to the Court of Protection between 2008-2018. I discuss my findings alongside that of Ruck Keene et al (2019, 2021), who conducted a similar case analysis. Finally, I conclude that if the enabling UN CRPD values are to be met, relational autonomy and the contextualization of the individual must be incorporated into legal practice. Moreover, the reliance on clinical tests in court and mistranslation of diagnostic capacity assessment results is a key barrier to achieving this goal. Ruck-Keene et al (2019) estimate that 95% of capacity decision do not require intervention in court. Therefore, my analysis of everyday legal experiences in my empirical chapters is essential to understanding capacity law in practice.

Autonomy and rationality: A theoretical explanation

Denying someone the ability to make a legal decision is to deny that they are a person before the law, hence denying their personhood (Arstein-Kerslake & Flynn, 2014). There is a disconnect between the ideas of personhood evident in the Law Commission's statements prior to the MCA being created (Hoggett, 1994) and the ideals of autonomy evident in the MCA today.[34] In their consultation paper, the Law Commission set out their principles, one of which was to normalise and enable people with disabilities and disorders. They achieved this in part through the presumption of competence.[35] The Law Commission included the status test as standard but emphasised the necessity for functional testing to avoid

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[34] See chapter 1 for full discussion of the history of capacity constructs.

[35] Competence is stated as something finite, capacity is conceptualised as something which can fluctuate. A presumption of competence is not equal to a presumption of capacity.

discrimination against people with mental disabilities (The Law Commission, 1991).[36] Assessing capacity in a society that values hypercognitive ideals means that attempts to enable personhood could be restricted by societal values and the cultural norms of neuroculture. This rhetoric reflects a medicalised, finite, and outdated concept of competency. Despite a conscious effort to reject competency measures, I demonstrate in this chapter how neuroculture and hypercognitive values result in brainhood (Vidal and Ortega 2007, Vidal 2009, Vidal and Ortega 2017). Brainhood isolates the anthropological notion of personhood to the organ of the brain. This is reminiscent of how individualistic ideals of autonomy isolate the person from their context, as both condense the human experience. I will now discuss this further, examining how individualistic autonomy affects mental capacity law.

Mackenzie (2008) states that legally 'autonomous persons are presumed to have the capacity, the right and the responsibility to exercise this [their legal] authority, even if they do not always exercise it wisely' (p. 512). If one is not individually autonomous in decision making, they will not be deemed capable of making legal decisions, as autonomy and mental capacity are constructed as inseparable. This is a guiding principle of capacity law that is explicit in capacity assessments. Individuals are required to be able to demonstrate their individual capacity to make a decision using their *own* cognition and based on their *own* values and beliefs. In the MCA this is seen by emphasising that the legal actor is an individual decision-maker. When referring to an ability to make a decision both in the Act and the Code of Practice, the individual has to make the decision *for themselves*.[37] The individual can be assisted to communicate a decision and must be provided with sufficient

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[36] See page 102-105 of the Law Commission's report for a full list of principles initially set out for the MCA.

[37] See Mental Capacity Act, 2005, Section 2, 1; Mental Capacity Act Code of Practice, 2015, Chapter 4.

and relevant information in the correct format as per principle 2. However, those practicable forms of support must remain separate from the act of decision making. Support, such as that from a trusted relationship, may be inherent to the relational self. When relying on an individualistic notion of autonomy, the focus on the sole ownership of a decision minimises the relational self that is allowed. The MCA moves away from the medicalised assessment of competency, but ‘has not yet been able to catalyse a shift to supported decision making in relation to wider life choices or complex decisions. (Harding & Taşcıoğlu, 2018, p.11). As Harding and Tascioglu (2008) demonstrate, supported decision making does occur on a day-to-day basis for people with intellectual disability. However, it is difficult to transfer these skills from the everyday to the 'legal' setting, given that:

a) The MCA seeks to protect the autonomous individual from potential abuse from external parties and b) Communication tools are cited as the most useful tools in the code of practice yet communication is not the only tool to enable supported decision making). Communication allowances emphasized in the MCA will not be enough to ensure people with disabilities have equal access to legal decision making. I will now explain how individualistic notions of autonomy and personhood are present in capacity law, why this is problematic for people with dementia, and is not conducive to achieving the principles of the UN CRPD.

Individualistic autonomy and rationality

Kant provides the defining philosophy for individualistic legal autonomy. This essentialist account of how autonomy exists and contributes to the self is embedded in the uncodified constitution of England and Wales (Laws, 1996; Poole, 2003). Firstly, I will examine what individualistic autonomy is, then I will proceed to demonstrate how it is present in the MCA.

Kant's theory of moral autonomy views humans as individualistic, rational and autonomous beings (Guyer, 2003). It is a reductionist theory that states that individuals have their own guiding morals, which supersede any influence from external factors that can affect the self and the actions people take (Bird, 2008). Contextual and relational factors are undermined and secondary. This concept is flawed when applied to the complexity of life and the circumstances and contexts in which people exist (relational, social, and material wealth). Kant also separates emotion, relationships, and 'non-intellectual' factors from everyday autonomy (Bird, 2008). If we adopt a Kantian view then (wo)man is enlightened, intellectual, and uses individual internalised guiding morals to make everyday decisions. Using the MCA, individuals are assessed on the basis that autonomy is vital to the ability to make a decision in relation to their own set of values and principles, and without the influence of another's values and principles. This is evidenced as the act and accompanying guidance emphasises that a legal actor is 'unable to make a decision for *himself* if *he* is unable' to meet the criteria stated.[38] I have added the emphasis to demonstrate that it is the individual self, and as stated, the cognitive abilities (or intellectual in Kantian terms) of this individual self that contribute to decision making capacity. Taking a Kantian approach to autonomy overlooks the influence of contextual factors and relational living from discussion of autonomy. Law follows suit.

Kant's theory of rationality similarly reflects these individualistic, unrealistic ideals of the intellectual, cerebral self. Kant includes in his principle of morality that the categorical imperative guides all morals. He argues the categorical imperative is where rationality exists, and it is necessary, objective, unconditional, and supersedes any other influences on

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[38] Mental Capacity Act, 2005, section 3, 1.

morals (Bird, 2008). In other words, Kant states that to act irrationally is to do so without morals (Kant & Beck, 1959). The word 'rationality' is avoided explicitly in capacity law, but what is important is this idea of the unwavering intellectual individual version of the self adopted in law.[39] The individual, if they are if they are given information as outlined in principle 2 of the MCA, they must be able to make a decision unaffected by relational influences. This theory is incomplete, it does not consider the environmental factors affecting morality, rationality, and autonomy, and it discounts the human complexity of the person.

Kantian autonomy and rationality reject notions that complicate the human sphere, such as social context and relationships. Current capacity law is entrenched in Kantian views of autonomy and rationality and is influenced by the reductive anthropological ideal of brainhood, which I will now discuss.

Brainhood: the anthropological explanation

The 1990s saw the popularisation of neuroscience and was labelled as 'the decade of the brain' (Uttal, 2011). The 2000s saw the introduction of neuroscience in anthropology, social sciences, and the humanities; and thus began the neuro-turn. This neuro-turn is where debated neuroscientific theory and knowledge were applied to personhood ideas (Vidal & Ortega, 2017).[40] Vidal (2005) first coined the term brainhood to explain the phenomena of examining a person as a cerebral subject, where their personhood is centrally and exclusively located within the brain. Brainhood developed as a result of neuroculture (Vidal

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[39] The Mental Capacity Act allows for 'unwise' decision making. But we cannot equate irrational with unwise, the term is explicitly avoided yet individualistic autonomy is nonetheless present through the principles of a capacitious legal actor.

[40] I say debated, as most if not all scientific theory and knowledge is debated, 'truth' and 'fact' are relative terms even in the neuroscientific field. Neuroscience is still a relatively young science; debate is inevitable and necessary.

& Ortega, 2007).[41] Therefore, any damage or difference in the brain will also alter the individual's personhood (Vidal, 2005). "The theory of brainhood is reductive and harmful, as it posits that humans are brains, rather than individual beings possessing a brain. If society truly values brainhood rather than personhood, individuals with neural differences or disorders are at risk of being seen as 'less than' in this culture, resulting in them being marginalised and degraded. In this chapter, I propose that there is substantial evidence that brainhood influences mental capacity assessment practice. Firstly, I will further outline brainhood as a concept.

If we accept that the neuro-turn is a reality (at least in most western contexts), then we may also accept that personhood is converted into 'brainhood' in this culture (Vidal, 2005). To expand the cerebral subject, the brain becomes the organ of the self, the only body part needed to retain the self (Vidal, 2005, 2009; Vidal & Ortega, 2007, 2017). In this theory the brain is contained in the body, the personhood in the brain. Essentially people *are* brains, they do not simply possess them. Phrenology is a clear example of the height of the popularisation of brainhood. Phrenology uses the physical and visible structure of the brain to explain characteristics of persons, it was the first psychological theory to locate behaviours in the cerebral cortex. It is also one of the most abused psychological theories to date, used to demean and de-humanise to justify the slave trade (Renneville, 2009; Uttal, 2001). Vidal (2005; 2009) demonstrates that the brain has become the location for modern interpretations of the self, personality, selfhood; an individual with autonomy and agency is the figure of modernity and this figure possesses brainhood, not personhood. There is an assumption that brainhood is evident in people with such agency, therefore the assumption

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[41] See chapter 1 full description of the historical progress of neuroculture and hypercognitive ideals.

is that it is not in those who lack traditional perceptions of autonomy and agency. I discuss this when examining relationality at the end of this chapter, interrogating this assumption using the alternative theory of autonomy and personhood.

The theory of brainhood and the influence of neuroculture has resulted in a population that is acutely aware of the value of their own brain, we have become 'brain-people' (De Vos, 2016; Weisberg et al., 2008). The impact of neuroculture and brainhood is illustrated by Idvall (2018) who interviewed patients with Parkinson's disease about their own understanding of their neurological treatments. The brain and neurology were perceived as complex and the rhetoric challenging to understand. This makes rhetoric a barrier to be overcome for people to comprehend their own disorder. Neuroculture is arguably the enemy of individual decision making, it creates a perception of information that is inaccessible to the layperson (Idvall, 2018). Neuro-rhetoric and neuro-ontology is evident in today's culture, influencing societal ideas of personhood. Patients with Parkinson's disease (and similar brain disorders such as dementia) use the language of neuroscience to describe and discuss their illness while simultaneously positing it as belonging to the medical profession, not themselves. By doing so, patients resist ownership of the disease and become a neurological entity outside of their own full accessibility (Idvall, 2018). This kind of examination of neuro-language has not occurred in the legal context, therefore I draw on this medical-based research to find parallels. My research will help address this gap in our legal knowledge.

When hypothetically applying brainhood in law, a person cannot be seen to be capable of human action, behaviour, or thought without the functioning brain. In this construction, law can only assess brain function to understand action, rationality, and mental capacity. This is alarming if evidenced, as effectively those with a disability of the mind or brain are being valued less than other citizens, and regardless of a functional test inclusion, legal practitioners will assess capacity based on diagnosis. In this hypothetical scenario, the positive enabling movement for equal access to legal rights in the UN CRPD will be further from reach.[42] Later in this chapter, I present findings from a review of capacity cases and those considered ‘experts’ in such cases, and explore why the overreliance on clinical assessors and assessment might be problematic moving forward. In this next section, I offer an alternative approach to autonomy than the reductive and problematic theories previously described and explain how this theory is more reflective of decision making and capacity in everyday life.

Relationality, an alternative approach

Relationality places social relationships within autonomy rather than outside of autonomy. Unlike the Kantian philosophy of autonomy, or the theory of brainhood, relationality adopts an externalist approach. This externalist approach rejects the idea of a categorical imperative, or 'inner citadel' as it is otherwise named, due to the metaphorical basis for the internal 'inner citadel' and lack of evidence (Oshana, 2016). The individual is valued as a whole, the person is not secondary to the brain as in brainhood. Social and cultural relationships not only influence agency and moral decision making (Keller, 1997), they are enabling factors for autonomy. Oshana (2008) states that using a relational framework of autonomy, social relationships can enable and equip a person with the skill needed to pursue specific goals and hold certain values. This might differ from an oppressive force, for example, the right to make a legal decision. Relationality is concerned with acknowledging

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[42] The UN CRPD states that all people should have equal access to legal rights regardless of any disability, and that it is the state’s responsibility to enable individuals with a disability to achieve equal access.

the interdependence of persons, and recognising the value and the deficit created by social relationships with others (Lloyd, 2000). Viewing mental capacity law through a relational lens, one can identify the insufficiency of current methods of assessing mental capacity, because social relationships are excluded from the MCA and b*anks v goodfellow* where individualistic autonomy prevails. Relational autonomy frames a person not as a cerebral subject (Vidal, 2009), but as an 'encumbered self' (Keller, 1997, p. 152) with relationships constitutive of the whole person's autonomy and decision making ability. A person can neither be isolated from their institutional nor personal context.

Relationality stems from the acknowledgement that selfhood (not brainhood) is reliant on relationships. Physical and mental relationships account for human behaviour (including decision making). Relationality recognises the dissonance between human relationships and theoretical models of decision making (Lloyd, 2000). The relational self will use individual cognition and spiritual, social, and moral relationships to make a decision. Relationality cannot be reduced to a behaviour model because each person's relations will be unique and have different influences (Mackenzie, 2008). It provides an alternative theory to the otherwise reductionist view of autonomy, rationality, and decision making, and provides relief from harmful neuroculture and hypercognitive ideals.

Now that I have explained the theoretical and anthropological nexus in which my thesis sits, I will examine if and how the development of cognitive psychology has influenced legal discourses of personhood, the self, and decision making capacity. Cognitive psychology is centrally used to diagnose, understand, and assess people who have or are suspected of having dementia and similar disorders. The following section demonstrates how cognitive psychology has benefited legal discourses. It also highlights how we must be wary of the inappropriate and excessive use of cognitive psychological explanations and assessments, where cognitive testing instruments are used beyond their original purpose and restrictions.

Cognitive Psychology's influence on concepts of capacity

Cognitive psychology influences the way capacity is assessed in clinical and legal institutions. There is a wealth of research on decision making, reasoning, judgment, rational choices and memory within this field (Eysenck, 2018).[43] I argue that cognitive psychology has implicitly influenced legal definitions of mental capacity. UK law has 'borrowed' cognitive terminology in its functional tests of capacity in the MCA, and Court of Protection judges frequently rely on expert statements from clinicians (largely medical psychiatrists, not psychologists) to determine a person's capacity to make a legal decision [44]. Though there are geropsychologists and elder law researchers seeking to address the gap between psychological assessments and legal requirements for capacity, it is difficult to find a comprehensive history of how cognitive psychology has influenced capacity legal practice (Brank, 2007; Moye, Marson & Edelstin, 2013). Cognitive psychological understandings of capacity dominate the discourse of capacity law through: concepts of capacity, cognition needed for decision making, and influences on these cognitions and impact on decision making ability. I explore how this dominant rhetoric is potentially damaging given the differing purposes of so-called 'capacity assessments' based on cognitive understandings of brain function (used primarily for diagnosis of disorders), and capacity assessment for making a legal decision. Firstly, I outline cognitive psychological examinations of capacity,

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[43] Eysenck, 2018, provides a comprehensive introductory overview of the large field. A google scholar search of 'cognitive psychology' produces approximately 3,260,000 results. This thesis is not the place, nor does it serve this research, to detail the field in depth.

[44] See chapter 6 and 7 for analysis of my observational data.

then I examine how these may be mistranslated in legal contexts, thus affecting what type of capacity is being assessed in legal spaces.

Cognitive psychology and the MCA

Cognitive psychology has influenced how the MCA defines capacity to make a legal decision. I will briefly summarise this large field of study before interrogating how we can see its influence in law.

According to cognitive theories, decision making is influenced by working memory. Working memory is:

> 'the system responsible for active maintenance and manipulation of information over brief time periods… this system is viewed as a part of larger memory architecture, in which information is perceived, attended to, and retrieved' (Mccabe, Roediger, Mcdaniel, Balota, & Hambrick, 2010, p. 3).

The controlled processes identified by both capacity law and cognitive psychology include attention, decision making and memory retrieval (Mccabe et al., 2010). Note the language used, ’manipulating information’, ‘perceived’, ‘attended’ and ‘retrieved’. This echoes the MCA’s definition of capacity to make a decision.[45]Additionally, discussions by the Law Commission in their consultation papers, produced prior to the MCA, evidence the conscious acknowledgment that 'the analysis of medical and psychological tests appears to have received comparatively little attention in this country’. The Law Commission recognised interdisciplinarity may aid in reforming legal definitions of capacity (1991, p. 45). Cognitive psychology has influenced the way capacity is constructed in law. It should be considered that knowledge from psychology regarding influences on cognition,

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[45] Mental Capacity Act, 2005, section 3, 1

environmental factors, and social aspects should also be consulted. This is somewhat disputed by those advocating for person-centred or integrated capacity assessments.

The pitfalls of using cognitive psychological theory as a basis for mental capacity in law is that the nuance and debate of cognition is somewhat lost. In short, cognitive psychological theory is not universally accepted and is often the result of cognitive task-based assessments in a controlled lab setting (seeking to prove or disprove a cognition which is present or affected by different variables). The adoption of cognitive psychological concepts and language, whilst progressing the medicalised rhetoric, is not conducive to a legal definition which is reflective of the social world in which everyday legal decisions are made.

For example, when examining any explanation of working memory and capacity, we must consider that ability can have a causal effect on motivation, which in turn affects whether a person can carry out a task (such as a capacity assessment). If a person with a disability feels unable to complete a capacity assessment, they will have low motivation, which will reduce their ability to carry out the task, potentially affecting the outcome. Motivation and its effect on ability and capacity can be mitigated by supplying quality information, a factor accounted for somewhat in the MCA (Roets & Van Hiel, 2011). The MCA states this in principle 3: ‘A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success’.[46] However, the extent to which this happens in everyday practice is relatively unknown, and even in Court of Protection cases, it was found to occur in just over half of all cases (43% of judgements did not cite support measures taken) (Ruck Keene et al, 2019). Cognitive psychological experimentation demonstrates how easily cognitive function may be affected and provides

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[46] Mental Capacity Act, 2005, Section 1, 3

compelling evidence for my argument, that although cognitive psychology provides important knowledge, its nuances cannot be directly translated for the purposes of assessing capacity to make a legal decision (Bechara, Damasio & Damasio, 2000; Roets & Van Hiel, 2011).

Cognitive psychology and its core principles have influenced how the MCA frames capacity and which skills are deemed essential for decision making in the functional test. Cognitive psychology is vast, decision making is a prominent and constantly developing field, and a full summary of these complex debates is, unfortunately, outside the scope of this thesis. The core principles of cognitive psychology are that human activity must be explained through internal constructs which exist within a limited processing system(s), that can serve multiple functions (Solso, MacLin, & MacLin, 2005). These are the principles that underpin the cognitive psychological rhetoric in the MCA. As within neuroculture, what is missing from cognitive psychological influence is the reality of lived experiences and the influence and constructionist nature of human life and everyday decision making.

As stated in the UN CRPD’s general comment number 1, paragraph 12: 'mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon'.[47] Yet, in both law and psychology, medical, clinical explanations are favoured instead of social and contextual factors. In UK law this presents as: the MCA diagnostic test, the b*anks v goodfellow* inclusion of a mental disorder, the Golden Rule relying on medical expertise, and overuse of psychiatrist testimonies in court.[48] In psychology, diagnosis-focused capacity assessments are favoured. This is demonstrated through the wealth of

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[47] Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session (April 2014).

[48] See chapter 4 for my data analysis and the case examination in this chapter for evidence of neuroculture and brainhood.

cognitive assessments that focus on the diagnostic outcome. The outcome of such tests, even when a scale is involved, is either the diagnosis of a disorder or the absence of a disorder. Capacity is either below a normative threshold or satisfactory (Mueller et al., 2015). The polarity of the outcome does not reflect the complexity of capacity and the cognitive, relational and contextual influencing factors. These outcomes are not useful for legal definitions of capacity which focus on decision-specific, and time-specific capacity. What I discuss next shows how this nuance may be lost in translation in legal spaces, where diagnostic tests overwhelmingly influence judgements of capacity.

Clinical and diagnostic capacity : The expert witness and status test

Despite changes in legal capacity discourse, there is a reliance on the clinical (mainly psychiatric) assertion of capacity (Case, 2016a, 2016b). When a psychiatrist is called as an expert witness in cases where capacity is in question, a judge is likely to favour and support their testamentary evidence (Case, 2017a). A psychiatrist may comment on a client's (lack of) insight due to the given diagnosis. A client’s diagnosis and the terminology of a client's (lack of) general 'insight' into their affairs may be used in courts to deny capacity reliant mainly on a status-based approach. This is in conflict with the functional approach adopted in the MCA. A status-based approach relies only on diagnosis, such that a person is defined by their status as *being* mentally disabled, rather than their actual ability (Arstein-Kerslake & Flynn, 2014). This is not UK specific, in Sweden an examination of psychiatrist testimonies found the quality ranging from in-depth paragraphs to a single sentence regarding capacity (Bjorksten, Falldin, & Ulfvarson, 2014). Furthermore, clinical definition of capacity differs from that used in law. Unlike in the legal definition, where specificity is emphasised, competency is often interchangeable with capacity.[49] Though the discourse of capacity in the MCA has evolved, diagnosis still plays a considerable role in capacity law in England and Wales and internationally. Status as a person with a disability can reduce a person's rights and encourage disabling rhetoric. If we were to instead focus on people's abilities to act enabled by relationships and consider contextual factors, the discourse of law could be more enabling and decision making capacity may become more realistic. My empirical research in the following chapters seeks to address how relationships might contribute to a person’s capacity to make a decision, and what this could mean for legal practice moving forward.

As I have discussed in the above, diagnostic cognitive psychological tests form the dominant rhetoric of capacity both in the medical and the legal fields. This mistranslation is a detriment for people with disabilities and restricts equal access to legal rights. In the following section I describe some common diagnostic assessments of capacity, before exploring more nuanced assessments of different types of capacity which might contribute to a better understanding of the complexity of capacity for legal decision making. I also point to the issue of misinterpreting diagnostic information as legally relevant for capacity to make decisions.

Commonly used diagnostic assessments

The MMSE is often used when patients complain of 'memory problems' (Alzhiemers Society, 2014; Woodford & George, 2007). The MMSE is also used as a benchmark for newer tests of capacity, which often outperform the MMSE for validity and reliability. The MMSE is a brief

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[49] See evidence of this in appendix D. I give a comprehensive list of capacity assessments from a semi-structured literature review and ‘berry picking’, though capacity was expressly searched for competency was often used in place of this to describe an assesment.

cognitive assessment conceived to evaluate psychiatric patients (Folstein et al., 1975). It consists of eleven questions assessing the cognitive abilities of orientation, registration, attention, calculation, recall and language. It takes only 5-10 minutes to administer in most patients (Folstein et al., 1975). However, although it is quick to administer, it is outdated and criticised for lacking sensitivity to the complexity of capacity and cognition (Mitchell, 2013; Nasreddine et al., 2005; Zadikoff et al., 2008). The MMSE does not test executive function or visuospatial function well, nor does it have good inter-rater reliability (Woodford & George, 2007).

Addenbrooke's cognitive assessment (Law et al., 2013) and the Montreal Cognitive Assessment (MoCA) (Zadikoff et al., 2008) are deemed superior to the MMSE. Both tests focus on functionality and rely on rating-scales and scores, like the MMSE. Their purpose is to test for cognitive deficit and test global cognitive functions. Depending on the score achieved, they can be used to aid in diagnoses of cognitive impairment and dementia (among other neurocognitive degenerative disorders using the MoCA). The score provides an indication as to whether the individual has a cognitive deficit, if they are incapable of carrying out tasks and/or should be diagnosed with a cognitive disorder (Cullen, O'Neill, Evans, Coen, & Lawlor, 2007; Mast & Gerstenecker, 2010). These tests dominate the discussion of capacity assessments and are validated through reliability and validity measures. However, if we consider that the cognitive approach to capacity is one of many, then these tests become part of a larger conversation.

When comparing MoCA to the MMSE in a comparative study in a UK memory clinic, clinicians found that the 'MMSE had a sensitivity of 17% to detect subjects with MCI, whereas the MoCA detected 83%. The MMSE had a sensitivity of 25% to detect subjects with dementia, whereas the MoCA detected 94%' (Tasha et al., 2007, p. 329). Given the increased sensitivity of this test, (found elsewhere by Gill et al., 2008; Nasreddine et al., 2005; Zadikoff et al., 2008) the superiority of its use as a cognitive screening tool for *diagnosis* is clear.[50]

The MoCA and Addenbrooke's cognitive examinations have proven themselves as good measures of cognitive capacity and are helpful for clinicians in diagnosis (Nasreddine et al., 2005; Tasha et al., 2007). However, we must question to what extent the use of cognitive tests dominates discussions of capacity. I have examined these tests because they are frequently cited, they focus on cognition, and are useful to highlight the relationship between cognitive capacity (and deficit) and diagnosis. Where this cognitive capacity is mis-interpreted as mental capacity is the issue I wish to explore, as this signifies the influence of neuroculture and hypercognitive idealism. The following tests from psychology demonstrate how broad the concept of capacity can be, and why contextual factors are important.

Financial and 'whole person' capacity assessments

Capacity tests can be used to assess specific capabilities, but the most prominent focus is financial capability. Managing one's finances is deemed essential for independent everyday living (Hershey, Austin, & Gutierrez, 2015). Functional capacity assessments are poor measures of financial capacity because generally they only include 1-3 measures of broad financial capacity (such as 'ability to handle finances') and do not examine the skills needed for financial decision making (Sousa, Simões, Firmino, & Peisah, 2013). However, financial capability is not solely reliant on cognitive capacity, but also wider contextual factors such as

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[50] Emphasis on diagnoses, as it is important to bear in mind as per the MCA and testamentary capacity, diagnosis does not equal incapacity to make a decision.

social status or culture (Sousa et al., 2013). Therefore, there is need for financial capacity assessments to move beyond just assessing cognition.

The Semi-Structured Clinical Interview for Financial Capacity (SCIFC) is a financial capacity assessment that takes the form of a semi-structured interview intended for clients with mild cognitive impairment (Marson et al., 2009). Marson et al. (2009) address this financial gap in the capacity assessment catalogue. However, few clinicians are trained to administer finance-specific capacity tests. This is an issue if they are increasingly asked to assess financial capacity but lack the knowledge or training (Marson 2016; Sherod et al., 2009; Sousa et al., 2013). This introduces the debate of who is responsible for undertaking these assessments and who should be trained, particularly for financial capacity where the clinicians have less investment than diagnostic tests of capacity which are essential to practice (Marson, Daniel, 2016). In the NICE guidelines on assessing individuals with mental disabilities (including older adults with dementia), there is no mention of financial capacity or assessment, only healthcare planning. This may reflect the assumption that financial capacity is not the responsibility of clinicians (NICE, 2016). However, this could be further investigated and defined by psychology to ensure full and proper assessment of the skills needed for financial decision making.

A person-centred approach to finance

The Lichtenberg Financial Decision Rating Scale (LFDRS) (or Lichtenberg Financial Decision Screening Scale, LFDSS) is a financial capacity assessment that incorporates person-centred practice. It accounts for the patient's previous financial knowledge and ability and is more externally valid than the SCIFC. Notably, multiple professionals used administered the LFDRS (including lawyers and financial planners), and results were consistent, demonstrating good inter-rater reliability and validity (Lichtenberg, Stoltman et al. 2015). In the full version, 61 multiple-choice items are rated on a scale by the assessor. A shortened 10 item version has also been produced increasing the practicality of the test. This is a well-considered tool for testing financial capacity regardless of diagnoses, and therefore is complementary to the MCA. The concept of the person-centred approach applied in the LFDRS (and the LFDSS) allows for an individual's personal circumstances to be considered, including their finances and support network. The LFDRS is a useful tool for assessing financial capacity and provides a tailored approach to interrogating a complex issue (Lichtenberg, Gross et al. 2020).

Psychology scholars’ acknowledgement that financial capacity needs to be assessed using different tools demonstrates that different factors affect decision making, dependant on the subject. This is something legal practitioners needs to consider. My argument for a more contextual capacity assessment may work well here. This approach considers a person's context and accounts for relational and social factors, as well as cognitive skills. This provides a better measure of an individual's legal capacity

Whole person dementia assessment

The whole person dementia assessment is a comprehensive integrated approach to capacity assessments. Both cognitive factors and person-centred approaches are used to assess an individual with dementia on their ability to make decisions. The assessment in its most straightforward interpretation combines the 'technical aspects of efficient diagnosis and detection and (2) the personal aspects of helping people live with the changes of dementia' (Mast, 2011, p. 5). The assessment draws upon Kitwood's (1997) six domains of person-centred care and combines these with the cognitive assessments commonly used by clinicians. This cognitive assessment is useful for people with dementia in the mild-moderate stages, as comparisons are used to track progression. The functional approach can highlight where deficits lie and where strengths occur, which can be used to alleviate deficits. This reasoning for including a cognitive test highlights the practical utility of these types of functional tests in a clinical setting. However, the focus on person-centred principles is essential when considering legal contexts. Mast (2011) stresses that including a person-centred framework for assessment means that the person with dementia is acknowledged and all stages are explained. The tester should assess the person with dementia's perspective and explain, listen, and understand any concerns raised (Mast, 2011). Furthermore, reports from the person with dementia should not be disregarded, as partner’s reports of financial ability are not found to be consistent or reliable (Wadley, Harrell, & Marson, 2003). One flaw is that although Mast (2011) offers a practical way to assess capacity, he neglects to fully conceptualise capacity and engage with differences between mental and legal capacity. In summary the theoretical underpinnings of Mast's (2011) assessment are sound, and his detailed exploration of the reasoning and applicability behind it are convincing. However, the literature on the assessment is limited and there is no evidence is has been adopted widely for capacity assessments. I have included it here as it closely reflects my argument that cognitive skills must be accounted for within the context of an individual's social setting and relationships.

Capacity in health and social care practice

As discussed, capacity in legal settings is largely evidenced through cases brought to court. However, within the wider social and healthcare settings capacity law is used regularly to aid decision making. I will now examine evidence from multiple literature reviews and one qualitative study examining how the MCA has been adopted in health care settings. These studies discuss how the MCA has been used for best interest decision making, and reference how a capacity assessment leads to this decision making process, who is involved, and why. I examine the research in chronological order to demonstrate if, and how, progression has occurred.[51]

In a review published only four years after the MCA was enacted, Stanley and Manthorpe (2009) discussed how the MCA was perceived and enacted by people giving daily care (such as care workers, social workers, personal assistants, and care home managers). Their findings largely point to the difficulties of doing capacity assessments in practice for so-called small acts of care, and how the MCA was perceived as more relevant for medical treatment and end-of-life care planning. From their literature synthesis they found that staff involved in the daily care of a person did not feel they were well-trained to carry out a capacity assessments, nor did they have the time or resources. Overall, though the MCA was generally perceived as having a positive influence due to its enabling principles. However, actually doing the capacity assessment, and subsequent decisions around best interest decision making, was difficult in practice. The MCA responded to a need to change the medicalised competency tests, and incorporate a contextually sensitive model of care for people. However, the practicalities of implementation were not yet addressed by those reporting their experiences in the studies of this review. One important point raised in Stanley and Manthorpe (2009) is the recognition that those who receive informal care in their own home are dependent on their relationships, rather than the formal structures provided by the care setting. If relationships are integral to decisions regarding care in the home, we must also consider their influence in legal decision making. This is particularly

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[51] Reviews cited range from only 4 years after the MCA came into practice, to 2020, 15 years later.

pertinent given that LPAs and wills can be made both in the home and in a legal setting, such as with a solicitor.

In 2014, Williams et al published findings from a large-scale qualitative study including questionnaire and interview data from various medical and legal practitioners, healthcare staff, and family and friends of a person ‘lacking capacity’. This research largely focused on how best interest decisions are made regarding healthcare for a person without capacity. The most notable takeaway from this research is that they found that the mental capacity assessment was the most problematic aspect of the MCA in healthcare settings. This highlights the importance of examining if and how guidance for assessing capacity might be adapted to ensure it is understood, and the MCA properly implemented. A best interest decision only occurs (in principle and according to the MCA) after a capacity assessment finds a person does not have capacity at the time required to make the decision. Under the MCA a person should be assumed to have capacity until the point where they fail a capacity assessment for a certain decision at the time it needs to be made. Therefore, it is troubling that this report finds that the capacity assessment is perceived as problematic to carry out. This issue is further evidenced by Williams et al.’s (2014) multimethod study examining reported implementation of the MCA in 2011. Their findings showed that 10% of participants in phase one of this study (an online survey of 385 participants) indicated that when a best interest decision had been made, the person subject to the decision *did* have capacity. This is indicative of the fact that though the MCA has encouraged an enabling rhetoric for people with disabilities, understanding how to implement the MCA is still unclear.[52] This theme of blurred notions of capacity echoes that of the findings I reported

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[52] See chapter 4 for my evidence of how people with dementia and their carers conceptualise capacity and how this differs with legal definitions.

previously regarding the court setting. Participants in the Williams et al (2014) study reported how a lack of confidence and understanding of the capacity assessment meant they would frequently defer to others perceived as more knowledgeable on the topic; frequently this person was a psychiatrist or medical professional. Though Williams et al (2014) focused on health and social care settings, capacity itself is not an objective, medically identifiable phenomenon. In the confusion of what capacity is and is not, participants deferred to a medicalised, competency-centric process. Again, mistranslation occurs regarding what capacity is, who is best suited to assess it, and what information is relevant to the issue Diagnostically assessed capacity does not equate to the legal definition of capacity. Williams et al (2014) show how capacity as a concept is not well-understood in the medical setting. In the remainder of this chapter I show how capacity is similarly problematic for practitioners and people subjected to capacity law in legal settings.

A systematic literature review found similar issues with how the MCA was applied in healthcare practice (Hinsliff-Smith et al, 2017). After a review of 38 articles which included 33 different studies, Hinsliff-Smith et al (2017) conducted a thematic analysis. In relation to MCA implementation and understanding they found that knowledge of what mental capacity is, and how to assess it, was lacking for healthcare practitioners. This can negative impact those being assessed. Williams et al (2014) found that where people with capacity were found to be lacking, a lack of knowledge was cited. This is correlational conjecture, but still worth highlighting the potential impact of such findings for people with dementia and their carers. This is also pertinent given that the majority of those consulted in the studies were physicians and psychiatrists, and therefore likely to be relied upon in court (Case, 2016a, 2016b, 2017).

Finally, in 2020, two systematic literature reviews were published examining how health and social care professionals implement the Mental Capacity Act (Jayesa et al, 2020; Scott et al, 2020). Scott et al (2020), find many of the same issues as previous reviews. One of the ongoing issues identified is that the principles of the MCA are positively welcomed by healthcare professionals, but many aren't confident in their ability to carry out capacity assessments. As a result, the review indicated that many practitioners deferred to a senior colleague to carry out an assessment (Jayesa et al, 2020). This indicates there is a prevailing medicalised model for capacity assessment in the health and social care setting. This is problematic given capacity is not a medically identifiable phenomena. Jayesa at al (2020) suggest that for capacity to be understood, a better understanding of what makes a good capacity assessment is needed, and that conversation and discourse analytic techniques are the way to do this. My thesis contributes to addressing this issue.

This literature demonstrates that since the implementation of the MCA, capacity as a concept has been consistently reported as being difficult to understand and use in practice. It is important to address this issue through further research and innovative techniques. The transfer of information across disciplines can be improved to ensure capacity is properly understood in all contexts. Adding to this, it is important that people who are likely to be subjected to a capacity assessment (and their informal carers) understand capacity and can protect their own right to make a decision. My research contributes to understanding this under-researched group, acknowledging that people subjected to capacity legislation should and can be the most knowledgeable about their own experiences of capacity law and its constructs.

Capacity in practice: case law

As I have demonstrated in the previous section, capacity is a complex concept to understand and the MCA is not easily translated into health and social care practice. I now examine how the MCA is implemented and capacity constructed in court settings. By doing this I can examine if and how the different theories of personhood influence capacity understandings, as well as examine who is deemed to have capacity expertise in this setting. It is important to understand who is perceived as the expert on capacity, particularly as health and social care practitioners do not report feeling confident in their knowledge of the capacity assessment. The other parties present in court are legal practitioners and those subjected to a capacity assessment (or a representative). In the following section I demonstrate how courts endorse a hierarchical nature of knowledge in terms of capacity and authority to speak on a person's capacity, why this occurs, and why it puts people with dementia and their carers at a disadvantage in this setting. Firstly, I demonstrate findings from my content and thematic analysis of court cases from 2006-2018, and the following court models I produce. Then I discuss my findings in relation to the more recent case analysis conducted by Ruck-Keene et al (2019). Finally, I discuss the landmark case of Cheshire West, which current capacity law draws upon to reinforce the principles of the MCA.

To assess whether neuroculture and brainhood are present in mental capacity law, I conducted a review of mental capacity cases spanning from 2006 to 2018 (present day at time of conducting analysis). Firstly, I conducted a basic content analysis of 123 cases either from the Court of Protection (hereafter COP), Court of Appeal, or the High Court. I searched Bailli, Westlaw and LexisNexis databases where cases are published.[53] I then selected cases

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[53] For a full list of these cases see appendix C.

where capacity of P was the main reason for the case being bought to trial. These mainly concerned disputes over medical treatment, place of residence, or wills, again adopting the berry-picking method used previously when conducting my review of capacity assessments (Bates, 1989). This content analysis consisted of importing all cases into NVivo and conducting a text search for terms I had selected based on my theoretical aim. The purpose of this was to find out if neuroculture was present to any extent within the court, and if this affected the construction of capacity. I used the search terms ‘brain’, ‘cognition’, ‘expert’, ‘neuro’, and ‘neurologist’. I used these search terms to determine who is considered an expert within the court, as well as how frequently neurological factors are cited, with the aim of identifying if and how neuroculture may be present within the court setting.

However, the initial content analysis did not prove to be useful. The search term which yielded the most frequent results was ‘expert’, but once an expert was identified their name was used thereafter, so the actual coverage of expert references was only 0.01-0.02% of the document. I went on to read cases where ’expert‘ was referenced with more than 0.01% coverage. I did this to ensure that I identified cases where experts were referenced by the judge as pivotal to the case. This method is like that of Boepple and Thompson (2014), who conducted a content analysis of online blogs. When using this secondary data, such as blogs or in this instance, case reports, refinement may be needed to ensure the aim of the analysis is properly met. Through this process of refinement I thematically analysed 14 cases. I use these cases to inform the models of legal practice in court I have produced.[54]

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[54] See appendix C for a list of cases included in the content analysis and a table of the cases thematically analysed, informing the models of law produced.

These cases were identified based on my focus on wills and LPAs and cases where P had a diagnosis of dementia or similar mental disability.

Using thematic analysis I established how and when ‘expert’ knowledge was being used, who was considered an expert (largely medical or psychological professionals), and what weight was given to their specialist neurological knowledge. From this I produce two models of legal practice in court: neurocentric, and person centred. The former is the most predominant model of practice, and demonstrates the prevailing authority afforded to medical reports of capacity. The second model is more reflective of the shift to person-centred practice in health and social care settings, and the expertise is shared among different professionals and sometimes family members of p. However, both models highlight capacity and a capacity assessment as something done ‘to’ a person, without acknowledging their own experiential expertise on their ability to make a particular decision. A relational perspective of personhood is not seen in these cases. I discuss both models of law produced with reference to Ruck Keene et al (2019) who carried out a review of 40 Court of Protection cases, establishing how judges met the stipulations of the MCA. While their focus is *what* constitutes capacity within the court setting (in line with the principles and rules of the MCA), my own is *who* contributes to this construction of capacity and if this is reflective of neurocultural values set out in chapter one of this thesis. This thematic analysis helps to contextualise how capacity is assessed in this one legal setting. Through my models of legal practice, I show that my empirical research is needed to understand how people with dementia and their carers construct their own understanding of capacity.[55]

Neurocentric Legal practice

In this model, family testimonies and social workers are either absent or largely disregarded in the report of the judgement. P is absent, other than when being referred to. They are not seen to give their own evidence, or given a consultation visit by the judge on the case (as is sometimes done to ensure P feels involved in the case). Medical professionals are consulted and their evidence is dominant in the final judgement. I give examples in the following analysis. This model is reflective of neuroculture which values neuroscience as superior to other knowledge. The medical model also subscribes to the individualistic notion of autonomy, where personhood is located in the brain. As a result, it isolates the person's autonomy, placing it as a separate entity from their context. P is essentially compartmentalised, their brain and the statement of authority as to whether they possess the capacity to make a decision belongs to the medical domain. The judge gives a neuro-centric explanation for their judgement, and the clinical experts are relied upon heavily. See the figure below for a pictographic explanation of the hierarchy of knowledge found from my thematic analysis of these case reports.

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[55] See chapter 6 for my analysis of solicitor-client interactions, and chapter 5 for my analysis demonstrating how interviewees with dementia and their carers construct capacity.

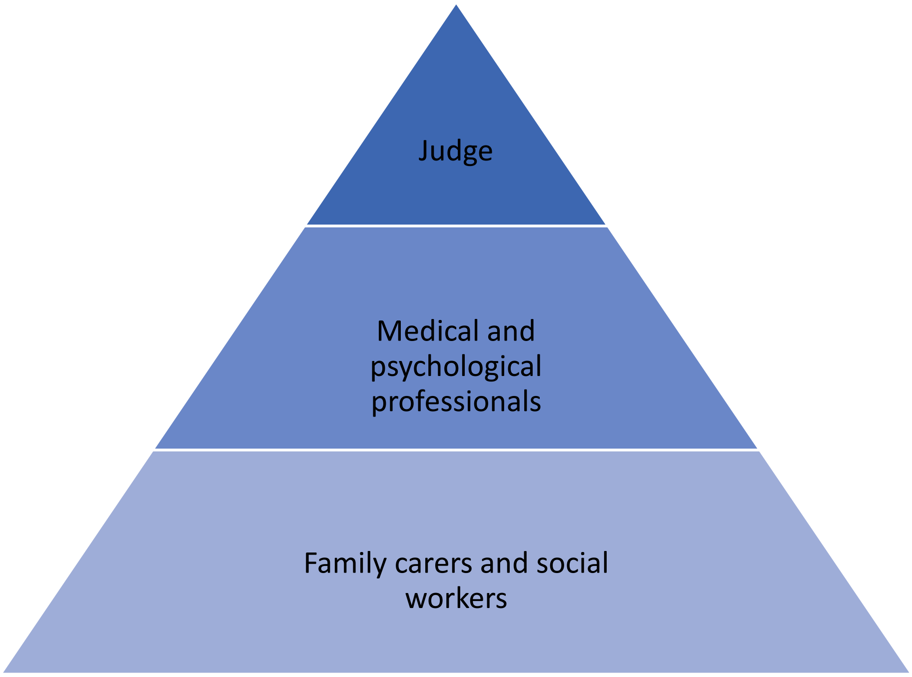

Figure 2.2, a model demonstrating the hierarchy of information in a neuro-centric court.

Cases

I will go in-depth here with several cases which demonstrate the emphasis of neuroscientific knowledge most clearly. Firstly, I examine the case of *D v R (Deputy of S) & Anor* [2010].[56] Briefly, the judge in this case must decide if S has capacity to make his own application to the high court chancery division, or if D has the authority to do so for him as deputy if he is deemed not to have capacity to do so. Mrs D describes herself as a friend of S, whom S has gifted just under £550,000 in 16 months. R, daughter of S and court appointed deputy, has begun pursuing a case in the high court chancery division to recover this money, stating S was under undue influence from D. In the report from the judge, the word 'expert' (or a stemmed word) is used 25 times, and this is without the addition of the individual names of the medical experts being used. In other words, the sheer number of times that these experts are cited in the 50-page transcript is of interest. These references amount to 0.04%

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[56] *D v R (The Deputy of S) & Anor* [2010] EWHC 2405 (EWCOP) (Henderson J).

of the document. This numeric data does little to inform about the case itself, but it does demonstrate the frequency with which courts/judges rely on professional expertise in capacity cases. I selected this case as it has a high frequency of neuro-language and concerns the deputyship of financial affairs (a court appointed role mirroring that of the attorney role if applying for a financial LPA). It is worth noting here that in all cases only professionals are cited as experts explicitly. When the term expert is mentioned, it refers only to medical, psychological, neurological, and (only once) social workers. Therefore, it appears that mental capacity is confined to clinical expert knowledge. This is concerning considering that many expert witnesses called in the COP are psychiatrists (Case, 2016a, 2016b, 2017). Psychiatrists are clinicians who can provide diagnoses based on clinical measurements, they are less concerned with the social world in which the individual exists, as defined by their role as diagnostician. It is important to balance this diagnostic information within the COP with the contextual and sociological knowledge that could be provided by, for example, P themselves, or social workers.

Returning to the exemplary case, *D v R (Deputy of S) & Anor*, I will now conduct further analysis of the case and judgement to demonstrate the neuro-centric model of the court. The judge uses the testimonies from three experts and extensively reviews each, two clinical psychiatrists and one neuropsychologist &clinical psychologist. Each professional is given an introduction detailing their professional history and credit in their respective fields, they are almost revered in the court for their achievements and kudos. Their knowledge is placed on a unique and higher epistemic plain than any other potential experts. For example, the judge describes the expert’s professional titles, achievements, accolades and 40 years' service in the clinical profession. This description may well be an accurate representation of this expert's career but does not necessarily mean they are best placed to assess the individual’s capacity, with whom they had not encountered prior to this case. By presenting the expert in this way, the judge is elevating their status using relatively superfluous information. This expert is well qualified to perform neuro-cognitive tests and assessments. However, they may be rather underqualified and uninformed about P's mental capacity if we consider this to be, as stipulated by the MCA, determined by other means than simply a diagnosis. The clinician is well qualified and knowledgeable in their field; this is not up for debate. The issue is that they have no existing relationship with the client., such as observations or assessments over a prolonged period. This is evidenced by the judge's report of the expert's interaction with the client. The judge cites five different cognitive tests which the expert carried out. These tests, as previously mentioned, help test cognitive function in isolated lab environments. The MMSE (cited here) is also primarily discredited in cognitive psychology as unreliable. Furthermore, cognitive function tests cannot be equated to tests of mental capacity; they are again being mistranslated in court. Tests like WAIS-III (cited in this case) are tests of individual cognitive function, not mental capacity. They are useful in assessing a patient's progression of brain function or deterioration. They are not useful in assessing how that brain function affects the individual on a day-to-day basis, in their own environment, with their own support systems in place.

Mental capacity expertise is placed in the hands of clinicians in this case. The extensive descriptions of the various qualifications of the experts and the fact that the debate for the case centres largely around the disagreement between the experts, means that the capacity being assessed here is negatively neurocentric. P is absent, as are any social workers attached to P or close relationships. P's capacity is decided based on three independent experts. The judge decides their knowledge is so superior that other testimonies are not required, and mental capacity needs to be assessed by three different brain-oriented experts. Because of this, P's capacity is located in the brain and their personhood is ignored.

Person-centred legal practice

Medical, familial, and social worker evidence is weighted equally in is model. This is more expressly acknowledged in this model, but is still largely present through external reports and evidence. In these cases, the court follows a person-centred approach where even if P is not present, their wishes and beliefs are placed at the centre of the judgement, rather than evidence given by medical professionals regarding cognitive skill.[57] This aligns with the person-centred model used in healthcare, which posits that to avoid ‘negative psychology’ care must be centred on the individual and their remaining skills, not the affected brain and deficits. The person must also be seen as belonging to their gender, family, and class, among other categories (Kitwood, 1997). These values mirror those set out in the MCA, yet these are not being enacted consistently.

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[57] See figure 2.2

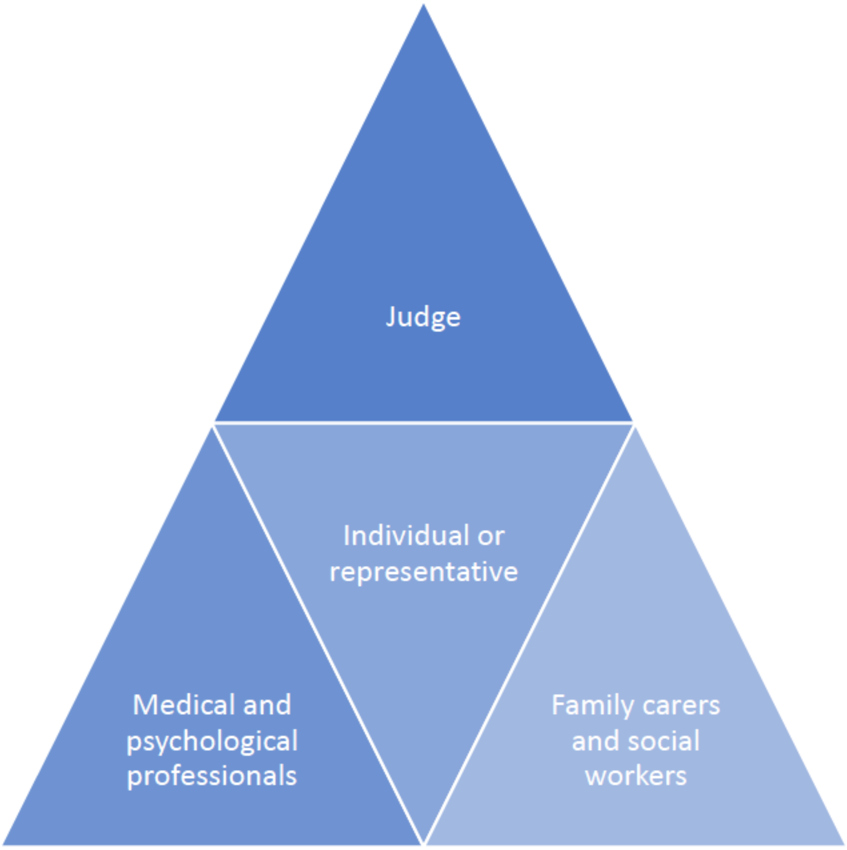

Figure 2.3, A person-centred model of law, demonstrating the equality of evidence from different sources.

Cases

In the case M*asterman lister v jewell,* the claimant's capacity to manage his finances and estate was confirmed. However, the outcome is of relatively little importance for this discussion.[58] The amount of evidence given by medical experts consulted in this case, a total of 6 clinicians, is the highest among those cases I thematically analysed. However, the way in which this evidence is interpreted by the judge means neuro-centrism was avoided. Three neuropsychologists and one neurologist assessed P's capacity and concluded that there was 'significant impairment of executive function ... compounded by a very serious deficit of

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[58] *Masterman-Lister v Jewell* [2002] EWHC(QB) 417, [166] MHLR 166 (Wright J).

memory'. This statement was necessary for the judge to establish the presence of a disorder, but didn't necessarily mean that the client's decision making ability was absent This evidence, though not in dispute by the parties in the case, was pointed out as being given by those clinicians who had not had long term contact with the individual. In place of family carers or social workers there were three other consultants, who had consulted with P on several occasions and had a deeper understanding of his ability to carry out decision making in daily life. These clinicians also state that the neurological evidence does not provide any conclusion about P's capacity. Significantly, the judge does not place the clinicians on a higher epistemic plain than P, labelling their evidence as 'opinion' rather than indisputable fact. Their expert position has been lessened by the fact that the judge places them on the same epistemic plain as P, who gives his own evidence in the form of diaries. P’s evidence is where person-centred law comes to the fore. The individual, and how they behave and manage their own condition, is placed at the centre. The focus is not on the deficit created by the diagnosis highlighted by the neuropsychologists, but instead how P manages these deficits in daily life using diaries. This is what causes the judge to conclude that P does have the capacity to manage his own affairs. Allowing for some linguistic analysis, the structure of this sentence places P at the centre of the judgement. By using the word 'opinion', the doctor's evidence is downgraded, diminishing their epistemic authority.". In this case, P is represented and their coping strategies for their deficit are cited. The judge aligns to person-centred ideals and recognises the person rather than the cerebral subject recognised by the neuropsychologists.

In *Cheshire West,*[59] person-centred law can be seen as pushing back against the rhetoric of the 'cerebral subject', brainhood, and hyper-cognitive values. Though this case did not dispute mental capacity per se, it is too infamous not to mention here, and does provide a good example of how the court has adopted a more person-centred approach. Specifically, Lady Hale's judgement that 'it is no criticism of them [P] if the safeguards are required. It is merely a recognition that human rights are for everyone, including the most disabled members of our community, and that those rights include the same right to liberty as has everyone else' stands in opposition to neurocultural values.[60] The rebuttal that P must be recognised to have rights on an equal basis as anyone else, rather than as someone who has an equally impacting disability, echoes the UN CRPD rhetoric. Additionally, it re-iterates the person-centred assertion that the focus should be valuing the individual's skills. By refusing to focus on P's disability and stating that they should have equal access to the right to liberty, Lady Hale destabilises the medical superiority and re-adjusts the focus of capacity. This case is reflective of recent findings that the COP has progressed over the years and has acted in a more person-centred way than when initially established. This is most evident through the review conducted by Ruck-Keene et al (2019), where they anecdotally state that judges in the COP (and cases on appeal from the COP) are starting to recognise that psychiatric and diagnostic knowledge is not central to the question of capacity. This shift in focus may stem from the so called ‘causative nexus’, whereby the previous two-stage test has evolved to become a three-stage test of capacity.[61] As Ruck Keene et al (2019) identify, courts tend to try to enable P to participate to some degree in proceedings. However, to what extent this influences the outcome is not detailed. Given my analysis signifying the

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[59] *Cheshire West and Chester Council* v *P* [2014] UKSC 19.

[60] Ibid, Para 1, p. 4.

[61] See chapter 1 pages 14-17 for a full explanation of this.

continued over-reliance on diagnostic clinicians, even in the person-centred model of law, P is still placed in a disadvantaged position when under scrutiny of the court. Though some judges clearly attempt to involve P, and this likely influences the outcome, they are still absent in the reports as an expert of their own experience and capacity. As Kane et al (2021) note, understanding what capacity is within the court and, as I have demonstrated here, who contributes to this construction of capacity, is important. What is missing is an understanding of what capacity looks like in the everyday legal landscape, outside of the court, where most legal decisions occur. My empirical work, which I detail in the following thesis, will provide insights to fill this gap in our current understandings of capacity law.

Conclusion

Neuroculture and hypercognitive ideals negatively influence how mental capacity is constructed in capacity law, both in doctrine and in action in courts. These two theories create a law where brainhood is valued instead of personhood, and Kantian autonomy prevails over relational autonomy. As a result, mental capacity law in England and Wales is reductive and exclusionary of human complexity People with disabilities or impairments are most at risk of losing their right to equal legal access. If we want to improve the law, we must adopt more inclusive, relational views of autonomy and apply them to practice in both legal and healthcare settings.

We are currently reliant on a legal system that submits to the ideals of hyper cognitivism and neuroculture. For people with dementia and older people in society it is necessary 'not to reduce their humanity to one organ', in this case referring to the brain and its neurocognitive ability (Whitehouse & George, 2008, p. 49). To prevent this from occurring we must then align with the ideals of the UN CRPD and enable all individuals, regardless of neurocognitive functioning, to make legal decisions.

Less reductionist theories, namely relationality, which I have explored in this chapter, are not influential for practitioners because we function in a hypercognitive society that values cognition regardless of the environment or information utilised. There is a growing trend which labels society as a neuroculture. As this trend grows in popularity, instead of becoming more aware of derivatively labelled 'folk psychology', otherwise known as social and environmental psychology, we may produce assessments with a narrower focus based on cognition and neurological evidence. What capacity lacks is a unifying rhetoric. This leaves lawyers, clinicians, diagnosticians, care professionals, and family and friends of people undergoing capacity assessments with a wealth of information, and a dearth of practical advice on the assessment of capacity to make a decision. To improve capacity assessment it must be recognised that capacity is complex and influenced by more than individualised autonomy and cognition. In the proceeding chapter I will outline how my empirical research method can address the gaps identified in the literature regarding how capacity law operates in practice and expand upon why it is necessary to examine capacity rhetoric in-depth.

Chapter 3: Methodology

In this chapter, I detail the empirical method of my research. To answer my research questions, I collected interview data and observational data to interrogate language used when discussing dementia and mental capacity. To reiterate, my research questions are;

1. How do people living with dementia and their informal carers access and interpret legal advice?
    iii) What is the content of this legal advice, and how does this rhetoric form the construct of 'capacity law'?
    iv) What impact does this have on their understanding of their legal rights and their mental capacity?
4. How do legal actors assess capacity, and how does this impact the legally relevant decisions made in the lives of people with dementia?
5. What is the contribution of observational methods, such as CA, to understanding legal decision making in action?

These have been answered using a social constructionist ontology. This encourages a deeper exploration of how law is a social phenomenon that must be studied within context and focus on the everyday legal actors which enact and create law's meaning.[62] Primarily, I use observational data to address questions 2 and 3, and interview data to address question 1. I preface my detailed explanation of my methodology by describing how I obtained ethical approval for my research. I demonstrate how this research was conducted conscientiously and introduce my method and participant groups in brief. Next, I describe the philosophical stance I take and how my methodology aligns with this, as well as give detail about how I

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[62] See chapters 1 and 2 for a discussion of how law's historical and social context is important for this research.

collected my data and conducted my analysis. I draw upon Searle's (2010) definition of social constructionism and detail the theoretical background of CA and TDA to demonstrate why and how language is spoken, and why this deserves attention in this socio-legal field. I detail the practical aspects of conducting this research, including recruitment practices and the difficulties I encountered when conducting novel research in the legal space of solicitors' offices. For this research (and arguably future research) observing actual meetings between clients and solicitors was imperative to accessing an accurate and nuanced insight into what occurs in such meetings, and how this informs the social construction of capacity law. Interview data was collected to give insight into the experiences of people with dementia regarding the law and their personal constructs, uninhibited by the 'legal space'. This is crucial given that both LPAs and wills can be made without a legal professional.[63] I detail how I use CA and TDA processes and ensure a rigorous analysis. Finally, I reflect on the methodology I have used, and what is needed for future research. This methodology chapter is integral as all empirical research conducted for this thesis inform all findings and conclusions. This chapter provides details of the foundation on which the remaining thesis stands.

Ethical Procedures

This research was approved by the University of Birmingham's ethics committee. Ethics approval also conformed to Join Dementia Research (hereafter JDR) ethical guidelines and solicitor firm individual confidentiality and anonymity agreements.[64] I next set out the

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[63] See chapter 6 for my analysis of how legal spaces may influence and restrict experiences of mental capacity law.

[64] A copy of the ethics submission form and data management plan can be found in Appendix A

actions taken to guarantee ethical criteria were met throughout the research, ensuring participants were not at undue risk or harm.

The observational research was deemed to pose no potential risks any greater than that experienced in everyday life, as this is naturally occurring data in a safe and secure environment at the solicitor's office. The only infringement on this environment was the presence of the recording device and the observer (on no occasion was the observer requested to leave, although this option was made available to all participants). Although office space was offered as an alternative location for the interviews, every interviewee opted for the interview to happen at their place of residence. Convenience is an important consideration when asking potentially difficult-to-access population groups to participate in research. This study was designed with participants' convenience in mind, minimising barriers to recruitment and ensuring that the required number of participants could be recruited. By carrying out the interviews in their own place of residence, the interviewees were comfortable in their environment and in a convenient location (with the additional presence of their ordinary familial support). A lone worker protocol was employed to avoid potential risk to the interviewer. The interviewer notified a nominated person when they arrived at the location of the interview and when they left, and if no contact was made after three hours from arrival, the nominated person would contact the individual to check their safety. This measure wasn't required in practice; the nominated person was only contacted to notify them of an extended interview time in the cases where the interview overran. This protocol allowed the interviewer to give the choice of location to the participant, making the process more convenient for them.

The subject matter is emotive and therefore could potentially upset the participants. It was important to be aware of this during interviews, and although exploration of emotive topics was of analytical interest, it was important not to pursue questioning beyond reasonable boundaries. On multiple occasions in interviews (with no correlation between questions asked) participants showed signs of emotional distress. At this time it was important to allow participants the space needed to continue discussing the topic and approach any interrogation of the cause of emotional upset with sympathy and caution (Brinkmann & Kvale, 2018). When necessary, it was also appropriate to move away from the emotionally distressing topic and do this markedly to signify the continuation of the interview and avoid conversation breakdown. Practically, this could be achieved through offering a summation of the interviewee’s talk, seeking approval for this, and continuing with the next question. Furthermore, when asking potentially triggering questions such as those hinting at end-of-life plans, it was important to remain impartial as interviewer with regards to the question and response. Answers to all questions were treated with respect and as valid, enabling rapport with the interviewees, and a more productive and interesting dataset (Brinkmann & Kvale, 2018). Ethically, to assist participants in this potentially distressing situation, all were given an information sheet detailing different supportive organisations for practical and emotional support.[65] Participants were also explicitly notified on the information sheets and consent forms that they could stop the interview at any time and did not have to answer every question asked. When troubles occurred, the interviewer could also check that the participants were happy to continue with the interview, or if they wanted to pause the interview. All participants taking part in an observation were given the opportunity to re-

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[65] See appendix E

confirm their consent at the end of the meeting, and it was explicit on information sheets given to them that they could stop the recording or ask the researcher to leave at any time. This is pertinent given that these participants may unexpectedly discuss topics that they may later not have wished to have had recorded.

Fully informed consent was obtained for this project. Easy-to-read information sheets and consent forms were used for the clients and interviewees. Solicitors were required to read and sign a separate information sheet and consent form prior to any recordings taking place. They were also required to sign and consent to each meeting recording. All participants gave their informed consent to take part. Dual consent forms were used, the participant kept one for their records, and the researcher kept the other. All participants recruited had the capacity to consent to take part in the research, as laid out by the MCA (2005) section 3 capacity assessment. This assessment stipulates that a person has capacity to consent if they understand the information, can retain it, weigh the information, and communicate their decision. It also states that the participant must be given all information to aid them to make the decision. All information was provided to participants prior to their consent and in the desired format (easy-to-read versions of forms, verbally reading out information). Every participant prior to consenting had evaluated and understood the information sheet.

Now that I have addressed the practical aspects of ensuring the research was ethical, I will outline the philosophical reasons for conducting the research in this fashion.

Philosophical reasoning for this research

The limitation of our language is the limitation of our world.

> ‘Everyday language is a part of the human organism and is no less complicated than it. It is not humanly possible to gather immediately from it what the logic of language

> is. Language disguises thought. So much so, that from the outward form of the clothing it is impossible to infer the form of the thought beneath it, because the outward form of the clothing is not designed to reveal the form of the body, but for entirely different purposes. The tacit conventions on which the understanding of everyday language depends are enormously complicated' (Wittgenstein, 2013, p. 66).

The choice of method for this thesis was influenced by the philosophical underpinnings, which aligned with how I sought to approach my primary research questions.[66] Additionally, they align with my conceptual framework using relationality, and I add to this as 'we (can) only start to learn more about the shape of "relational autonomy" by observing it in practice during everyday life' (Dowling et al, 2019, p.1064). To comprehend what laypeople understand of mental capacity (and the law which adopts this term) we must interrogate the language they use to describe it, and the autonomy adopted. As Wittgenstein (2013) states; language is not a simple act that can be investigated through semantic meaning alone. Similarly, CA posits that it is impossible to know what anyone but oneself knows and understands of their world, but we can build robust assumptions based on how they represent their world through the ways they use language, the types of turns of talk they take, and the purposeful organisation of social interaction (Hammersley, 2003; Maynard, 2013b; Sacks, 1992).[67] Investigating legal practice through the lens of social constructionism allows me to address the socio-legal problems at play, as these laws are a part of the social world created through discourse (Parker, 1998; Parker & Burman, 1993). Essentially, I approach mental capacity, legal capacity and my research questions from a social

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[66] See chapter 1 for my research questions.

[67] I discuss turns of talk later in this chapter on page 111, briefly, the can be described as a spoken sentence.

constructionist ontology. I subscribe to Searle's (1996) approach to social construction theory, whereby some facts of a so-called 'reality' are independent of human observation, but others are constructed by it. Language is part of this constitutive construction, particularly regarding an institution such as law. Searle (1996) proposes reality is completely independent of our ideas and representations of it and the social world is constructed around or upon the 'real' world (Searle, 1996; Wittgenstein, 2013). Searle distances his ontology from other narrower constructionist approaches like solipsism, and acknowledges the limits of human observation and its impact on what exists and what does not exist.[68] The mind, language, and civilization are natural products of the basic facts of the physical world described by physics, chemistry and biology (Searle 2010). This point needs stressing as I am answering socio-legal questions, therefore I am exclusively interested in the socially constructed world. My conceptual framework influences how I approach my choices for recruitment, data and analysis. I acknowledge that I do have some influence on this research and cannot ascribe completely to the purist ideals of unmotivated looking associated with the origins of CA (Sacks, Schegloff and Jefferson, 1978). This research is a product of my conceptual framework, and seeks to answer specific research questions. My findings are informed, but not driven, by my epistemological and ontological stances. Summarily I use a pragmatic approach within a grounded approach, similar to applied linguistic research practices, where specific questions are set out, and socio-legal research practices, where a conceptual framework is set out, prior to empirical investigation. With this in mind I will, now describe how my methodology ascribes to these philosophies and ontologies, and therefore are most appropriate to answer my research questions.

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[68] Searle does not explicitly reference solipsism. I give this example to demonstrate how I have arrived at Searle's interpretations of social constructionism.

Ethnomethodology, discourse and conversation analysis

Ethnomethodology is a sociological field of inquiry interested in how members of society act, create, and contribute to social life (Heritage, 2013c). CA and Discourse Analysis (hereafter DA) could be considered sub-categories of ethnomethodology (Travers & Manzo, 2016). Their focus on dialogue and how members create, contribute and make sense of their social reality through the ordered rules of interaction (Garfinkel, 1974).

Ethnomethodological enquiry seeks to understand how members of society interpret and understand the law.

> ‘Ethnomethodology (Garfinkel, 1967; Heritage, 1984) is an area of sociology that concerns the practices of ordinary persons in daily life, in concert with other social actors, that create the appearance of enduring, stable, and predictable social order. Ethnomethodology is the study of the organisation of everyday activities, the "how" of social organisation.’ (Travers & Manzo, 2016, p. 5).

Law has been investigated as a socially constructed phenomenon. Early works focused on jurors’ reasoning for a verdict, paying little attention to ‘legal reasoning’, instead seeking to understand the context of the jurors and the vocabulary used (Weider, 1974). The traditional dominance of legal rule falls in the hierarchy when investigating with an ethnomethodological stance. It is the members of the court (to give one example) who are the actors of law, who become the focus. It is their interpretation and language, rather than the legal rulings themselves which enact law (Travers & Manzo, 2016). Ethnomethodology follows a bottom-up approach to research whereby knowledge and theory must come from observed phenomena, rather than assuming the law is enacted as it is written

Law is indisputably a social phenomenon. Law only exists because there are people to constitute law and legal actors carry out legal work in real-time. To understand the law, we must examine the potentially centuries-old legal acts and examine how legal actors interpret, use, and understand them as they are being used. Law exists as it does because legal actors behave in specific ways; how someone communicates about the law can give us insight into what that law does and how it operates in people's everyday lives. Without this type of inquiry, we would be left without understanding the reality of the law (Pomerantz & Atkinson, 1984).

Searle's social constructionist approach to reality underpins this research and aligns with the socio-legal approach to understanding law In the sections that follow I introduce CA and how it has been used previously in legal settings and explain why it was best suited to analysing my naturalistic data. I then discuss TDA and explain why it was the appropriate approach for my interviews. I then draw these two methodologies together to demonstrate how they work cohesively for my research.

Conversation analysis

CA can be likened to looking for a pattern of needles in a haystack. In other words, the minutia of conversation is analysed with microscopic detail to understand how participants achieve goals through conversation, and how unconscious conversational practices take place in sequential real-time conversation. To conduct a CA is to seek out what, when and why conversational practices are used. Position, practice and speaker influence what is said, and how it is interpreted and oriented by the audience (Sacks, 1978 1984; Jefferson, 1984). Broadly, conversation follows either expected patterns of talk (which can be examined using the next turn proof procedure, identifying if what was said was treated as expected) or deviant cases (where the audience demonstrates what was said was not expected) (Sacks, Schegloff & Jefferson, 1978).

CA demands naturalistic data where researcher influence is minimised as much as possible. It does not hypothesise or imagine what talk is, but instead relies on grounding its assumptions in data and what is lived (Maynard, 2013b). CA requires that I abandon assumptions about political, social or institutional positions whilst conducting the research, and instead pays attention to the roles being carried out by the speakers, understanding the audible ways in which participants consider and understand another's words. This focus allows CA to identify how talk occurs as an inhabited human experience and action, and how individuals construct the social roles that may be otherwise assumed of them (Maynard, 2013b). It is imperative that I abandon the labels 'individual with dementia' and 'carer' and 'solicitor' when examining talk, and instead investigate the way that roles are naturally assigned to actors in the conversation. Through this, I can understand how participants comprehend the capacity of themselves and others. How this is enacted will inform my findings concerning the theories discussed. Importantly, CA allows me to identify how participants perform their roles or subvert assumptions in this institutional setting. Furthermore, through examining everyday interactions, we will garner a better understanding of how doctrine is interpreted and how the law operates on a real basis for many people who access it.

Moving on from how data is collected to how it is analysed, CA is based on understanding how a conversation plays out in real-time. During analysis, one must look at the conversation sequentially, analysing it with the same contextual knowledge that the participants had at the time. Participants in a conversation create orderliness in situ, it is not a product of analysis but an element of the data (Ten Have, 2007). This orderliness must be identified and then deconstructed to understand why certain conversational practices were employed. Conversational patterns and structures should be described, and if there are frequent similar occurrences, this may be considered a phenomenon of the data (Psathas, 1994). Phenomena are ascribed as social actions which are structured, organisational, and consistent. The robustness of CA relies on the non-linear approach to research. Data must be familiar, collections must be built and restructured, and phenomena must be interrogated and questioned (ideally by multiple researchers) before findings can be considered robust (Peräkylä, 1997). To simplify, talking is an action which can be studied. Talking in institutional settings has particular significance as it can become a trainable phenomenon. Furthermore, conversation is constructed by the participants, who are not passive but active agents who pursue their own goals in a conversation. To fully explain the justification for CA and method, I will now outline the process of analysis and then explain how it is particularly useful for this setting and in answering my research questions.

CA was used to assess everyday legal decision making and understand how the capacity assessment occurs as conversational practice. CA has a largely social constructivist ontology and interpretive epistemology. CA can be used in positivist ways, particularly in more linguistic analysis, but this use answers different research questions and motivations, whereas my research (like much of the CA work focusing on institutional interaction) aims at answering broader, more contextual questions.[69] CA may be described in two stages: the

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[69] See earlier references to Sacks and Jefferson who pioneered the method in the 1970s, the methodology has since evolved and been adopted and adapted to allow for more question motivated and context aware research.

first stage of identifying patterns of talk is inductive, the second stage describes participants' orientations in the conversation, ascribing the functions of the organisation of talk is analytic and interpretive (Heritage, 1988).

Historically, conversation analysts have focused on courtrooms, plea bargains, and conversations submitted as court evidence (John M; Conley & O'Barr, 1990; John M. Conley & O'Barr, 1998; Drew & Atkinson, 1981; Levi, 1990). I refer to this courtroom analysis as it highlights how the method of conversation analysis can provide insight into legal interaction, but this insight is currently limited by the legal settings in which is has been used. Only in the 1970s did the law receive sociological research interest. Given the relative newness of this interest, most of the law has yet to be adequately examined. If ‘the rules which govern the process of law enforcement only become comprehensible when they are seen in action: in the abstract, they seem a hopelessly abstruse and confusing muddle’ (Barnard, 1974, p. 1 as cited by Atkinson & Drew, 1979, p. 9) then the only way we can understand the law is to examine law in action. Furthermore, since most law does not occur in courtrooms, further research must be carried out in different legal settings (Atkinson & Drew, 1979). Legal discourses are noticeably distinctive and through using detailed TDA and CA, we can begin to understand how law is enacted One may claim that law and the judicial process entirely consists of language; thus, studying law is to study language and it is necessary to rigorously interrogate the language we use to create law (Levi, 1990). The study of law and the language of law is an interdisciplinary inquiry incorporating the relationships between language, social, political and economic environments. Studying discourse in this setting can yield results that can inform positive changes (Levi, 1990).

CA has been used to understand how the law operates in courts in the UK by Atkinson and Drew (1979) and in the USA by Conley and O'Barr (1990). Atkinson and Drew (1979) investigated how judicial interaction occurs, how organisationally it compares to 'normal' conversation, and what specific linguistic tools are used when conducting court proceedings. The research took place in the UK in the Coroner's Court and a Tribunal of Inquiry. The justification for selecting these courts seems mainly due to previous researcher knowledge about the kind of courts they were, and the cases likely to be handled. Though they do not claim to be able to apply their findings to all courts, it should be noted that the term 'court' encompasses a considerable variety of settings and issues, and when referring to findings from this study, it is essential to recall the specific settings. It should also be noted that Atkinson and Drew (1979) did not follow the prescribed method of CA as, during analysis, they did not have access to audio recordings, only the transcripts produced. Atkinson and Drew (1979) highlight the significant differences they find between preliminary verbatim transcripts produced for their research and those official transcripts shared with lawyers. Atkinson and Drew (1979) provide background to research that has followed, investigating legal settings and arguably the broader field of institutional interaction. Their initial observations were that courtroom interaction can be studied and that the findings demonstrate just how unique an interaction this is, and how members 'break' the conventional rules of conversation when in a courtroom. As they stated, 'rigorous understanding of the methodical bases of action and order in courts is unlikely to be arrived at independently or in advance of an adequate understanding of the organisation of verbal interaction' (Atkinson & Drew, 1979, p. 216). Observational research and a focus on discourse can provide information to reach a better understanding of this unique legal interaction. The findings from this research highlight how legal spaces might be interrogated using CA, and why it is fruitful to explore other legal spaces, and seek to understand the varying discourses within them to understand how law works in all its spaces. If mundane legal spaces are to be understood, such as solicitor and client meetings, observational research is necessary, and yet to be undertaken.

Conley and O'Barr (1990) follow a similar design to Atkinson and Drew (1979). Their research occurred in the USA's 'informal' courts, named across states as 'small claims courts', 'magistrates courts', 'justice of the peace courts' or 'prose courts'. These courts generally deal with small consumer financial claims, mediation and arbitration. Their philosophical grounding was less focused on the CA framework than Atkinson and Drew's (1979), and instead incorporated ideas of relationality. They conducted an ethnographic study observing these small courts and produced various themes and sub-themes, emphasising how individuals act within the court. They looked at how the system of the court and the rule of law influences the way people act, potentially affecting the outcome. The study is an anthropological exploration of what a court is, how it behaves, and how the perceived structured uniformity of 'law' and 'court' can be deconstructed. It is a complex system in which actors must navigate their own identity, maintain the system, and deal with outcomes. In their conclusion, Conley and O'Barr (1990) remark that 'the official discourse of law comprises two major categories: a professional discourse…and a more general discourse about the nature of law' (Conley & O'Barr, 1990, p. 168). The voices of litigants are selected, and the majority are excluded from legal documentation or use. Conley and O'Barr (1990) give equitable access to those voices heard in court, but again the issues arise that law does not only operate in a courtroom setting, and most legal actors and decisions do not occur in courtrooms (Drew & Atkinson, 1979). It might be assumed then that most law has yet to be thoroughly investigated. Socio-legal scholars understand law as a sociological phenomenon consisting of a grand infrastructure of acts and precedent and courts, and the everyday actions of citizens in society (Feenan, 2013). In this sense, one can draw similarities between how socio-legal scholars understand law, and how ethnomethodologists understand sociological investigation:

> We must investigate ‘the "seen but unnoticed" features of social life, features whose presence is so taken for granted that they are only "noticed" when they are missing … Ethnomethodological studies present social life in fine-grained detail, they allow one to see "the trees for the forest", by uncovering phenomena that participants are at once completely dependent upon and usually completely unaware of’ (Travers & Manzo, 2016, p. 12).

Sacks, Schegloff and Jefferson (1974) stipulate that conversation is governed by implicit rules followed by the speakers. Together, the rules form the known patterns of conversation and inform how the speakers talk. The rules can be applied to interactional scenarios regardless of the context. Interaction is an ordered activity and a procedure that can be studied in any setting (Ten Have, 2007). CA is used across disciplines but interest in institutional interaction is prevalent and recommendations for improvements to the institutional setting can be suggested based on CA. The researcher can orient to the specific institutional setting and understand the specific goals of the conversation (Antaki, 2011a, 2011b; Ten Have, 2007). For this research, observing actual meetings between clients and solicitors was imperative to accessing a nuanced insight into what occurs in such meetings and how this informs the social construction of capacity law. Using audio recorded naturalistic data, I examined what conversational tools are deployed to navigate such conversation. I examined which tools work well and why, and which should be incorporated in future practices or recommended for other institutional settings such as counselling settings and GP surgeries (Fitzgerald, 2013; Maynard & Heritage, 2005). As solicitor-client interaction has not been observed in this way before, I refer to other institutional interaction literature later in my analysis. These observations as I discuss later in this chapter, are challenging to access. Yet, if improvements are to be made based on actual practices, observational data is needed to provide unique and valuable insight into the conversational practices that form this legal action. Though ingrained and valuable, case law and doctrine cannot provide the same type of insight as observing everyday legal practices. For capacity law practice to progress, we need to understand the interactional situation in which it can occur.

Method

To address my research questions, I have collected two different types of empirical data for my research: interviews with people with dementia, and observations of solicitors and their clients with dementia (or similar memory problems). The recruitment and data collection occurred between 2018 and 2019.[70] I discuss the rationale and process for interview data and observational data separately as they are mechanically different in practice, but analytically similar. Both align with my epistemological and ontological stance, and are concerned with the way language constitutes lived experience.

Observational data

These data consisted of naturalistic observations of solicitors and clients with dementia discussing a will or LPA.

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[70] Therefore unaffected by the Covid-19 pandemic

Rationale

The rationale behind the data collection is as follows; audio recording real meetings of solicitors and their clients with dementia means one can repeatedly analyse an actual life situation without relying on the temperamentality and inaccuracy of memory (Sidnell, 2013). Audio recording also allows for quick set up of equipment and minimal intrusion by the researcher (in contrast to video equipment). Furthermore, audio recording data means that conversation can be analysed in-depth, and although body torque aspects are absent, the richness of the data overcomes some potential deficits. The question being addressed using these data essentially focuses on a conversation, the mental capacity assessment is a verbal questioning of the client and acts as part of the overall meeting (Mental Capacity Act 2005 Code of Practice, 2007).

The audio recording provides adequate data for this research; analysing these data using CA means finding and detailing particular cases of actions used by participants in the interaction. It is also used these to build an overall picture of collections of phenomena, and accurately describe and evidence how solicitors and clients construct mental capacity with dementia (Sacks, 1992; Sacks, Schgloff, & Jefferson, 1978). For simplicity, CA abides by the rules of ‘looking for natural data, setting it in its context, watching for its non-literal meaning, and identifying the social actions performed’ (Antaki, 2008, p. 437). Through understanding conversation using these rules, one can identify: practices that work well for the interaction's goal, practices that do not work well, and interesting phenomena that may be otherwise subsumed in social/political contextual assumptions or semiotics.

Participants and Recruitment

Recruitment of solicitors used a necessarily varied approach as they proved to be a difficult-to-recruit population group. Generally, I contacted solicitors via email, attaching a recruitment document (see appendix G). See below in table 3.1 for a breakdown of the different recruitment methods used, the response rates, and the success of these methods. Solicitor firms were initially contacted in Birmingham, this then broadened nationwide when little success was achieved. Where possible, the head of the private client department was contacted directly. Emails were sent on my behalf from 3 professional contacts. I also contacted firms associated with specific charities (Age UK, Headway, Alzheimer's Society), demonstrating an alignment of values with the firm. I contacted the network organisations listed below, which advertised my project via newsletters, internal emails, and regional meetings.

Table 3.1, Table for recruitment rates for observation

Method of recruitment	Contacted	Responses (n)	Participants recruited (n)
Cold Email (+ Follow up)	181	16 (9% Response rating)	0
Email via contact	12	7 (58% response rating)	0

Network Advertisements	Organisations: The Society of Will Writers Institute of Professional Will Writers Age UK (wills advisory service) Solicitors for the Elderly STEP Birmingham	6	3 (1 of which later declined to participate).

This table demonstrated the poor uptake and response rate from solicitors. Solicitor firms appear to be unresponsive to research opportunities. If a refusal to partake was received, the reason cited was often a lack of time available or issues with confidentiality compliance. However, it should also be noted that I offered to address these concerns and emphasised the minimal effort required. I also advertised my research via Twitter with a specific advert for solicitor/wills writing firms, however this approach received no response.

Of those firms recruited, one individual (Solicitor A) carried out both wills and LPA appointments at a firm, one individual (Solicitor B) carried out wills appointments only, and one firm which signed up (Solicitor Firm C) carried out both wills and LPA appointments. At this latter firm, three solicitors agreed to take part.[71]

Solicitors were required to ask any clients with an upcoming meeting regarding wills or LPAs if they would like to participate in the research (see appendix H for a template email provided to all solicitors). I was notified if clients pre-consented to partake, and spoke with them before their meeting, whereby I would explain the research to clients and they would

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[71] See table 3.2 for a breakdown of the data collected from each firm/solicitor.

have the opportunity to read and sign the consent and information sheets (see appendix I). I discuss this further in data collection procedure section next.

I collected participant demographic information (prior to recording starting) from clients (see appendix J for the form used). I asked participants also to state whether they had a diagnosis of dementia or a memory problem. No clients observed identified themselves as a person with dementia or other memory problem.[72]

Data Collection Procedure

If clients informally agreed to participate in the research, they would be asked to attend the solicitor's office 15 minutes before their assigned appointment time. We would then use an empty office and discuss the research. Clients were given the opportunity to refuse to participate at this stage, and it was made clear that this would not affect their appointment with the solicitor. It was also emphasised that the research required naturalistic observations; the meeting should continue as though the researcher and recorder were not present. Clients were given the option of me leaving the room and leaving the recorder only. Prior to the beginning of the meeting the solicitor would return and I would start the recorder when verbal agreement to begin was given. Field notes were taken throughout the meeting if I was present. When the meeting finished, the recording was stopped before all participants left and I would re-affirm on the consent forms that all parties wished to submit the recording. See table 3.6 below for a breakdown of data collection.

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[72] Please see table 3.3

Table 3.2, Recruitment of clients for observation

	Meetings attended	Client refusals	Recording without presence	Hours collected
Solicitor A	5	1	0	4.5 hours
Solicitor B (Later rescinded participation)	0	0	0	0
Solicitor Firm C	0	0	0	0

All data was anonymised for CA and the Jeffersonian transcription of observational data used pseudonyms with the same number of syllables as the original information. The Jefferson technique requires this attention to word sound when using pseudonyms. All data were anonymised, and information was kept confidential within the research team, whilst not compromising the quality of analysis undertaken. As can be seen below, some clients self-selected that they had a disability, however no clients stated they had a disability that affected their mental capacity prior to the meeting in conversations with the solicitor.

See table 3.3 below for the demographic information for clients who agreed to be observed.

Table 3.3, Table of observation client demographics

Meeting code	Pseudonym	Gender	Age	Marital status	Children	Average yearly income	Housing status	Disability	Highest qualification
2	Clara Moor	Female	75	Widowed	2	declined	Own outright	Yes	No formal qualifications
4	Clara Moor (as above)								
1	Flora	Female	69	Married	3+	£30,000-£39,999	Own outright	yes	University degrees
1	Nasirah Mahmoud	Male	66	Married	1	less than £15,000	Own outright	No	A-levels/College

3	Alana Jean Bryce	Female	56		2	£40,000-£49,999	Own outright	Yes	Professional Qualifications
3	Stuart Andrew Bryce	Male	56	Married	2	£40,000-£49,999	Own outright	No	Declined

All participants observed were heterosexual. Four of the five clients observed were part of a married couple. Clara attended with a non-relative who was asked to leave before her meetings began. One client refused participation based on personal belief conflict, which I detail later in this chapter. It is reasonable to expect clients that are discussing sensitive issues to be curious about the researcher's interest. Once the recording was conducted, I was happy to answer questions about my interest (within reason). Disclosure with participants is an issue to be addressed and reflected on throughout the research process. As stated, I learnt through the research process; if disclosure after an interview or recording would satiate any curiosities of the participants, whilst not detracting from the purpose of the research. Minimal disclosure prior to an interview or recording helped build rapport with participants. Primarily I tried not to impose personal beliefs or opinions during any interaction with interviewees to ensure comfort and ease of discussion was maintained.

Data analysis procedure

All raw audio data was initially transcribed verbatim In this process, all identifying information was anonymised in the transcript. Non-lexical human sounds were transcribed in the data (such as coughing) and non-words such as 'mhm'. Background noises were not transcribed as they were deemed irrelevant. It was noted in the transcripts if any participant left the room, and at what point they returned. Once a transcript was completed, I reread it while listening to the original audio to make edits where needed. This also formed part of the process of familiarising myself with the data to begin unmotivated looking, a core principle of CA (Sacks, 1984). Familiarisation through reading and listening to the data means that one can identify interesting phenomena and potential areas for detailed examination. The principle of unmotivated looking encourages the findings to be data-driven, rather than researcher driven. The process of CA is cyclical, so this process may occur multiple times.

Unmotivated looking (Sacks et al., 1978) is followed by selecting data extracts for Jeffersonian transcription (Jefferson, 2004). This involves selecting a short extract (normally 30-180 seconds) of data to transcribe using the Jefferson transcription technique, whereby symbols are used to indicate different verbal tools such as prosody, pitch shift, pauses and emphasis (see appendix L for a full list of symbols). These transcripts are then analysed to identify conversational techniques being used by participants. Patterns of talk can then be inferred with regards to a specific phenomenon, and collections of types of talk occurring can be built.

Patterns of talk can be identified through paying attention to the types of techniques being used in a sequence, the order of the sequence, how particular Turn Construction Units (hereafter TCUs) are being uttered and how epistemology operates within the conversation (Heritage, 2013a; Schegloff, 1999). The data is rich and so it is important to refer to the original purpose of the research when conducting such analysis, thus this research does not strictly align with the pure CA philosophy of unmotivated looking. This practice in its purest form is impractical and positivistic, and not useful for addressing questions relevant to my research. This study utilised an applied CA approach, which acknowledges the uniqueness of institutional interaction and the need to identify trainable and useful outcomes for all participants involved.

Semi-structured interview data

These data consisted of semi-structured interviews with participants with dementia and their informal carers (see appendix L for the interview schedule).

Rationale

Conducting semi-structured interviews with both individuals with dementia and their informal carer(s) allowed me to analyse the collective construction of dementia; how it has affected their lives as a unit and how they have approached legal decision making. The dyadic interview is somewhat common practice in the field of dementia research as it is understood that their support is beneficial, particularly when building a narrative for the person with dementia (McCleary et al, 2013). As Kindell et al (2017) state after researching group dynamics in interviews, 'conducting a conversation can pose challenges to people with dementia…conversation can also reveal unique skills and competencies that people with dementia have retained…as well as skills employed by conversation partners to scaffold such abilities' (p406). To address any potential imbalanced answering, I directly addressed each participant when required. However, contrary to assumptions raised by the ethics committee, it was not consistently the case that the individual with dementia was spoken for or of by their carer, and no definite correlations can be drawn about whether the individual with dementia spoke less. This is an interesting finding as it refutes the ethics committee's presumption that people with dementia will participate less in an interview if their informal carer is present to speak for them. Semi-structured interviews were advantageous as the flexibility allowed for addressing each participant and probing further points, whilst also providing a direction for the interview. Semi-structured interviews were used to provide insight into people's understanding of legal advice and how individuals approach making legal decisions in the broader context of their lived experiences; they are not restricted to observable phenomena or created conditions. DA assumes that an individual's speech is not a passive action, but a way for researchers to investigate a person's world through analysing their rhetoric (Pooter & Whetherell, 1987). In summary, language is constructive and constitutive for a person's understanding and to answer research question 2, TDA was used to understand legal actions grounded in the perspective of individuals affected by capacity laws.

Participants and Recruitment

I used various recruitment tools for this participant group, and although I primarily recruited through the Join Dementia Research website (hereafter JDR), I will detail all recruitment methods used to show how I attempted to engage with a less research-literate population group. See table 3.4 for a breakdown of recruitment methods used, participants who expressed interest and participants who took part in the research from these methods.

Table 3.4, Recruitment methods and rates of uptake for interviews

Method of recruitment	Responses (n)	Participants recruited (n)
Poster	2	0
Charity newsletter advert	1	0
Twitter advert	0	0
Direct recruitment through charities	2	1
Join Dementia Research Website	121 matched profiles	19

Posters were used in day centres, dementia cafés, lunch clubs (in churches), local cafes with noticeboards and around university buildings. See appendix A for the poster used. The sites were found through a general Google search for local dementia support services and the Dementia Roadmap Birmingham. I visited several sites in-person and asked the staff directly to display the poster (of which none declined) and contacted others first by email and phone (some were unresponsive or stated they had since closed). The Dementia Engagement and Empowerment Project (DEEP) linked my website and my contact details in their newsletter. I also shared a link to my website via Twitter, and this was re-tweeted several times. However, I received no uptake through this method. I suspect this was because of the participant group I was aiming to recruit and my relatively small social media presence; however, this is conjecture.

I had previous connections with an Age UK day centre and asked staff their if they knew of anyone who may be willing to participate in the research. I had a meeting in person with the centre manager to explain my research and how I would be using the data. Through the staff email network, I was able to share the link to my website and advertise this to staff. They passed on my information sheet and consent forms to relevant potential participants. However, a lack of willingness to identify as an individual with dementia was cited as the reason by staff for not sharing my research information sheets.. One potential participant identified was unable to take part as, after speaking with the individual, their partner, and their daughter, the individual with dementia (and Parkinson's) seemed unlikely to have the capacity to consent to take part in the research.

Most of my participants were recruited through the JDR website, a National Institute for Health Research platform[73]. People with dementia (and their informal carers) can register their details on the website and signify their interest in participating in research. The register is funded by the Department of Health and Social Care and contributes to increasing efforts to improve people with dementia's participation in research. To use the website, I filled in an application form which detailed the type of research being conducted, the ethical approval status (approved at the time of submitting), and two brief statements summarising the research to be used for the user-facing advert (this information was the same as that used in my website with format adjustments). After having the application approved, I undertook the JDR training, which consisted of online modules detailing the rules for use and how to navigate the online platform. After completing the training, I took part in a Google Hangout meeting with two delivery officers for JDR who set up the website and detailed information about participant requirements and catchment areas for the research. Please see A1 in appendix B for a breakdown of all options specified for JDR (note that clinical researchers often use JDR and medical information from participants can be very detailed and specific).

Once this information was complete and specified, the study was made active, and a personal user account that only I (and JDR) had access to was created. The study specifications could only be changed by JDR staff. The JDR website then gave me access to volunteer information (52 initially, 109 after broadening catchment area), and their preferred contact method and contact details. Participants could indicate interest in the

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[73] https://www.joindementiaresearch.nihr.ac.uk/

study or, alternatively, as with the majority of those recruited, I would contact volunteers about the study after reviewing their information.

I collected participant demographic information from all participants in interviews (see appendix C for the form used). I asked participants to also state on the form whether they had a diagnosis of dementia or a memory problem. The answers to this question varied from ‘yes’ to a specific diagnosis, e.g. ‘mixed dementia’. However, of all the interviewees that identified as a person with a memory problem, 100% had a diagnosis of Alzheimer’s, dementia or Mild Cognitive Impairment. 0% of the interviewees that identified as an informal carer had a diagnosis of dementia or other memory problem. See table 3.3 for a detailed breakdown of the interview participant demographics. This table includes both the person with dementia and informal family carer(s). After recruiting 15 participants and noticing the homogeneity in my sample of white British Christian participants with spousal relationships, I contacted the Birmingham LGBT hub who work with older LGBTQIA+ people. I also contacted the carers hub in Birmingham. Both organisations distributed a flier but there was no uptake, thus I continued to recruit from the Join Dementia Research website.

Racially homogenous research participants are a common problem for research, non-white races are consistently under-represented (Shavers, Lynch, & Burmeister, 2002; Vyas, Raval, Watt, & Tang-Wai, 2018). This issue with the sample was largely due to the homogeneity of participants available through the JDR website at the time of recruitment and language barriers. Similarly, the heteronormativity may be rooted in the participant pool available on the JDR website, which if the information was listed, were largely heterosexual. Heteronormativity in ageing research is identified as a key issue and bias, so future research and recruitment needs to address the problems with recruitment diversity.

The type of diagnosis was not specified nor was it a requirement, as this study is primarily interested in how people with all types of dementia are affected by the law. This is in part because the law does not differentiate between different types of dementia or memory problems on a doctrinal level, thus neither does this study. Regardless of type of dementia or memory problem, all participants could be assessed in the same manner by law, using the same capacity assessment.

The sampling process for this research impacted what participant groups I interacted with. It was expressly stated that I was seeking to speak with people with dementia who had an informal carer. This was necessary to answer my research questions and was based on the sound research showing that dyadic interviews enable people with dementia to share their experience. However, it may have led to a bias in my data whereby I only interviewed people who felt they were in a supportive relationship. This is somewhat conjecture, and some tensions were certainly observed, but it is still worth noting and being aware of this potential deficit in my research. I reflect further on my recruitment methods at the end of this chapter.

The table below details the demographic data of my interviewees.

Table 3.5, Table of interview participants and demographic information

Pseudonym and Interview code	Diagnosis	Diagnosis Date	Gender	Age	Marital status	Children	Average yearly income	Housing status	Religion	Disability	Highest qualification
Kenan 1	Dementia	2017	Male	58	Married	3+	less than £15000	Own Outright	Christian	Yes	Other vocational/work-related
Sonia 1	carer		Female	55	Married	3+	less than £15000	Own Outright	Christian	No	Other vocational/work-related
Edmund 2	MCI	2013-2014	Male	74	Married	3+	£70000+	Own Outright	Christian	Yes	A-Levels/College
Fran 2	carer		Female	74	Married	3+	£70000+	Own Outright	No religion	Yes	A-Levels/College

William 3	Dementia Alzheimer's	2019	Male	72	Married	1	£30000-£39999	Own Outright	Christian	Yes	Other vocational/work related
Olive 3	carer		Female	72	Married	1	£30000-£39999	Own Outright	Christian	No	Secondary school
Pearl 4	Alzheimer's	2019	Female	82	Married	0	£20000-£29999	Own Outright	Christian	No	Other vocational/work-related
Jack 4	carer		Male	82	Married	0	£20000-£29999	Own Outright	Christian	No	Professional Qualifications
Lesley 5	yes	2012	Female	72	Married	2	£40000-£49999	Own Outright	Christian	Yes	University Degree(s)
Mark 5	carer		Male	70	Married	2	£40000-£49999	Own Outright	Christian	No	Doctorate

Arnold 6	Alzheimer’s	2017	Male	83	Married	3+	£20000-£29999	Own Outright	Christian	No	University Degree(s)
Karen 6	carer		Female	83	Married	3+	£20000-£29999	Own Outright	Christian	No	University Degree(s)
Bill 7	yes	2014	Male	85	Married	1	less than £15000	Own Outright	No religion	Yes	Secondary school
Helen 7	carer		Female	83	Married	1	less than £15000	Own Outright	No religion	Yes	Secondary school
Sam 8	late onset dementia/Alzheimer’s	2015	Male	84	Married	3+	less than £15000	Own Outright	Christian	No	Professional Qualifications
Irene 8	carer		Female	81	Married	3+	less than £15000	Own Outright	Christian	No	Other vocational/work-related
Mel 8	carer/child		Female	57	Married	0		Own Outright	Christian	No	Professional Qualifications

Tim 9	Dementia	2016	Male	62	Married	3+	less than £15000	Rents	Christian	Yes	Other vocational/work related
Courtney 9	carer		Female		Married	3+	less than £15000	Rents	Christian		Secondary school
Norah 10	Dementia		Female	68	Married	2	£30000-£39999	Own Outright	Christian	Yes	A-Levels/College
Daniel 10	carer		Male	72	Married	2	£30000-£39999	Own Outright	Christian	No	Other vocational/work-related
Frank 11	yes	2017	Male	79	Married	2	£15000-£19999	Own Outright	Christian	No	A-Levels/College
Anne 11	carer		Female	76	Married	2	£15000-£19999	Own Outright	Christian	No	Secondary school

Claire 12	Early-onset Alzheimer's	2015	Female	60	Married	0	less than £15000	Own Outright	No religion	Yes	Secondary school
Garth 12	carer		Male	56	Married	0	less than £15000	Own Outright	Christian	No	Secondary school
Hank 13	yes	2012	Male	78	Married	1	£15000-£19999	Rents	Christian	Yes	Professional Qualifications
Lina 13	carer		Female	76	Married	1	£15000-£19999	Rents	Christian	Yes	No formal qualifications
Dominique 14	MCI	2019	Female	84	Widowed	3+	£15000-£19999	Part owns/part rents	No religion	Yes	Other vocational/work related
James/Jimmy 14	carer		Male	79	Widowed	0	£15000-£19999	Part owns/part rents	Christian	No	No formal qualifications

Eve 15	Atypical dementia	2014	Female	61	Single	0	less than £15000	Own Outright	Christian		University Degree(s)
Val 15	carer		Female	53	Married	0		Own Outright		Yes	University Degree(s)
Connor 16	Vascular dementia	2015	Male	68	Married	3+	less than £15000	Own Outright	Christian	Yes	University Degree(s)
Bella 16	carer		Female	63	Married	3+	less than £15000	Own Outright		No	University Degree(s)
Andrea 17	Alzheimer's	2018	Female	62	Married	2	£70000+	Own Outright	Christian	No	Professional Qualifications
Hugh 17	carer		Male	64	Married	2	£70000+	Own Outright	No religion	No	University Degree(s)
Rodney 18	Early onset Alzheimer's	2017	Male	65	Married	2	£20000-£29999	Rents	No religion	Yes	No formal qualifications

Mary 18	carer		Female	59	Married	2	£20000-£29999	Rents	No religion	No	A-Levels/College
Rob 19	Dementia	2014	Male	72	Married	2	£20000-£29999	Own Outright	Christian	No	Professional Qualifications
Beth 19	carer		Female	72	Married	2	£20000-£29999	Own Outright	No religion	No	Secondary school
Paul 20	Alzheimer’s	2015	Male	69	Married	3+	£20000-£29999	Own Outright	Christian	Yes	University Degree(s)
Kendra 20	carer		Female	63	Married	3+	£20000-£29999	Own Outright	No religion	No	Professional Qualifications

Overall the participants with dementia were between the age of 58 and 85, 60% male, 40% female. Participants identified as carers were between the age of 53 and 83, 71% female, 29% male. 3 out of the 21 carers were not married to the person with dementia that they cared for (one child, one friend, and one partner).

Data Collection Procedure

I invited relevant people to participate in the interviews using one of the previously discussed methods. I sent all participants the information sheet and consent forms (in both easy-read and standard format) prior to setting an appointment for the interview.[74] This allowed participants to make an informed decision prior to informally agreeing to take part in the interview by setting a date and time for the interview. All interviews took place in the interviewee's home, though office space was an alternative option. Typically, I arrived at the person's house at the agreed-upon time, checked in with my safety protocol contact and introduced myself to the interviewees. If needed, I had a University of Birmingham ID card for identification. Prior to beginning the interview, paper copies of the information sheet and consent forms were distributed, and the opportunity to ask questions about the interview was made explicit to all interviewees. If a difficulty with reading or writing were apparent, I would verbally go through each form with the interviewee (this was particularly relevant for the demographic information forms). All forms would be filled in prior to the interview, including the demographic information sheet. I also gave interviewees the 'useful information' sheet before starting the interview.

Poster responses (participant screening)

Two participants made contact from the poster advertisement. After conversations via text message and email, one individual was deemed unsuitable for this research project (a 26-year-old female with brain damage and no formal carer). From the posters at the university, one individual contacted me on behalf of his family member with dementia, after emailing it transpired their dementia had progressed too far for research participation.

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[74] See appendix P

Charity newsletter responses (information sharing)

One couple was recruited through charity contacts. I passed the information and consent forms on to the charity contact, who forwarded these to the couple. I phoned the couple to ensure they had received the information and were happy to participate, and a date and time were then decided for the interview. Another couple expressed interest after seeing the advertisement in the DEEP newsletter, but, after discussions, decided not to participate.

JDR website (recruitment protocols)

One hundred and eleven individual profiles matched my study criteria within a 20-mile radius of the University of Birmingham. Each profile was reviewed, with attention being paid to the comments section and whether a carer was listed. After review, seven individuals were not eligible for the study, and comments of relevance indicated the volunteer’s unwillingness to participate at that time or the progression of dementia beyond mild symptoms. Twenty-three volunteers declined to participate after being contacted. In line with JDR guidelines, volunteers are deemed to have declined if they do not reply to the initial inquiry and follow up. Four volunteers expressed interest in participating as indicated on the website, all other volunteers were cold contacted via the preferred method. In line with JDR guidelines, participants who expressed interest were contacted within five working days. Volunteers may be contacted via a representative (usually the listed family carer), and all information was sent directly to the representative and addressed to both representative and individual with dementia.

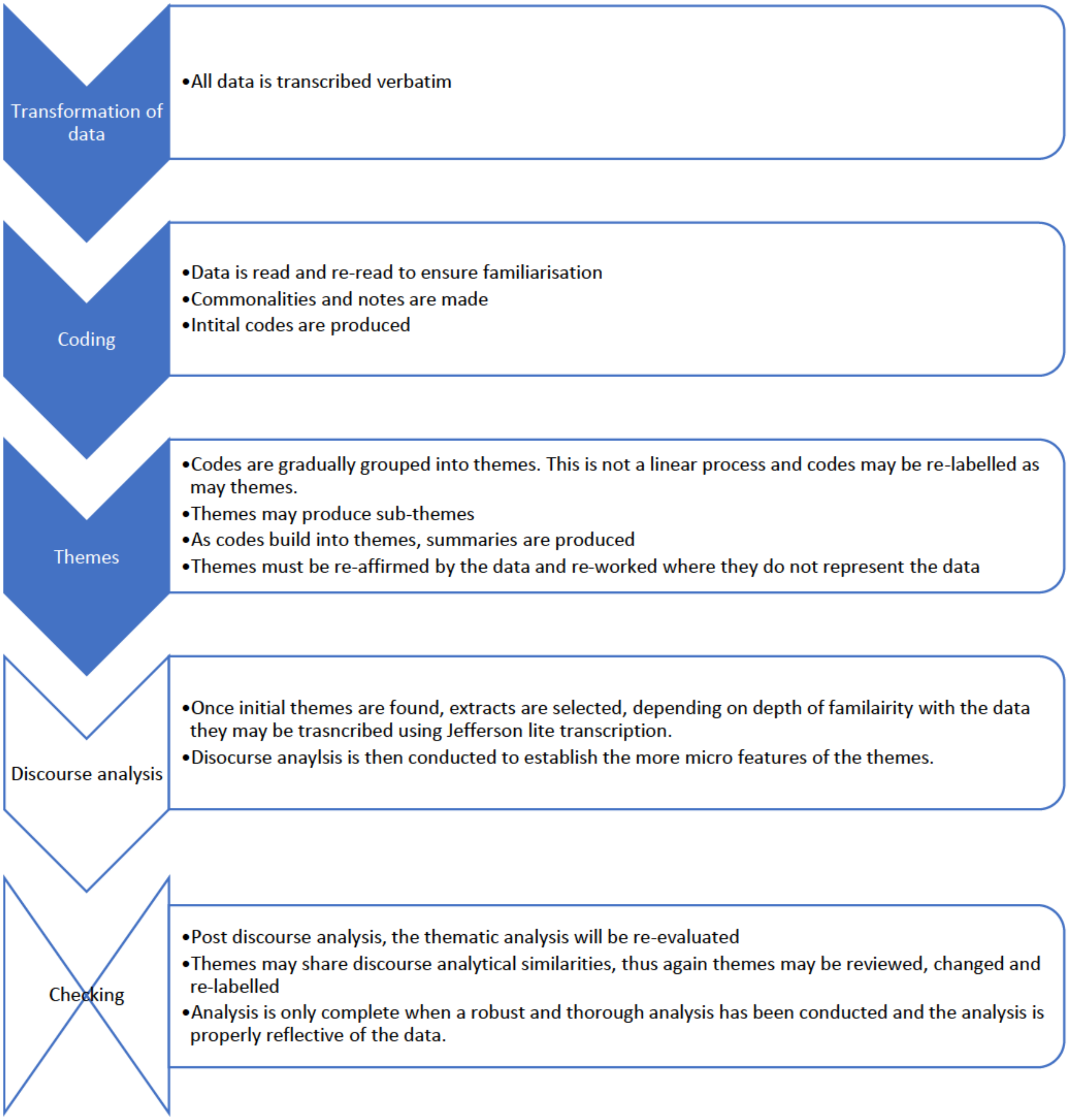
Data analysis procedure

The data was analysed using TDA. All interviews were transcribed verbatim including non-lexical sounds (e.g. coughing). A transcription service was used for all interview data; within my ethical approval the service adhered to all confidentiality and anonymity rules. Transcripts were stored and analysed using NVivo. Once the transcripts were received, I read through each while listening to the original raw audio to make corrections. All identifying information was anonymised when being transcribed. Audio recordings were anonymised if used for presentation outside of the research team (identifying information was removed from the recording and the pitch was shifted to avoid voice recognition). Codes were marked regarding constructions of the self, legal rules and practices, and future decisions to name a few when I familiarised myself with the transcripts (see Appendix E for a complete list of codes). These codes were used to select extracts for Jeffersonian transcription and build initial collections of phenomena (Jefferson, 1984). Jeffersonian transcription allows for a visual understanding of conversational tools and verbal indicators such as pitch, pauses and intonation (see appendix F for a list of Jefferson transcription rules). It allows discourse practices, such as requests and accounts, to be identifiable through how they are uttered by participants in a conversation, when conducting a more in-depth analysis. Particular attention was paid to discursive psychological practices, such as moral status reports, wishing, and internal state reports. Additionally, as an initial search technique, pronoun use was analysed to identify if and how pronoun use constructed autonomy and choice. This was quantified initially to examine if there were significant differences and a viable way to search the data for constructions of the self, as used in other studies (Hydén & Nilsson, 2015).

DA focuses on how the self is theorised in discourse and by the individual speakers rather than searching for true nature, and the self is contextualised through the speaker's construction (Potter & Wetherell, 1987). Constructions of the self is a focus for this TDA. The analysis procedure followed this step-by-step process; raw data uploaded to transcription service, verbatim transcript received, corrections made (if needed), familiarisation with data through re-reading transcripts, initial coding carried out, extracts selected according to code groupings, Jeffersonian transcription of extracts and data sessions (group and individual) carried out to identify discursive practices. This initial analysis stage is repeated and recycled as collections of phenomena are built and phenomena are supported or changed. This ensures a robust finding. Furthermore, through taking part in group analysis sessions, a form of triangulation ensures researcher bias is lessened, multiple researchers contribute to the discussion so consensus can be built. It is also important to acknowledge the constructed nature of an interview during this analysis period and be aware of the interviewer as a participant creating the discourse. This is one drawback of interview data, but when accounted for, the impact is minimised and interviews allow for the focus on this specific topic for a particular population.

I used TDA to analyse my interview data. A thematic analysis follows the general stages seen in figure 3.1 from Braun and Clarke (2006), with the addition of the last panels to demonstrate TDA (Peel, Parry, Douglas, & Lawton, 2005; Taylor & Ussher, 2001). TDA includes conducting a latent thematic analysis (Javadi & Zarea, 2016) focusing on the meaning rather than explicit semantics, followed by DA. The process is not strictly linear, themes change, and codes are re-categorised and added to when the DA occurs. Through conducting TDA, I negate some issues associated with the interpretivism of thematic analysis, and maintain the objectivism needed to ensure I do not impress my own values and predictions on my data and work within language-focused constructionist framework of my philosophical stance (Gibson, 2006). In combination with DA, thematic analysis focuses on how participants use language and interpret their own experiences, rather than focusing on researchers’ semantic interpretation.

Figure 3.1, Data transformation and TDA analysis process



Transformation of data

- All data is transcribed verbatim

Coding

- Data is read and re-read to ensure familiarisation
- Commonalities and notes are made
- Intital codes are produced

Themes

- Codes are gradually grouped into themes. This is not a linear process and codes may be re-labelled as may themes.
- Themes may produce sub-themes
- As codes build into themes, summaries are produced
- Themes must be re-affirmed by the data and re-worked where they do not represent the data

Discourse analysis

- Once initial themes are found, extracts are selected, depending on depth of familairity with the data they may be trasncribed using Jefferson lite transcription.
- Disocurse anaylsis is then conducted to establish the more micro features of the themes.

Checking

- Post discourse analysis, the thematic analysis will be re-evaluated
- Themes may share discourse analytical similarities, thus again themes may be reviewed, changed and re-labelled
- Analysis is only complete when a robust and thorough analysis has been conducted and the analysis is properly reflective of the data.

TDA follows a similar pattern of analysis, however given the focus on discourse, the coding may become more specific to discourse features, as do the themes. TDA can be utilised (as it is in this study) by following these general stages. One may add a caveat to the above model: codes and themes may be (but not necessarily) discourse oriented. Once themes have been identified, extracts can be selected to conduct a more in-depth macro analysis of the data to find what discourse markers are used and why. Extracts within a theme may then demonstrate discourses within that theme or across themes. Essentially, thematic analysis is a way to analyse interviews for general-purpose. DA allows a more detailed examination of the data and to understand how the interviewees are constructing their world in real-time.

TDA allowed me to focus on commonalities across my data that were relevant to my research questions. The data collected is incredibly rich, and thematic analysis allowed me to identify emerging, relevant patterns systematically and rigorously (Braun & Clarke, 2006; Braun, Clarke, Hayfield, & Terry, 2019; Javadi & Zarea, 2016). The analysis is inductive and data-driven but, given the wealth of data, the thematic analysis allowed focus within the research questions. A particular philosophical stance does not traditionally accompany thematic analysis (Braun & Clarke, 2006). I use TDA with a social-constructionist philosophical stance, which is most appropriate for answering my research questions. Additionally, CA necessitates a social constructionist approach, using TDA in combination it is important to be consistent in my approach. In summary, thematic analysis was used as a primary analysis tool, using a moderately inductive method. The thematic analysis provided a foreground for the DA which followed.

TDA, much like CA, takes a social constructionist approach to language, whereby meaning is uncovered by analysing how words are uttered by participants, rather than assuming semantic meaning. TDA is a relatively under-utilised form of analysis and I followed the ideas set out by two research studies (Peel et al., 2005; Taylor & Ussher, 2001) with the figure above outlining the method.

Overall:

> TDA 'applies insights from discursive psychology to thematic categories (we) identified in the data within a social constructionist framework…thematic discourse analysis focuses on both the rhetorical design of themes and on their ideological implications.' (Peel et al., 2005, p. 782).

The search for meaningful themes is expanded upon by acknowledging that discourse meanings shift and alter (Parker & Burman, 1993). Discourse must be analysed within the context of the research and be found to have meaning through commonalities and patterns (Taylor & Ussher, 2001). Again, note the similarity with the principles of CA whereby commonalities and patterns of talk are examined to understand how meaning is constructed 'in real time' by participants in a conversation (Sacks, Schegloff & Jefferson, 1978).

Anonymity process for all extracts

To ensure anonymity, all identifying information was pseudonymised. For the convenience of reading the transcripts, all initials followed by a letter C indicate the carer, and the letter D indicates the person with dementia. IV indicates the interviewer. All names, addresses telephone numbers or other identifying information seen in the extracts presented in this thesis (and in any other format) are not the real ones of the participants. When anonymising, all replacement names have the same number of syllables. This is important when using the Jefferson transcription technique. Where any utterances that have been pseudonymised are subject to Jefferson lite, I listened to the original raw data and marked the pseudonym to mirror syllables in the original. Any pseudonyms of places or telephone numbers are completely random.

Reflection on research practices

These reflections were informed by those stated in (Gregory, Hallowell, & Lawton, 2005).

Presentation as a researcher for interviews

I would always attempt to align to the representation of those I was interviewing to build rapport with the interviewees. This was not to deceive my participants, but to make them feel comfortable. I would dress in casual office wear to maintain a sense of professionalism but remove any jacket in casual households. I always covered any tattoos which could have been visible, only if an interviewee had visible tattoos might I roll up my sleeve. Essentially, through image as well as dialogue, I aimed to be amenable to my interviewees and make them feel comfortable talking about potentially upsetting topics.

Before starting the interview, interviewees would often ask where I was from (my accent does not match the regional accent). We would have an informal chat while I readied the paperwork. I always felt it necessary to do this to demonstrate a genuine interest to them, and by disclosing a few things about myself prior to the interview they would feel happy to disclose to me during the interview. Initially, I sometimes over-disclosed irrelevant information during the interview, after a few incidences of this I made conscious decisions when and what to disclose with interviews. This avoided too much deviance from the interview topics and prevented any breakdown in rapport.

Presentation for solicitor-client meetings

When attending the solicitor-client meetings, I attempted to mirror the same level of professionalism and image as the solicitor. I felt this would show respect to the solicitor for allowing me to record and made me more likely to 'blend in' in the room when the client(s) had their meeting.

Navigating difficult incidences

During interviews, the carer and person with dementia did not always agree when answering a question and this sometimes led to potentially conflict-driven discussion. I was wary that I am in general more comfortable with upset than conflict, and while I attempted to let a conversation continue and pursue certain avenues, I am aware that I tended to highlight positive aspects of the situations and sum up when I felt I needed to and move on to a different question. When navigating upset, my interpretation of facial expressions decided whether I pursued any line of inquiry or moved on.

I had one refusal to take part after arriving to observe two elderly clients make a new power of attorney. I knew some background of the case, as this was not their first power of attorney. The clients cited my lack of religious beliefs as their main reason for refusing to be recorded. Prior to the interview, the clients were uneasy about my credentials as a researcher and that they had not met me before. They questioned whether I would do what I had said on my consent forms if they agreed to participate. Unfortunately, this led to a questioning of my morals, which in turn led to religion. The conversation was difficult as I did not feel comfortable nor did it seem necessary to disclose my personal religious beliefs. I offered not be present in the room while the recording occurred, but this was not accepted This was the first instance in my career where potential participants have refused to take part where I am present. I endeavoured to remain professional throughout the conversation, though I felt uncomfortable with the situation. This encounter encouraged me to be more proactive in presenting myself as a researcher from the University of Birmingham and be prepared to evade personal or intrusive questions.

Final reflections

For my research questions, it was necessary to recruit participants who were in supportive relationships. However, I note that the breadth and type of these supportive relationships is limited. I recognise that to ensure I have a more diverse participant groups in future research, I would need to build relationships within different community organisations and allow sufficient time to recruit from ‘difficult to reach’ groups. I also acknowledge my research is somewhat limited by the fact that I focus on those people who identified themselves as being within a relationship where support may be provided, potentially biasing my participant population. However, as is evident in my data which I discuss in the remainder of this thesis, supportive relationships did not equal agreement or even similar construction of different topics discussed. Relationships, as I discuss in chapter 7, are a complex and nuanced phenomena, which we must be careful not to assume to be either supportive, trusting, or having other negative or positive influence.

Chapter 4: Conceptualisations of ‘dementia’ and ‘capacity’, from the interviewees’ perspectives

Introduction

In this chapter, I introduce two themes from my interview data. Firstly, ‘*dementia narratives*’ with the subthemes of ‘*the anonymous subject of dementia*’ and ‘*emotional experience and reactions to dementia*’. I then discuss ‘*capacity constructions by people with dementia and their carers*’, by looking at two different constructions, the ‘*implicit everyday capacity*’ and ‘*explicit decision-making capacity*’.[75] These themes address research question 1 and further interrogate if and how limiting neuroculture rhetoric may influence the way people with dementia construct their sense of self in relation to capacity. Implicit discussions refer to everyday skill and ability, whereas explicit capacity discussions refer to legal capacity or ‘formal’ capacity (assessable and referred to in legal decisions). Individuals with dementia and their partners co-construct ideas of capacity and dementia using metaphors. The use of metaphors is a recurring and prevalent linguistic tool used throughout interviews as both dementia and capacity can be difficult concepts for lay people to discuss.

There is a difficulty with interpreting metaphors from a discursive viewpoint. The DA stance means an expression of inner emotion is not assumed, strictly speaking we can only evidence how the expression is stated and received. However, metaphors (and their counterparts such as similes and idioms) have been investigated for their usefulness regarding chronic illness. As Peel and Ellis (2018) demonstrate, metaphors can be a valuable way to understand the lived experience of

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[75] I use the term dementia to refer to all memory problems in my interviewee sample, this includes different dementias, Alzheimer’s, and mild cognitive impairment.

illness, and not always a tool of belittlement used by the prejudiced ‘healthy’ society (Sontag, 2001). As I discuss, giving examples from my data, although metaphor is used to perpetuate hostile neuroculture rhetoric, it can be used to express complex and specific lived experiences. These data show how neuro-language can negatively influence how people perceive dementia and ‘brains with dementia’. Neuro-language and neuroculture ensure an adverse effect on people with dementia’s perceived societal worth, but the separation of the brain from the self, in some sense, protects the individual. This is discussed further through the differentiation of implicit and explicit capacity and the somewhat spectral form of the anonymous subject of dementia. The meaning of dementia and capacity arises from their individual lived experiences and is constructed in and through the interview conversation. These interviews offer a unique insight into views of people with dementia and their informal carers, and DA means interactional nuances are accounted for. Understanding these constructions will enable a bottom-up approach to understanding legal frameworks and practices concerning capacity.

Dementia narratives

Globally, the dementia narrative has slowly shifted from the hyperbolic metaphors of ‘ticking time bomb’ and ‘living death’ to the now more accepted ‘living well with dementia’ (Peel and Ellis, 2018; McParland, 2017).[76] However, this rhetoric refers to the macro view of dementia. In my analysis, I identify the personal narrative of dementia for my interviewees and how it affects their personhood and sense of self. A congruent and consistent sense of self is valuable for managing dementia for both family members and the individual (Erol, Brooker, & Peel, 2015). Given the

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[76] Living well with dementia: A National Dementia Strategy, Department of Health, 2009, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf

negative stereotypes previously used to describe dementia, and the ongoing prevalence of neuroculture and hypercognitive ideals, people with dementia and their carers must find ways to protect their sense of self from this damaging rhetoric. Interviewees acknowledge but separate the negative impact of dementia and potential deficits through othering and careful pronoun use. Interviewees work hard to construct dementia as something which has not affected the personhood of the individual, and in so doing, demonstrate how neuroculture and hypercognitive ideals are present and are perceived as something to actively protect oneself from. This reflects Bryden's (2020) belief that as a person with dementia, she still has a sense of self. She states,

> 'Although I am losing capacities to express my sense of self, I still have unique personal characteristics, which are not lost because of failing cognition. Even if I have lost a reliable connection with my past, and to the future, I am the Christine who, even without language, has the feelings of 'What is happening to me?' My constant struggle is not only to battle with my neurological deficits, but also with the external discourses of loss. Recognising my continuing sense of being an embodied self within dementia is important for regarding me as having a valid subjective perspective' (Bryden, 2020, p.76).

The self is maintained as separate from the brain. Neuro-centric accounts of dementia focus on loss, whereas individuals, to protect their selfhood, necessarily separate the brain's loss of function from the self.

I carried out an initial thematic analysis in which I identified 'definitions and descriptions of dementia' as a theme. This theme demonstrates how dementia is represented through juxtaposition. It is emotive and personal, whilst also being an objectified other. Several interviewees also reference how dementia affects the brain. The brain's faults are used as evidence that 'there is a problem', neuroscientific language is adopted to legitimise and give epistemic authority to their statement and experience (this occurred in 12 of the 20 interviews). The disease of dementia is depersonalised and described as ‘it’, with negative emotions detailed. Experiencing dementia, especially for carers, is again depersonalised, ‘it’s been difficult’ (Sonia C)[77] (this occurred in all 20 interviews). Carers avoid making a negative statement about the person with dementia, focusing instead on the disease. In all 20 interviews, metaphors, similes or idioms were used to describe dementia when talking about the diagnosis process and their understanding of dementia. Metaphors and personification to describe dementia are often common but violent, ‘well that hit us like a tonne of bricks to be quite honest’ (Beth C). Dementia is experienced as personally emotive, but the disease itself is depersonalised and is generally objectified.

In common with previous work, these data demonstrate how dementia is simultaneously a source of personal emotional concern and an anonymous monstrous subject for both people with dementia and their carers (Clark, Prescott, & Murphy, 2019). Clark et al. (2019) conducted interviews with couples with dementia and analysed the data using thematic analysis. Interviewees demonstrated that directing anger at the distinct malevolent disease is a form of coping, protecting their relationship. In my analysis I show how this protective measure is applied when talking about the disease of dementia. Phrases like ‘it’s a thief’ (Tim D) and ‘this wretched thing’ (Fran C) position dementia as an unwanted external force acting negatively in the interviewees’ lives. Tim (D)achieves this through personifying dementia as an immoral other, Fran through negatively objectifying dementia. These techniques avoid assigning any negativity to the individual. Furthermore, carers and people with dementia often accompany a description of the difficulties of dementia with a positive or neutral description, be it a topic shifting stoic idiom like ‘it's just, you

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[77] All interviewees have been given pseudonyms, which can be cross-referenced with Table 3.5 in the methods chapter displaying corresponding demographic information.

know, you just carry on' (Mel C) or a topic shifting statement like 'We're, we're doing well' (Paul D). Through my TDA, I show how the discourse of dementia is dualistic (in its representation as an 'other', and as an emotional experience) and how through close analysis of the discourse we can understand how people with dementia and their carers protect personhood and self from negative associations of the disease. I also identify the stark difference between the legal language I examined in chapter 1 and the language used by people with dementia themselves. This disparity is a cause for concern if both forms of discourse are at odds with each other when a person with dementia and their carers enter a legal space (as I discuss later in chapter 6), or when making a legal decision affected by a diagnosis of dementia (such as wills and LPAs).

The anonymous subject of dementia

For clinicians, 'othering' the issue is a common practice thought to help patients continue with their lives and maintain healthy perspectives (Mazurek, 2015). Envisioning the harmful illness as a separate entity means people with dementia and their carers can protect their sense of self and avoid a crisis of biographical disruption (Bury, 1991) particularly if interviewees attend to the normative linear experience of the sense of self which is reliant on memory. Interviewees achieve othering in several different ways; dementia is objectified entirely (it becomes a literal unwanted object) or becomes an anonymous subject, often in the form of an unwanted third party in the dyadic relationship. Dementia when explicitly being talked about as a disease, not the symptoms experienced, is mainly referred to as 'it…'. 'It' is not the symptoms that are assigned to the individual.

Presenting their understanding of dementia through universal metaphors and idioms lets interviewees avoid complex medical explanations. The metaphors and idioms imply a universal understanding of the negativity of the disease and make it difficult for others in the conversation to contest the “monstrous” image of dementia (Castaño, 2019). The use of negative metaphors to describe dementia communicates an emotive response to an amoral diagnosis evaluation (Entman, 1993). This negative image is, importantly, not explicitly describing the individual with dementia. Often, even where descriptions of deficits are used, participants balance this with either a positive attribute such as ‘he’s a bright man’ (Fran C) or more generally using the terms ‘s/he still (insert skill)’, or through using stoic statements like ‘we carry on’, or alternative idioms like ‘we take it one day at a time’. This supports the observation that idioms can be resisted by presenting a different idiom in response (Kitzinger, 2000) and reflects the stoicism identified where couples adjust to make sense of life with dementia (Clark et al., 2019). In these data a negative idiom (or metaphor) is used when describing the disease of dementia, and a positive or neutral idiom (i.e. stoic phrases like ‘we carry on’) is used when describing the individual with dementia or the continuing lives of the couple. This decreases the potential harm of the previous negative idiom about the disease of dementia.

Extract 4.1 shows how dementia is personified and justifies why a person with dementia may need to give up working, without laying the negative associations onto the person with dementia. Rodney reports that the doctor told him that he would need to give up work because of the dementia diagnosis. Rodney was diagnosed with young-onset Alzheimer’s. He previously worked as a truck driver, and though it is also disclosed that Rodney had been behaving dangerously at work (not putting the handbrake on, leaving the vehicle for long periods on random roads), he posits the reason for having to give up work below. When asked what the journey with dementia has been like so far, Rodney talks about the fact that he had to give up work. His wife Mary discloses later that there had been problems at work before the doctor suggested he give up work. In this report, the dementia is personified, and the dislike of stress (and subsequent consequences on the ability to work) is assigned to dementia, not to Rodney personally.

Extract 4.1
Recording: i_12_08_19_PE

Extract Start: 00:06:29

Extract length: 00:00:15

Rd: Person with dementia, Rodney

Mc: Wife of person with dementia, Mary

IV: Interviewer

Rd: And then he said you know (0.4) ‘you
know you won’(.) you won’t wor:k
again’.
IV: Mmm.
(0.3)
Rd: cuz any (1.0) >>an I<< and I asked him
why and he said .hhh because any
stress le:vels
IV: Yeah?
(0.3)
Rd: dementia doesn’t like it.
IV: Right yeah.
Rd: you know

1

In lines 1-6 Rodney’s speech is halted and repetitive indicating difficulty in telling this negative story. The difficulty may come from it being positioned as directly relative to Rodney through the reporting of the doctor directing it at ‘you’ (Rodney). In lines 7-11 Rodney’s speech is fluid and coherent, the deficit of not being able to work belongs here not to Rodney but dementia. Throughout the data, dementia is objectified and referred to as an anonymous ‘it’, here Rodney, through reporting the doctor’s reasoning to him, personifies dementia as an ‘other’, capable of reacting to stressors. By doing this, Rodney can remove the reaction of stress from his person and assign it instead to this ‘other’. The personification means Rodney can assign emotional reactions to the disease, rather than to himself, and through personifying the illness manages to shift the pronoun from a directed ‘you’, to an impersonal ‘it’. In this phrasing, it is not Rodney who ‘doesn’t like’ or cannot cope with stress, it is dementia.

Furthermore, Rodney displays his agency in this report in line 6, positioning himself as asking the doctor questions. In this short sequence and using a pronoun and perspective shift, Rodney moves from the incapacitated ‘you’ as reported by the doctor to an engaged individual patient in ‘I asked him why’. He manages to positively present himself in this statement about why he cannot work and removes the reason from his person to the personified other of dementia. His use of the report from the doctor also shows that this was not ‘his’ decision, but that of others. It is the doctor who had told Rodney not to work again, it is dementia that reacts negatively to work. Rodney does not take ownership of the negative traits which mean he is unable to work. Dementia as a personified other allows people with dementia to retain their own identity and means people with dementia do not have to work to report their own ability and capabilities. If dementia is the anonymous, objectified source of the deficits, the individual can still be a capable person able to contribute skills and knowledge to the couple’s lives.

I will now discuss how dementia is discussed as a shared emotional experience, rather than an individually owned disease. I will then discuss how people with dementia and their carers use the language of the brain to factualise their experience (demonstrating the importance assigned to this neuro-information), and how they also use this language in sequences littered with pauses and re-formulations, signifying a general difficulty with the language and explanation. In other words, neuro-language is not easy for interviewees to repeat and use but is done so because of the perceived legitimacy it will give to their report of their experiences.

The emotional experience and reactions to dementia

Metaphors of emotion can help explain the experience of being diagnosed with dementia and offer an opportunity to achieve epistemic balance in the conversation. Individualistic details of a diagnosis may be unique and perceived as complex for all to relate to but using a generic idiom that portrays a familiar, negative image means affiliation is likely (Gibbs Jr & Franks, 2002; Golden, Whaley, & Stone, 2012; Kitzinger, 2000). The interviewees may struggle to describe what dementia is, but can produce metaphors and idioms to describe the emotional experience which accompanies dementia. They may also do this to achieve affiliative responses from the interviewer and confirmation of understandings. Littlemore and Turner’s (2019) work into how pregnancy loss is communicated found people used metaphor to express a loss of a perceived future self. Here, interviewees similarly used metaphor to express loss for a future that will no longer exist due to dementia. This is also reflective of the theme of ambiguous loss discussed by Littlemore and Turner (2019). With dementia, what may be communicated is an anticipatory loss adjustment as phases of dementia occur Using metaphors of shock and lack of agency is a way to communicate grief for what was and is, and this is particularly prevalent for those individuals with young-onset dementia (as seen in extract 4.2).

In the extract below, Claire describes what she feels dementia is. Garth then steps in (in overlap) to offer a response to the question, referring instead to the emotional experience of dementia, not what dementia is itself. Claire has been diagnosed with young-onset Alzheimer's. Both Garth and Claire talk about how difficult the initial diagnosis was, and state that for the first few days they just stayed in the house to come to terms with it and did not speak to anyone. They also say they wished it had been a cancer diagnosis, because they would have been able to cope with that better. Claire does not speak much during the interview and uses her hands to express difficulties. She often looked to her partner to answer the questions and would often only answer when directly addressed by the interviewer or by Garth.

Extract 4.2

```
Recording: i_27_02_19_GL
Extract Start: 00:11:06
Extract length: 00:00:40
Gc: Husband of person with Dementia, Garth
Cd: Person with Dementia, Claire
IV: Interviewer
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```
 1   IV: Um, so what do you >sort of< both
         know:: or understand about having
 3       memory problems (.)  Like uh about
 4       >having Alzheimer’s<=like what do you
 5       know: about it Claire.
 6   Cd: .hhh (.) Um, well I’sj- I know that
 7       it’s (1.6) started.
 8   IV: Mhm.
 9   Cd: O:kay An::d now it goes on and it jus-
10       (.) going to go one after the other
11       °after the other, after the other and
12       then° ((claps)) it’s just going to go
13       ((claps))
14   Gc: >I think<-
15       [>a lot of the- a lot of the<]
16   Cd: [    that’s all I can say    ]
17   Gc: problems with Claire was .hhh >when
18       we- when we-< the diagnosis come
19       through obviously the- the world fell
20       out of our (.) [ bo]ttom=
21   IV:                [Yeh]
22   Gc:                          =fell out of
23       our world.
24   IV: Mmm.
```

The interviewer poses the question directly to Claire, her answer is treated as unfinished and in need of expansion. This is evident through the significant pause at line 7, the hedging on line 9 through the extended sounds and the significantly quieter talk on line 11, where her TCU trails off rather than coming to a definite end. When Claire finishes her utterance and adds the non-verbal clap, this is not responded to by the interviewer; thus this can be interpreted that further explanation is needed. The ‘speaking for’ a person with dementia is not always indicative of exclusion, Garth interrupts on line 14. In lines 6-9, Claire’s turns are halted, with pauses indicating some trouble formulating an answer. This is somewhat overcome in lines 10-12, perhaps due to the additional physical gestures she used to accompany her words. In lines 13-15 Garth begins to answer the question alternatively and works to ‘fill in’ the narrative. He refers to the initial diagnosis, rather than Claire’s understanding of the present and future situation.

He also shifts pronouns in line 15, from Claire, to ‘we’, the narrative now becoming more inclusive, and demonstrative of the diagnosis' effect on both parties (Hydén & Nilsson, 2015; Nilsson, Ekström, & Majlesi, 2018). This may be in response to the initial phrasing of the question in lines 1-5. Garth re-directs the narrative to include himself and Claire and shifts the focus from memory problems to how they emotionally respond. The conceptual metaphor in lines 17-20 is commonplace in the English language (with variations). It is produced problematically with the repetition and cut off words in line 19, and repair of the turn in line 20 with a micropause mid-turn, however the commonality of the idiom, and the implied preferred response (using ‘obviously’) means the interviewer agrees at line 21 (in overlap, perhaps due to the repair). The idiom offers a visual for the negative emotions felt when the diagnosis was received. In this extract Garth also works hard to negate blame falling onto Claire for the ‘bottom falling out of their world’. He begins line 17 by stating ‘the problems with Claire was’. This is problematic, he is firmly asserting that Claire was a problem, but he lessens the negative by positioning this Claire in the past. He further attempts to undo this negative blame by depersonalising to ‘the diagnosis’. The diagnosis is not assigned explicitly to Claire, and *it* is the cause of the subsequent negative emotion.

Furthermore, on line 20 Garth uses the pronoun ‘our’ to show how the negative emotion was an equally shared experience. The metaphor is used to express negative emotion that can be understood by all present, but it also shifts the topic from what dementia is to how it has affected the couple emotionally. The focus shifts from Claire’s understanding and knowledge of her disease to a shared negative emotional experience. Garth works hard to pivot the conversation from focusing on Claire and her problems (demonstrated by her halted talk and explicit reference in line 15) to an equally shared emotional experience. In this sense, dementia itself is absent, but the emotional experience is perceived as an adequate explanation of what dementia is.

Dementia is described as the cause of emotional distress. The individual with dementia is blameless and the emotion is shared between the couple. The person and self are protected through re-direction of the dementia narrative and through 'othering' the disease. Dementia is described as the cause of an emotional reaction that is universally understandable (through metaphor use). It affects a couple's emotions, not their personhood or self. The individual with dementia is protected by repositioning dementia as a joint negative emotional experience, reflective of therapeutic work to enable couples to cope with difficult diagnoses, creating a shared ownership of an illness beneficial for the person with dementia. This protects their personhood, and for the informal carer it enables an understanding and supportive relationship (Fergus, Ahmad, Ianakieva, McLeod & Carter, 2017). Othering dementia is a therapeutic protection measure, used here by spousal interviewees, hinting at the importance of relationships for individuals with dementia.

To reiterate, dementia is constructed as an 'other' to protect the self and a shared negative emotional experience. This protects the sense of self and personhood of the individual with dementia by separating the person's negative attributes or experiences. However, there is also evidence that neuroculture and negative metaphors influence people with dementia's self-perception. Sontag's (2001) belief that the metaphor of an illness cannot be wholly separated from the experience of the illness is relevant here. The influence of neuroculture and the frequent reference to damage to the brain results in an interesting dichotomy for persons with dementia. They must simultaneously acknowledge the damage and impact to their brain, while working to elevate and protect their personhood in the face of a demeaning society and restrictive capacity law. The medical colonisation of dementia discourse means interviewees work to portray knowledge of the location of their illness (the brain) while simultaneously demonstrating personal value (Beard, 2017; Mitchell, Dupuis, & Kontos, 2013). I go on to discuss this below. In some senses, law has moved beyond the medical colonisation of dementia discourse through rejecting the competency rhetoric prior to the MCA (Hoggett 1994). Simply put, the occurrence of dementia in a couple's life results in an 'us' versus 'it' rhetoric. As I discuss in chapter 1 the introduction of the mental capacity act was instigated by a recognition of the need to separate a disorder from 'lacking competency'. However, legislation still focuses on the individual capabilities of someone with an impairment and does not allow for solutions that fully consider the relational nature of personhood. The MCA shifted rhetoric away from complete medicalisation, echoing my findings of the divide between the unwanted dementia and relational personhood. The split and rhetoric shift are a recurring idea and I discuss this later in this chapter when examining how interviewees construct capacity.

Dementia in the brain versus personal resistance

In these extracts, interviewees locate dementia in the brain which is separated from the person experiencing the symptoms of dementia. The use of reporting neuroscientific knowledge has been found in autobiographical accounts of experiencing dementia. These texts serve to legitimise the personal narrative; writers with dementia may quote from medical discourse to legitimise and explain personal experiences of behaviour changes or memory loss (Zimmermann, 2017). This theme was identified as when interviewees were asked about diagnosis, or what they understood about dementia. A number cited pseudo-medical descriptions of dementia and talked of the results of brain scans (some of whom had seen their brain scans, others had not). Generally, the evidence provided by a brain scan solidified the diagnosis and served to locate and separate dementia. As already discussed, dementia is depersonalised, but here we see it located in the brain, which is rarely spoken of as belonging to the individual. This distances the harmful activity of the brain, and the individual is less threatened by the damaging discourse by reframing dementia as belonging to the brain, instead of the individual. Furthermore, the descriptions of the brain were often contrasted with descriptions of how the individual (I, she, he) is *still* capable. This somewhat reflects distinctions between the ‘life world’ and the ‘health world’ (Higgins, 2018). HIV and AIDS discourse research has found that individuals create a lifeworld in which their behaviour and actions are separated from the health world, in which their illness resides. In my data, it is worth examining this phenomenon not with regards to ‘contracting’ dementia, but in the individual’s agency and ability to manage and live with the disease. In the ‘lifeworld’, the individual’s behaviour and actions are manageable. However, the brain exists in the ‘health world’ (or ‘brain world’), where the interviewees can’t exercise as much agency to manage problems.

In the following extract Edmund uses a metaphor to describe how his brain appeared in the scan, and how this solidified the diagnosis for Edmund. The physical image of the brain scan legitimised the doctor’s diagnosis of MCI and provided an absolute which could not be argued. When Edmund went to the specialist for further testing, he was offered the chance to participate in a PhD student’s research looking at memory. While Edmund was getting the diagnosis, he took part in this study which involved having various brain scans and memory tests. For Edmund, this confirmed that there was something wrong with his brain (and he was not depressed, which the GP and his wife had both suggested and suspected).

Extract 4.3
Recording: i_14_06_19_RY

Extract Start: 00:02:53

Extract length: 00:00:43

Ed: Edmund, Person with dementia

Fc: Fran, Wife of person with dementia

IV: Interviewer

```
Ed: So:: I had scans,
IV: Mhm
    (0.4)
Ed: Uhrm:: (0.6) and tests agai:n,
    (0.3)
Ed: and scan agai:n.
Fc: Mm.
Ed: .hh Uhrm (0.5) which was in:teresting
    for me=this is w- sortof on the si:de
    really but it was interesting for me
    because .hhh uhr the doctorate student
    u::rh (.) u- (1.0) pro:vided me with a
    copy ofh .hh the scan of my brain=
IV:                                  =Mm
Ed: .hhh Ahnd it looked like the last
    cauliflower on thee shelf.
IV: [((Laughter))]
Fc: [((Laughter))]
Ed: [((Laughter))]
Ed: ((clears throat)) .hh (.) I was (0.3)
    quite surprised.
IV: Yheh:.
Ed: .hh Uhm….
IV: ((Clears throat))
Ed: But there I had in front of me
    confirmation that there was certainly
    something wrong.
IV:  [ Mmh]
Ed: >[What] it was gunna be I don't know.<
```

Edmund has disjointed speech in this extract when speaking about the official medical language, the 'scans' and 'tests', but is fluent and confident when explaining how it affected him personally. Edmund displays a level of difficulty recounting the medical experience, but confidence explaining how this made him feel. This is common in reports where 'expert' language is used and reflects the inaccessibility of neurological information (Pierce, Lamers, & Salisbury, 2016). Despite this Edmund continues to pursue this medical legitimisation of his diagnosis, but uses a metaphor that appears to ease his explanation. The metaphor is a universal knowledge; epistemically, the negative image of a cauliflower is expected to be understood by all and is received as such.

The laughter which follows signifies a confirmation that this metaphor has been successful in explaining otherwise potentially difficult terms. The laughter facilitates continued discussion after this negative disclosure. Edmund can then continue his narrative in lines 20-21 discussing his emotional response delivered in disjointed talk with an emphasis on line 21. The shock is emphasised and difficult for Edmund to recount, but he closes the topic in lines 25-29 by moving to the evidence that there was something wrong in his brain. Edmund is one of the few participants who take slight ownership of ‘my brain’, but note that he does not close the statement by personalising the ‘something wrong’. The brain scan provided evidence that there was something wrong for Edmund in the brain, the source and location of the issues have been identified and confirmed’. In this sense, Edmund is protecting his self-identity. The issues he has been experiencing are due to a faulty brain, rather than his whole person.

The following extract offers a clear example of how the brain is depersonalised and separated from the skills of the individual with the disease. The depersonalisation of the brain, being located as separate from the individual, was frequent. The personhood of the individual is protected by separating the ‘dysfunctional/affected’ brain as a distinct entity, a description of a faulty brain is often accompanied by a description of what capabilities the individual has. This is evidence of brainhood, as for the ‘faulty brain’ to not affect the individual personhood, interviewees frequently justify a person’s worthiness in skill following any descriptions of the brain. The faulty brain then is perceived as a threat to the person's worth and value, so interviewees use positive skill affirmation specifically assigned to the individual with dementia to negate perceived negative connotations of having a faulty brain. In the below extract Frank and his wife Anne have both been to a course to learn more about living with Alzheimer’s. Both have said this was helpful, especially for Frank to help him accept his diagnosis.

Extract 4.4
Recording: i_22_02_19_HY

Extract Start: 00:07:58

Extract length: 00:00:23

Ac: Anne, Wife of person with dementia

Fd: Frank, Person with dementia

IV: Interviewer

IV: Okay so:: um (.) what do you sort of
both understand about having
Alzheimer’s.
(0.5)
IV: What do you sort of both know about
Alzheimer’s.
(0.7)
IV: now(.) that you have (.) a diagnosis.
Ac: Well °the° brains deter:ioratin:
IV: mhm
Ac: uhm .hhh Most things you can do and
en:joy and quite happy.
Fd: [yeh]
IV: Y[eh]
Ac: [I] know it gets worse:
IV: mm
Ac: [yeah]
IV: [yeah]

In this extract, after several re-formulations of the question by the interviewer, Anne answers the questions using a reference to brain deterioration. On line 9the word ‘deteriorating’ is elongated and thus has emphasis. This is received with a minimal receipt from the interviewer. On lines 11 and 12Anne offers a more favourable alternative to line 8, and although the brain is deteriorating, ‘most’ is emphasised, minimising the amount that Frank may not be able to do. The turn is then completed by an emphasis on Frank’s emotional state rather than ability. Furthermore, Anne again uses the objective versus the personal to assign different types of ownership to Frank. Personal pronouns in lines 11 and 12 contrast with the objective ‘the’ in line 9 This serves to increase the positive attributes assigned to Frank and minimise the negative implications of brain deterioration. These simple shifts signify an acknowledgement of the potential negative implications of a ‘faulty brain’ and protect Frank’s personhood by focusing on his individual character's positive attributes and emotions. Anne’s separation of her husband’s deteriorating brain and his personhood resist neuroculture’s emphasis on the brain. Frank’s personhood is not entirely reliant or even related to his deteriorating brain. This separating of dementia, the brain and the self, protects the person with dementia and constructs them as an able, valuable individual.

The recent public health discourse used to promote ageing well is problematic when considering dementia and may explain the othering of dementia (Peel & Ellis, 2018). The rhetoric of ageing well offers the negative alternative that ageing with a chronic or long-term health condition such as dementia is poor aging. However, through constructing this illness as an independent subject within the relationship using metaphor and idioms, interviewees can still adhere to society’s successful ‘ageing well’ rhetoric. Furthermore, interviewees can avoid the damaging rhetoric of neuroculture and assure that personhood is not solely located in the (damaged) brain. The impact of neuroculture is present, and individuals can either incorporate the damaged brain to their self (extract 3), or work to separate the brain and the person to protect their personhood (extract 4).

Interviewees use separation to acknowledge personhood and adopt neuro-language when speaking of the brain's deterioration, acknowledging the brain's role in dementia without solely locating their sense of self there. Legislation similarly focuses on the location of the impairment. Explicitly an impairment ‘of the mind or brain’ is seen to be the internal cause of the impairment to an individual’s capacity. Capacity law largely identifies the brain, the internal biological factor belonging to an individual, as responsible for any potential capacity loss, again evidence of neurocultural influence. The constructions of dementia seen in these data demonstrate the nuanced and subtle ways that people with dementia and their carers protect those with dementia from damaging societal expectations and rhetoric, and a neuroculturally influenced capacity law.

Capacity constructions by people with dementia and their carers

In this theme, I disentangle two distinct forms of capacity discussed by interviewees. ‘Implicit everyday capacity is the capacity implied by either the partner or person with dementia. This capacity is personal and unique, and often reliant on a deep relational knowledge. ‘Explicit decision-making capacity’ refers to when interviewees explicitly reference capacity as a concept. This type of capacity is less clearly defined by interviewees, who tend to give examples of others who do not have this capacity instead of expanding on it themselves.

These two types of capacity were consistently discussed in distinct parts of the interview. ‘Implicit everyday capacity’ was discussed by all interviewees and at the beginning of the interview, where the interviewer posed the questions ‘What do you both understand about having memory problems?’ and ‘In your day-to-day life, how does your dementia (/problems) affect both your lives?’ Interviewees spoke of skills (or lack thereof) covering a broad range of topics such as physical ability, ‘The walking is a big handicap’ (Karen C); household activities, ‘I mean dad still does most of the cooking, doesn't he' (Mel C); language, 'knowing how to explain things, that is quite difficult' (leaflet written by Eve D explaining her atypical dementia); handling money, 'I use my card because another thing is I can't count my cash' (Rodney D); and memory, 'I'm forgetting a few things but nothing dreadfully' (Andrea D). The reports of these skills reflect a value-laden capacity and everyday use of the individual. This may somewhat reflect the concept of mental capacity identified in interviews with individuals with disabilities investigating supported legal decision making (Harding & Tascioglu, 2017).

Mental capacity is conceptualised in law as an individual's decision-making skills and abilities; it is personal and unique. In these interviews, as evident in the previous quotes and the following extracts, 'Implicit everyday capacity' is spoken about using personal pronouns. It is seen as belonging to an individual. In contrast, the second subtheme, 'Explicit decision-making capacity' was discussed in relatively few interviews (only 11/20, whereas Implicit everyday capacity was discussed in every interview). This discussion often occurred in the legal section of the interview and would follow a prompt (if interviewees had used the term themselves) 'what do you see capacity as, in your own words?' As this type of capacity was constructed where legal decisions were being discussed, it is more reflective of the concept of legal capacity defined as 'the formal ability to hold and to exercise rights and duties' (Harding & Tascioglu, 2017, p. 19). Interviewees who discuss this more 'official' type of decision-making capacity construct it as temporally dependant, 'As it is, I can sort of give my opinions and theories and whatever now. But I know it's not always going to be like that' (Connor D). Interviewees also do not go into great depth about what official capacity consists of, it is summarised using terms like 'I still understand the right and wrong in all, all that' (Kenan D), the addition of 'all that' signifies the end of explanation and the hesitance to provide more detail, as does providing an alternate topic of the individual without capacity.[78]

Significantly, in this subtheme, interviewees offer an example of a person who does not possess capacity to demonstrate what lacking this type of capacity is. This example person is often either entirely unrelated to either individual or is constructed as an uncertain future self, ‘if my condition had deteriorated, it obviously would have made a difference’ (Rob D)Discussions of ‘Explicit decision-making capacity’ are less common and, where it is discussed, interviewees do not demonstrate confidence in explaining this type of capacity and are more confident in their stories of others who do not possess said capacity. I will show through the following extract how capacity is constructed in two distinct ways and how interviewees protect their personhood and are uneasy with official terminology.

Implicit everyday capacity

Everyday capacity discussions are often value-laden. Even where deficits are reported, interviewees work to minimise the impact; ‘Mainly *just* the thinking, you know’ (Hank D), or *‘little things* like the microwave have become *a bit* of a mystery’ (Kendra C)[79]. This recognition of the importance of usefulness may reflect an understanding that having use in the relationship and society improves self-esteem perception (Cotter, Gonzalez, Fisher, & Richards, 2018). I will explore the extent to which interviewees demonstrate the importance of usefulness in my data and how this contributes to their constructions of everyday capacity. Interviewees also demonstrate an awareness of the importance of cognition through their frequent and consistent minimising of any difficulties

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[78] see page 163-170 of this chapter for an in-depth analysis

[79] Emphasis added to highlight minimising terms, to lessen the extent of the defect being reported. These are just two simple examples of many across the data.

experienced. Interviewees, like in their construction of dementia, view cognitive deficit as something to be protected against or minimised. Participants protect themselves from the damaging influence of neuroculture and hypercognitive ideals by minimising the impact of cognitive deficit on the personhood of the individual with dementia. Where more everyday activities are being discussed and minimisation is far less frequent, and is interpreted as not being perceived as necessary to protect the individual's personhood or brainhood. 'Implicit everyday capacity' is identified as being rooted in the person's usefulness, as being unique to them (i.e. the skills they may have had previously or continue to have) and covers a broad range of topics such as socialising, physical activity, financial management, household activity and moral knowledge.

The interviewees in extract 4.5 portray the moral value of the person with dementia and how this differs from 'some people' and how the person with dementia continues to partake in usual activities in their lives. Anne and Frank spoke about how their daily routine has changed. As Frank can no longer do the more manual jobs around the house (painting/gardening/fixing) Anne has now taken these up and instead Frank now takes up other tasks like making cups of tea and cleaning. They have done this to make sure Frank is still able to help around the house. Frank himself finds it difficult to understand dementia, and often asks whether there is a cure. Frank's usefulness, moral value and active engagement in day-to-day life are expressed regarding his 'Implicit everyday capacity'.

Extract 4.5

```
Recording: i_22_02_19_HY
Extract Start: 00:10:09
Extract length: 00:01:46
Ac: Anne, Wife of person with dementia
```

Fd: Frank, person with dementia

IV: Interviewer

```
Fd: R- I- it’s SO LATE ON isnit.  I mean I
    dunno (0.7) Often people (.) get
    Alzheime[r’s]
IV:         [ mm]
Fd: an how ol:d they are °yuknow°.
   (0.3)
Fd: I mean I: wuz (1.1) >iwa-< seventy
    before:=
Ac:        =Seventy ei:ght something
    [>but yeah no<]
Fd: [((inaudible))]=
Ac:                  =seventy seven so you
    fee:l you was old anyway.
IV: Yeah.
Fd: Mmm.
    (1.0)
Ac: But you WASN’T ol:d rea:lly in f-
    (0.4) for yur a:ge:.
Fd: [mm]
Ac: [th]at’s what everyone used to say
    when he used to take the kids swimmin
    and things li:ke that [((inaudible))].
IV:                       [    Yeah     ]
    .hhh
Ac: And uh (.) he still goes football with
    the one grand[son  ]
IV:              [O:kay]
Ac: So (>he does<) so that sort of thing
    [(he does)]
Fd: [ I don’t ] ACtually play I just
    watch.=
Ac:         =((lau [ghing))]
IV: [((lauging))]
Fd: [((e(h)uh))] °don’t°
    (1.0)
Ac: .hhh But umm
    (1.5)
Fd: [°no°]
Ac: [°no°].hh hh NO on the whole:: the
    biggest thing is: (1.9) yur a very
    pleasant per::son.
    (0.4)
Fd: Yeah: I’m not anymore: am I.
Ac: NO you arhh(h)e .hh(h)h
Fd: h(h)uh h(h)uh
Ac: You are:: actually.
```

Discursively, this extract provides a wealth of devices used to maximise Frank’s personhood, despite Frank himself not being the majority speaker in this sequence. The extract begins with Frank posing that he felt he was old anyway, implying dementia has not had much of an impact on his daily life. Framing any decline or effect through age is used frequently by people with dementia to protect their personhood, a way to negate any decline by conferring it to belonging to the blameless, universal and inevitable ‘old age’ category. The ‘factual talk’ means it is inarguable and Frank is protected from the obligation to meet any other expectation of his abilities (Jolanki, Jylhä, & Hervonen, 2000; Pierce et al., 2016; Wooffitt, 1993). On line 17, Anne offers an alternative by stating that ‘he was not old really’, and then follows this up by providing evidence for how Frank was not old through reporting others’ opinions of him and his activities. Again, this is reflective of the dichotomy of the discourse of ageing; society demands individuals remain helpful by having value but accepts that ageing necessarily means physical and mental deterioration (Jolanki et al., 2000).

This also reflects the awareness of the value placed on mental usefulness in hypercognitive society, and Anne implies through this rhetoric that ageing and the associated decline of dementia could harm Frank’s personhood. In this sequence, ‘being old’ is not formulated as a positive and Anne works to undo any perception of Frank being old. The ‘really’ marks the preferred affiliative response. Frank and Anne have now jointly positioned him as ‘not being old’ but can also blame any decline to his old age. In this juxtaposition, Frank and his everyday capacity are protected. Between lines 20-26 Anne shifts from the past tense to the present, emphasising what Frank can do in the present with the diagnosis of dementia. On line 25 Anne emphasises the temporal marker, placing value on the activity and his consistent involvement in it, enforcing that Frank still partakes in regular social activity. In line 28 she summarises that Frank’s social activity is not limited to this alone, as he does ‘that sort of thing’. In this first section of the extract, Anne actively demonstrates how Frank is an active citizen in the present and never behaved ‘old’ before the diagnosis.

In line 30 Frank corrects the story from Anne in another initiated repair, in overlap, stating ‘I do not actually play’. Frank emphasises the lack of physical activity and the use of ‘just watch’ suggests that watching football has less value than if he were to play. He is downgrading the activity from ‘actually play[ing]’ to ‘just watch[ing]’. From this downgrade of his own activity, it could be interpreted that Frank is less confident in his everyday capacity. The following laughter serves to close the topic (Holt, 2012). It also treats Frank’s statement as laughable and minimises Frank’s negative statement about his level of participation. Frank’s statement is made humorous by Anne, the superior status of the activity of playing football is downgraded by Anne treating it as a laughable activity for Frank. [80]

In the final section of this extract, at lines 39-41, Anne emphasises that the ‘biggest thing’ is that Frank is a ‘very pleasant person’. Anne places emphasis on Franks moral character. She switches pronouns to the more personal and directed ‘you’ after a long pause, indicating anticipated trouble with the following compliment of Frank. In line 44 Anne has laugh particles in her speech, inviting laughter from Frank, which he mirrors in line 45. In this exchange, the laughter acts as an affiliative display (Nilsson et al., 2018) that strengthens the optimistic assessment of Frank. Frank’s skills and abilities are evaluated as less relevant

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[80] In discourse analysis, laughter is not assumed to follow humour. Instead, participants in interaction can treat utterances as ‘laughable’, the laughability of an utterance is not inherent, but is added retrospectively by the receipt. I also do not propose why the utterance is laughable, to resist the inclination to make assumptions about the internal thoughts of the speaker. See Glenn & Holt (2017).

than his pleasantness (the biggest thing). Finally, at line 46, Anne repeats her statement of Frank's pleasantness. She places this in the present tense and emphasises this time marker. She ends the utterance with 'actually', strengthening her argument and refuting Frank's negative self-assessment at line 43.

To summarise, Frank and Anne both evaluate Frank's capacities compared to other older or unpleasant people and emphasise his sociability and morals. I propose that this extract exemplifies how couples can protect the individual with dementia by stating their present and enduring skills, activities, and personalities, thus constructing an implicit everyday capacity specific to the individual. Though this narrative is littered with disaffiliated responses, Anne's insistence on the Frank's positive attributes work to produce a cohesive narrative of Frank as a capable and pleasant person.

Explicit decision-making capacity

Capacity was discussed explicitly by interviewees in only 11/20 interviews. I searched for 'Capacity' in NVivo. 'Capacity' appeared in all interviews, but interviews where the term was used by the interviewer and not expanded on by the interviewees were excluded. These discussions often occurred where legal documentation or legal knowledge was being discussed. Capacity in these interviews could then be interpreted as a term belonging to the 'legal' lexicon. Explicit constructions of capacity contrasted greatly to the implicit constructions of capacity discussed previously. These constructions of capacity are often brief, and the word 'capacity' is somewhat used in place of more detailed explanation and it is not used exclusively to talk about the person with dementia, if it is personalised at all. In this sense, these findings are like those of Pierce et al. (2016) where people displayed a lack of confidence in explaining their diagnosis of ‘Mild Cognitive Impairment’ and potentially a lack of knowledge about the disease.

The term ‘mild cognitive impairment’ was not frequently used by interviewees to talk about their illness. Capacity is perhaps deemed in the authority of legal professionals rather than within the epistemic authority of the individual. Interviewees, particularly those with dementia, did not demonstrate confidence when using the term capacity. However, speech became more fluid (demonstrating confidence or ease with talk) when providing an extreme case to give an example of someone who does not have. The following extracts show that the term capacity is problematic for interviewees, why it is used little and why interviewees struggle to communicate what it means to them. I give examples of how this explicit ‘official’ capacity is constructed and how the talk demonstrates a lack of confidence when discussing explicit decision making capacity..

Andrea and Hugh talk about capacity explicitly and extensively in their interview (7 references, out of 21 across all interviews). Andrea is an ex-judge and Hugh, her husband, is a retired businessman, and they are reluctant to accept Andrea’s diagnosis of Alzheimer’s. Before this extract, there was a lengthy discussion of how each person understands capacity in their own words, of how their financial affairs are managed, and of how they have absolute trust in each other to make decisions and in the NHS to be there for medical needs. This comparison comes at the close of this topic and acts as a contrast. Both Hugh and Andrea state that they do not have issues with capacity but can foresee how it may affect others. This extract demonstrates how providing a story of another person who presumably does not have capacity provides a stark comparison to how Andrea and Hugh frame themselves. In this extract we can see the work being done to distance oneself from an extreme case, how using idioms and laughter achieve affiliation that this extreme case did not have capacity, and how this lack of capacity was managed within the community.

Extract 4.6

Recording: i_12_07_19

Extract Start:00:53:26

Extract length:00:00:57

Ad: Andrea, Person with dementia

Hd: Hugh, husband of person with dementia

IV: Interviewer

```
Ad: Yeah giving written >in<instructions in
    adva:nce
IV: Mhm?
Ad: Is reasonable=the only mi:nor problem is
    (.) .hh ti::mes an thing:s change and what
    [ was]
IV: [Yeah]=
Ad:       =said two year:s ago (0.4) .hh may
    not be the right thing to [do:]
IV:                           [ Ye]ah.
    Abso[lutely ]
Ad:     [u-uh, w]hen you've lost your
    mar:bl:es an: (0.9) different things are
    °happe[ning°]
IV:       [ mm: ]
Hc: >yeh< .hh >I mean< we don't know (.) when
    we lose our capacity do we
IV: No.
Hc: That's the problem.
IV: nyeah.
Hc: >I mean< there's a la:dy who used to live
    near us in Church:ill (.) thir:ty years
    ago.
IV: Mhm
Hc: She: used to sweep the leaves off her
    long: drive (.) in a howlin gale.
Ad: h(h)m [h(h)m h(h)m]
IV:       [   Ri:ght  ]
Ad: .h(h)m h(h)m
Iv: £Okay£
```

```
31   Ad: .hh(h) [h(h)hh]
32   Hc:        [  And ] she was >at it< for
33       [hours ]
34   Ac: [u(h)hm] h(h)m
35   IV: Yeah.
36   Hc: Now she was living f- qui:te normally.
37   IV: Yeah.
38   Hc: Apart from (.) few things like that.
39   IV: Mm-hmm.
40   Hc: But clear:ly (0.8) off her trolley
41       completely
42   Ad: CUH(h) H(h)u THAT'S HIS ver:sion
43       [(she annoyed)] you.
44   IV: [ ah(h)a h(h)a]
45   Ac: [ ah(h)a h(h)a h(h)a hh)]
46   Hc: [no she was you know com]pletely- No, >she
47       was you know< neigh:bours were helping.
48   Ad: Yeah, yeah.
49   Hc: The community was there for her.
```

Andrea and Hugh reference 2 cases of ‘lost capacity’ (line 17), initially in the story about their neighbour but also in lines 12-13. Andrea uses the idiom here to signify when it is perhaps not a good idea to change one’s written instruction. Andrea references time frequently at the beginning of her turn, signifying she is aware of the temporality of this explicit, official capacity. On line 5 Andrea introduces time as having a significant impact on the official act of writing things down, and lines 8-9 furthers this by giving an example to strengthen her statement and encourage agreement, resulting in the strong affiliative response from the interviewer in lines 10 and 11. Interestingly, Andrea emphasises the word ‘lost’ possibly due to the previous overlap, but this also signifies that Andrea constructs capacity as something definitive. If it is lost, this suggests one is either in possession or not in possession of capacity. The phrase she uses here is a common English expression, meaning to become incompetent or of unsound mind. This idiom is followed by a pause and an expansion which somewhat mitigates the potentially harmful image of an individual who has lost their marbles, adding the impersonal ‘different things are happening’. Andrea trails off here ending her turn. Perhaps due to this addition, Andrea's idiom is not met with the expected strong agreement. Andrea's pronouns also signify how capacity is being constructed impersonally. She begins her turn using no pronouns simply describing a situation and shifting to the impersonal 'you'. Though Andrea is the individual with a diagnosis of dementia and thus the person likely to be affected by laws about writing down future wishes, the capacity (or lack thereof) is not directly related to herself. Andrea protects her 'official' capacity by distancing herself from the idiom she uses. Andrea here constructs an official capacity that is temporal (line 5, 8, 14), morally dependant (line 9) and not directly relevant to herself (line 12). Andrea finishes her sequence by using an idiom to summarise what not having capacity entails ('losing your marbles').

In line 16-20, we can see the lack of strong affiliation to Andrea from the interviewer results in Hugh constructing a question which is likely to receive an agreement response. After strong agreement from the interviewer, Hugh continues to tell his story to demonstrate how a person without capacity may behave. Hugh begins his turn with the phrase 'I mean' which is typical when starting a complaint sequence (Maynard, 2013a), or as is achieved here, delivers a story defensively. Hugh has made it difficult for others in the conversation to disagree with his story of this person who has lost capacity. This is somewhat evident in the interviewer's minimal continuers. However, Andrea does question the validity or neutrality of his story through the laughter particles in lines 27, 29 and 31. Laughter here hints at the difference in the image of the individual being spoken about, there is ambiguity about the objectivity of Hugh's report (Yahalom, 2019). Hugh works to establish the abnormality of the neighbour's behaviour, emphasising the task's size ('long drive') and how long she would spend doing this, in presumably unacceptable weather conditions. Hugh concludes his story, on line 40 with the idiom to surmise her lack of capacity. This may be as

Hugh has only received minimal responses to his story, and as discussed previously, using an idiom allows the speaker to generalise an otherwise specific event. However, instead of receiving an agreement, Andrea responds with laughter and reframes the story as 'his'. Her laughter is loud and she takes ownership of the story through this, shifting the narrative of one from a neutral neighbour noticing odd behaviour to Hugh's interpretation of events due to an adverse emotional reaction to her. . On line 47 Hugh reinforces his evaluation of the woman and using additional evidence to support his assessment, and again on line 49. In this way, personalising the story through his dislike devalues the portrait of the woman and Hugh's impartiality, but Andrea is not directly rebutting the lack of capacity.

The story still demonstrates what a lack of capacity may look like. It is placed in another person, a woman known in the past who is detached from the interviewees, and Hugh uses it to protect their status as people with capacity. Hugh's comparison allows for a more positive evaluation of Andrea, like how hospice managers evaluate good and bad deaths by giving an example of one, and reinforcing the evaluation of the other (and vice versa) (Semino, Demjén, & Koller, 2014). Essentially, though his story is ridiculed, Hugh does manage to portray how lack of capacity presents through apparently ridiculous behaviour that belongs to an unnamed other, and not in their present personal state.

Capacity is constructed in two distinct ways by interviewees, reflecting the different values attached to implicit everyday capacity and official, explicit decision-making capacity. The breadth of skills accounted for with everyday capacity indicates an inclusive, valued, and protected personhood. Explicit decision-making capacity is communicated with less certainty but is perceived as under time constraints. Interviewees change topics from what official capacity may be, to what a lack of official capacity is. This is reflected by the change in pronouns, and the stories of unrelated others in the form of extreme cases. The differences in the types of capacity being constructed are like Harding and Tascioglu's (2017) findings that where, when complex decisions are being discussed, disabled participants express less certainty about making such decisions and a greater need for support. There is a lack of clarity in interviewees' discussions of official decision-making capacity. This is particularly pertinent when considering that most participants had made at least one legal decision. Interviewees (if they discuss this at all) do not use the term capacity concerning their day-to-day life, and struggle to construct what official capacity may be.

In contrast, skills that contribute to everyday capacity and personhood, like supporting the household and engaging in social activity, are managed and supported. Carers and people with dementia consistently report how their capacity to continue and 'carry on' is being supported by their environment, partner, family, home, the stability of the home's location and changes to or continuation of physical and social activities. Again, this reflects the scaffolding techniques used by professionals to assist people with disabilities in making more complex decisions (Harding & Tascioglu, 2017). However, it is both the person with dementia and the carer who work to negate the reported lack of skills. The importance of the relationship provides a foundation for this type of capacity. Relationality is central to implicit everyday capacity, it enables the person with dementia to possess a useful, valued, and multidimensional personhood. I have shown in these interviews how people with dementia and their partners construct everyday capacity and official decision-making capacity differently. This finding demands attention when considering legal interpretations of mental capacity.

Conclusion

The two themes presented in this chapter provide a basis for questioning and adding insight to improve legal interpretations of dementia and capacity. The discourse analytic approach shows how people with dementia and their carers construct capacity and dementia. Importantly, people with dementia and their carers arguably use various linguistic tools (metaphors, pronouns, othering) to protect the individual with dementia from being adversely affected by societal expectations due to neuroculture and ‘healthy ageing’ rhetoric. The theme of dementia narratives highlights how people with dementia and their carers work to protect their personhood and negate the consequences of locating the self (solely) in the brain (brainhood). Dementia is discussed throughout all interviews and constructed consistently as a negative, unwanted, experience or other. However, capacity is constructed in two distinct ways; every day and official decision making. Capacity, when spoken of in terms of everyday skills and ability, is broad. It increases an individual’s value and is relationally managed. Official decision-making capacity is constructed with difficulty as temporal and a moral decision. However, the interesting finding here is the clarity with which interviewees expound what they see as insufficient capacity in a person unrelated to themselves, compared to how well they can comprehend capacity in their own situation. This is important when considering how people with dementia and their carers are affected by capacity law. I discuss this finding further in the following chapter regarding interviewees’ expression of legal documents, law and rights.

Chapter 5: Making future plans, interviewee perspectives

Introduction

In this chapter, I use TDA to show how interviewees construct different types of future plans. I have identified four themes for this chapter, each of which incorporates different constructions of time and the future The legal orientation of decisions is different in each. The themes are '*relational and moral future plans*', '*anticipatory and protective future plans*', '*delayed and disrupted future plans*', and '*desired rights and control in the future'*. Within the last theme, I will discuss assisted dying and ADRTs. Interviewees discussed ideas of the future across all interview topics (not only when discussing legal plans made). Time and dementia's disruption were inseparable from interviewees' lives and experiences. The high instance of future-orientated talk is to be expected, given the focus on future-oriented legal decisions which allow people to plan for inevitable and potential futures (death in case of wills or loss of capacity in the case of LPAs). Interviewees constructed multiple futures and multiple ideas of time, each unique to the activity that was being planned. This is important when considering how law constructs time and whether 'legal time' and the time described by interviewees can co-exist. In each theme I consider how legal time may present a barrier or be reflective of interviewees' constructions and what impact this has on the uptake and use of legal planning tools.

The future, as a concept, has multiple interpretations. Structuration theory states that the future is a constant reflexive task whereby individuals act in the present to actualise the future. Agency is required in the present to achieve a planned future (Giddens, 1991). This is somewhat reflective of the discussion in chapter 2 where I describe how law presents agentic individuals as acting to protect and enable their future selves. When this idea of a future is disrupted or the agency to achieve a plan is removed, anticipated life trajectories can collapse or need adapting to protect individual personhood and the future self (Shirani & Henwood, 2011). Additionally, structuration theory aligns with my approaches to my research questions, using a social constructionist theoretical approach. The presence of dementia impacts law's requirements to work towards this interpretation of the future. Personhood is put at risk where a diagnosis of dementia is present. Legal time is co-constructed between human and non-human legal actors (Grabham 2014), it is a product of the legal action of writing a will and the person writing the will. In this sense, legal time must work to reflect and work with the human actor to be genuinely reflective and impactful. Wills and LPAs (and other legal documents not in focus for this thesis) cannot simply act as legal placeholders because they exist across lived experience and are co-produced by human actors.. They affirm a linear temporality in which a person can exist in binary polarities (capacitous or not capacitous). Legal time reflects structuration theory, in which agency and ability in the present are necessary to plan the singular and fixed future. Though the MCA acknowledges capacity's fluctuation over time, its insistence on the individualistic nature still means future planning relies on the idea of agentic, able individuals who can work towards a singular future independently. Relational and moral aspects of personhood are absent. Again, this reflects the neuroculture in which law and society exist, compounding individualistic autonomy in what I demonstrate to be the relational lives of people with dementia and their carers.

Interviewees demonstrate a keen awareness of their future plans and acknowledge the capacity (and sometimes lack of capacity) required to achieve their future goals. 38/40 interviewees had made, or were active in the process of making, a legal decision in the form of an LPA or a will. There was a general acknowledgement of uncertainty about the future, and that the continuity of life prior to dementia had been irreparably disrupted. This exists in contrast to the findings in chapter 4 where personhood is maintained through continuities such as everyday skills and relationship dynamics, despite losses in other abilities (such as those required for planning, managing finances or logic).Everyday capacities and relational personhood are undermined by law’s focus on cognitive skill and agency for an individual to actualise their future plan.. In this second empirical chapter, I add to the evidence that people with dementia and their carers do not construct, envisage, or make legal decisions as individualistic agents; instead they do so within their relational lives, with the unwanted impact of dementia as a 'third party' within their relationship.

The four themes and the distinct types of future planning and ideas of time are reflective of extracts across the interviews. Though I asked the questions 'what are your plans for the future?' or 'do you have any plans for the future with the dementia?' (with no significant difference in response due to formulation), futures were discussed throughout and interviewees spontaneously discussed plans when talking about wills, LPAs and everyday life. In summary, the way future planning is discussed throughout the interviews insinuate futures are not dependent on legal decisions. I describe each theme and give examples of short quotes and in-depth TDA to demonstrate how time is constructed. I will discuss each theme concerning legal concepts of time and situate these discussions within the relational and social world in which the participants live. Where neurocultural theories contribute to my understanding of dementia, I additionally examine how thanatological theory may explain why some types of planning are made and accepted, while others, like end-of-life care plans, are absent.

Relational and moral future plans

Interviewees constructed care plans as morally dependant (to be implemented at the 'right time') and relational (belonging to the home-life of the person with dementia and their partner). Care plans proposed by interviewees were temporally dependant on dementia's progression and focused on practical, incremental changes to be implemented. Formal care planning was not discussed at length and end-of-life plans were utterly absent from care plans. Interviewees expressed difficulty with thinking about the trajectory of the disease and implementing official care plans. When asking one participant, they said of care planning,

> 'I am thinking of various things all the time…and what might happen. But we haven't done anything about it…and quite honestly, you know, it's difficult to know which way to go or what to do… you think of what might happen in the future…but that is in the future. There's no point…in getting concerned about it at that time…or at the moment.' (Jack C)[81]

Jack also shows how interviewees see care planning as a concern for their future selves, rather than their present self, the unknowable nature of this future makes it futile to attempt to plan for an event that has yet to occur (such as loss of capacity or increasing need).

Interviewees' care planning ranged from possessing care home or care support brochures (to look at in the future or consider further at an unspecific future time) to having already made adjustments in the home which anticipated changing needs in the future. For example,

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[81] Ellipses indicate where I, the interviewer, offers a continuer like 'mm' or 'mhm', removed here for ease of reading the extended quote.

> 'So the shower cubicle's been taken out, there's a bath there with the shower above it so that when it gets to the point I could sit her in the bath…fill the bath up and she can have a bath and I can kneel on the floor and do what I need to do to sort her out' (Garth C).[82]

Garth shows how care plans may be incorporated by practical everyday modifications anticipating changes in the future. Given the adaptions Garth has made in the home, he is constructing a future where he cares for his wife at the home, whilst anticipating her decline and making physical changes to the home to allow for this future to become a reality. These physical, practical changes are anticipatory and contribute to Garth's idea as a carer for his wife in the future. The location of future care was the most common way to discuss care plans, but they were not discussed around LPAs and were less formalised than financial plans. They were constructed as part of the couple's everyday life and incremental (potential) changes to the home and to their relationship.

The above examples may appear contradictory, but the consistency is that the plans are relational, and belong to the home-life of the interviewees. The location of their care, i.e. the home, also houses the location of these decisions. Care plans are personal and linked to the body and physical capability; they belong to the informal care relationship (familial or spousal) rather than formalised legal decisions. Legal spaces and legal formalities like health and welfare LPAs are not seen as intrinsic to this kind of future planning. This is problematic if this limits the intended scope of health and welfare LPAs, or prevents other types of care planning from being considered (such as ADRTs). As this interviewee says, 'we did…we had lots and lots of conversations, but mum and dad are really not keen to…to move' (Mel C).

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[82] See footnote 76: ellipses indicate interviewer continuers

Care plans were and are formed through conversation within the family unit. Relationality is integral to the construction of future care planning from the perspective of both carer and person with dementia, 'I've already told him he must put me in a home…when I get impossible' (Lesley D). Lesley demonstrates knowledge that she is reliant on her husband to carry out her future care plan if she becomes 'impossible' or loses capacity. She states she has informed her son of the same. Again the family unit is intrinsic to future care planning.

In the following extract, future care plans are discussed concerning time, the importance of the relationship, and the 'informality' (i.e. non-legal nature) of plans. This extract incorporates different aspects of how interviewees constructed care plans and shows how dementia complicates the temporality of the future for both the person with dementia and their informal carers. This disruption causes a shift for both persons' futures and is dependent on anticipated changes to a person's everyday capacities. As discussed in chapter 4, everyday capacities belong to the relationship, thus so does care planning. The 1 minute of talk in extract 5.1 is a succinct example of how care plans are constructed throughout interviews by people with dementia and their carers. Potential implications for legal planning are detailed in the discussion section of this chapter.

In extract 5.1, the location of care is the focus for the current future planning, as is the unpredictability of the future and the need to enjoy the present instead of planning for an uncertain future. This longer extract shows how ideas of care, unpredictability, time and uncertainty of life entwine to construct a future plan where dementia is present. The length of this extract shows how different ideas intersect, why care and its location are at the centre of what the future is, how to plan for it (if possible) and how dementia is constructed as a barrier. Connor has had two strokes and has vascular dementia. Connor and Bella's life has changed quite significantly. Connor has struggled to adjust and allow his wife and family to take on more tasks, as he is less physically able to do them (he cites becoming tired frequently). Bella states that Connor used to become quite aggressive, but he is much calmer since she has simplified his life. This sequence responds to the question 'do you have any sort of plans for the future at all?' Connor's speech is affected by his strokes; therefore his speech is quite breathy, and he speaks less throughout the interview as he says talking can tire him out (but that he misses his conversation with his wife).

Extract 5.1

Recording: i_09_08_19_MY

Extract Start: 00:28:36

Extract length: 00:01:12

IV: Interviewer

Bc: Bella, carer and wife of Connor

Cd: Connor, person with dementia

```
1   IV: So:: hh do you have any >sort of<
2       pla:ns for the future at all.

3   Bc: Um (1.1) ↑no not- (0.2) n’not really↑
4       .hh  erm (.) the hope (1.2) >we just
5       have to see< how this play:s ou:t (.)
6       I mean >obviously< (0.6) you: >can’ne-
7       < (0.3) I
8       know that I don't know:: (0.2) like if
9       I: would get ill: [like]
10  IV:                   [ mhm]=
11  Bc:                          =what would
12      happen to Co:nn:or stuff like that
13      .hhh we don't know: (0.7) ho:w the
14      dementia’s gunna play out* [b-]
15  IV:                            [mm]
16      (.)
17  Bc: the only (.) plan we havfe >>°for
18      the°<< (.) which I've (0.2) al:ways
19      promised Co:nnor that WHILE I'm a:ble
20      (0.6) an: WHile HE is: (0.5)
```

```
21          ↓uw::↓WELL enough to be at ho:me he
22          >[will be a]t< home.
23      IV:  [  mmm:    ]
24      IV: Mmm
25          (0.5)
26      IV: [Yeh]
27      Bc: [Um ] (0.2) >but obviously: we< don’t
28          (0.8)know:: (0.2) what (0.2) the
29          futuhr:e (0.2) [ Is]
30      IV:                [Yeh]=
31      Bc:                      =gunna bring
32          >whhith whhith th-< (0.2) diagnosis of
33          dem:entia
34      IV: Mmm
35          (.)
36      Bc: SO >i’s basically it’s just< (0.8) one
37          day at a ↑TI::(h)h.(h)me↑
38          [.h(h)e h(h)u]
39      Cd: [    Myeah   ]
40      Bc: [ .hh]
41      IV: [Yeah]
```

On lines 1-9, Bella starts answering the question by referring to her health and how Connor's care relies on her continued health. Bella's initial formulation is full of pauses, restarts and repairs. In line 4 she starts with 'the hope', which is followed by a long pause. She does not continue to explain what this hope is, instead restarting her answer by stating the uncertainty of dementia. Bella's initial response refers to how there are no plans currently because they do not know what the future holds, due to dementia's presence. Bella is somewhat ambiguous in her formulation of 'how this' will play out and continues by referring to her health, not dementia. Bella does this by proposing an interesting epistemic dilemma in lines 11-14 as she knows what she does not know. She demonstrates a self-awareness of her lack of knowledge and thus ability and agency to plan for an unknown future and proceeds to give an example of what she does not know.

In lines 8-9, Bella gives a personal example and makes her wellbeing and ability to care for her husband relevant. She finishes this with the more general and joint future 'we', repeating the initial phrase of not knowing, specifying dementia as the disruptive barrier to planning. In lines 17-22, Bella states that they have one plan for the future, which is temporally dependant. The sequence has the time markers; 'always' and 'while' emphasised through extended vowels and increased volume. There is an emphasis that this plan is heavily dependent on Connor's progression and Bella's ability. It is presented as a conditional plan that has been promised continuously, but again at lines 27-29, this is followed by stating that the future remains uncertain.

Furthermore, where the uncertain future is stated, it is prefaced by a quick 'obviously' (line 6). Bella asserts that this statement is universally known, it is stated as factual and she is therefore challenging to contradict (and neither IV nor Connor contradicts in response). She responds to the question posed by giving conditional, temporally dependant plans for the future. Bella closes her sequence with the common phrase 'one day at a time' with laughter particles in her utterance, encouraging affiliation from the interviewer who so far has offered minimal receipts and continuers, while Connor has not responded to this sequence at all. The phrase ‘one day at a time’ has been used by people who experience upsetting life events (such as terminal illness or unexpected death) to express an understanding of how the previous concepts of the future are no longer held and delay re-imagining a new future given the life disruption (Devin, 2019; Shirani & Henwood, 2011). In this context, it also aligns with how this phrase can allow for minimal care planning. This is achieved through constructing the micro stages to achieve an outcome (the care plan having been broken down into manageable stages) (Christopoulos et al., 2013).

Following this phrasing, Connor does the minimal confirmation of the care plans that Bella has stated. Later in the interview, he responds that he is 'resigned to it', but he offers no further explanation. In this extract, Bella demonstrates how her well-being affects both their futures and how the future is very conditional and will potentially be even further disrupted by the presence of dementia. Despite repeatedly stating that the future is uncertain and they are taking it 'one day at a time', Bella does report their current plans for the future and how care and place of care are centrally important.

As identified in chapter 4, dementia is the unwanted third party in this relational decision, its presence has disrupted an anticipated trajectory of time and its continued presence means future plans are now dependant on dementia's progression, as well as the moral choice of acting at the right time and making said plans possible through the relationship. This theme addressed the holistic, bodily, physical and moral aspects and needs of future plans, the next theme offers a stark contrast. While care plans are constructed as informal and relational, financial plans are seen as related to formal legal planning and act to anticipate and protect the interviewee's future finances.

Anticipatory and protective future plans

Wills and financial LPAs were constructed as integral for anticipatory and protective planning; notably, the focus of such documents is financial stability. Interviewees constructed future financial security and potential changes in managing finances as a critical reason to make these documents. These documents act as precautionary measures to protect the interviewees' future selves. Formal legal decisions were deemed financially dependent and their importance was reflective of personal wealth. Interviewees used legal decisions to plan a future that would protect financial assets from disruptive life events and were not always linked to the dementia diagnosis. For example, 'As we slowly accumulated possessions and some money it became more important to get it right' (Edmund D). Using these tools gives participants a sense of control over their futures.

The greater an interviewee's wealth, the more likely they were to have made wills and LPAs (and used a professional service). Family involvement was also posited as a significant factor to how legal decisions were made. Also, interviewees state they can protect finances for their family's sake, such as changing house deeds to ensure some inheritance, 'this way, only half the house…would go, so there would be better security for the kids' (Kendra C). Generally, the family is considered when making financial decisions such as, 'the children want it… we're not allowed to sell the house' (Andrea, D) and 'I think we've, we've tried to think about as many things and different roads that might cause problems for family, haven't we?' (Pearl D)' and 'we can't sell the house because the kids want it'. Pearl and Andrea have both made financial LPAs and wills, and here they explicitly incorporate the family as an essential consideration when making financial decisions. Both ultimately acknowledge that the decision must be formalised for it to become a reality in the future.

The way interviewees spoke about LPAs and wills indicates a potential lack of engagement with the full range of planning that *could* be formalised in these documents. As with the previous theme, where the usefulness of health and welfare LPAs is either absent or lacking in interviewee constructs, the tools mentioned here are only constructed with minimal engagement of their potential. Wills and LPAs are primarily a financial planning tool, but could be used further, as I note in the discussion section of this chapter.

The following extract shows how interviewees constructed different types of financial planning to exert control over disruption caused by dementia. This extract shows the different documents and actions people take, and how legal documents are constructed as a practical, precautionary activity. An absence of in-depth discussion about legal decisions, and focusing on the financial protections offered, indicate how legal plans are constructed in a reductive way. Unlike the previous theme of care belonging to the home-life and the relationship, financial decision making is positioned in the legal domain. Extract 5.2 shows how legal decisions help obtain some control where dementia has disrupted an expected life trajectory.

Extract 5.2

```
Recording: i_14_08_19_HG

Extract Start: 00:34:50

Extract length: 00:00:31

IV: Interviewer
```

Kc: Kendra, carer and wife of Paul

Also Present is Paul, person with dementia and husband of Kendra

```
 1  Kc: I kno:w that- .hh in the beginning I
 2      was running around doing lots of legal
 3      things::
 4  IV: Right [yeah ]
 5  Kc:       [>Like] a:< a headless chicken
 6      rh(h)eally.
 7  IV: .hu(h) h(h)u [.hhh]
 8  Kc:              [  I ] think cause I felt
 9      that there was something I could do:
10      t' [        manage this       ]
11  IV:   [something you cud contro:l]=
12  Kc:                                =Yeah:
13  IV: Yeah:
14  Kc: an- and I know that the will- re::did
15      the will:s,
16  IV: Mhm
17  Kc: °We-° (0.5) re#did the:# (0.6) house,
18  IV: Mm.
19  Kc: An::d we got the L P As.
20  IV: Yeah, okay.
```

Kendra initiates her turn by positioning herself in a strong epistemic position with the elongated sound in 'I know', she is the authority to report her own experience of future planning using legal decisions. She positions the story in the past, as 'the beginning'. They have moved away from discussing day-to-day activities, to a report of the past and the concept of time is given importance in the construction of making legal decisions. Kendra, in lines 2-3 gives a vague description, with 'legal things', but emphasises that there were 'lots' of them. In this first utterance, she presents legal decision making as multitudinous, but the use of 'things' prompts a continuation by the interviewer at line 4, as the description is not treated as adequate to end the topic of discussion. On line 5, Kendra continues her report with an idiom; as previously discussed this works to create mutual understanding between all participants in the conversation, and from a very personal stance, Kendra is now working to create shared meaning with the interviewer.[83] The idiom, 'running around like a headless chicken' is a common phrase for carrying out tasks in a frantic or disorganised way. Kendra initially formulates the legal planning as an active (doing) and personal (evident through personal pronoun use and report ownership), yet disorganised activity. In line 7 the interviewer affiliates through laughter, displaying understanding and matching the laughter particle in Kendra's speech on line 6.

On lines 9-10 Kendra emphasises the activity involved in making legal decisions, with emphasis on and elongation of 'do' and emphasising the word (in overlap) 'manage'. Legal decision making in this utterance is reframed from a potentially frantic experience to an act of control. Legal decision making is constructed as a way for Kendra to exercise some agency in planning for a future with her husband's dementia. This is reformulated by the interviewer at line 11 and confirmed at line 12 by Kendra. Kendra follows this by listing the specific types of legal decisions that have been made, shifting from the personal report style of her initial utterance to a plural 'we' in lines 17 and 19, including her husband in the decision-making process. This is legally relevant due to their joint shared ownership of the property and that Kendra is Paul's attorney (disclosed previously) and works conversationally to include Paul in the discourse of making the legal decisions. She lists the types of decisions *they* have made which enabled a sense of control for Kendra at the beginning of the illness. However, the details describe how Kendra felt about making the legal decisions and when they were made, not how they are assumed to help with future planning. This, coupled with the initial response that they find any future plans challenging to discuss, indicates that legal documents do not enable couples to talk about potential

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[83] See chapter 4

future plans and that LPAs, regarding the health and welfare LPA, are not being used to their full extent to aid future planning and care plans.

Kendra and Paul constructed legal decision making as valuable and timely, and their focus on the financial hints that they have assets they would like to protect. Rodney and Beth are the only couple who have made no legal decisions, but they have experience applying for Personal Independence Payment (PIP) benefits and using the legal system to challenge the court on the decision. Prior to extract 5.3, when asking about the future, Rodney and Beth initially talk about how they no longer go on holiday abroad as Rodney finds airports stressful. Rodney also says he has no idea what will happen because 'nobody knows' how he will progress and there is no 'wonder pill' to remove dementia from their lives. Beth initially states she just doesn't think about it, but then follows with this discussion of her awareness of legal planning tools.

Extract 5.3

Recording: I_12_08_19_PE

Extract Start: 00:44:54

Extract length: 00:00:28

Bc: Beth, carer and wife of person with dementia

Rd: Rodney, person with dementia

IV: Interviewer

```
Bc: The o:nly thing that worries me
    sometimes like .hh it's like (0.2) um
    dementia (.) > Rodney'se' < go to a
    young dementia group [ an]
IV:                      [Yeh]=
Bc:                            =the s- and
    the lawyer ca:me in .hhh hh  And u:m
    >' e was on about< power of atto:rne:y
    and all that sorta stuff.
```

10 IV: Right.
11 Bc: well it's li:ke shevhen hundred and
12 fhifty pound?
13 (0.1)
14 IV: Mm.
15 (0.7)
16 Bc: YI’know if- (0.3) [it’s not that]
17 Rd: [eh- car:]n’t
18 afford it.
19 IV: [Yeah]
20 Bc: [I'd] ra:ther go on 'oliday than
21 spend sehven hundred an fifty pound on
22 a pie:ce of pa:per

The way Beth starts this utterance minimises the following talk, with 'only thing'. Beth further downgrades her worry about the future (and their lack of planning) by using the word 'sometimes'. In line 2 Beth has trouble formulating her talk (pauses, breaths and non-lexical sounds). She restarts her turn at line 4, instead reporting previously known information (spoken of prior to this extract). This receives a positive continuer by the interviewer on line 5 in the overlap. This overlap results in some slight difficulty at the start of Beth's turn on line 6. She continues her explanation of her worry disclosing how she does have an awareness of legal decisions. In lines 7-9 she states how a lawyer had attended Rodney's group. She formulates legal decisions as 'power of attorney and all that sort of stuff'; this formulation is dualistic. She uses official terminology but with 'sort of stuff' she removes any detail. The legal terminology is not expanded upon and instead lay language is adopted.

Cost is emphasised in the following utterance. The price quoted by Beth is wildly inaccurate; LPAs can cost as little as £82 per document if completed at home without the assistance of a professional. The cost associated is only for registering a power of attorney with the Office of the Public Guardian. The price Beth is informed of is closer to what may be estimated for the average solicitor to assist with creating power of attorney documents[84]. This reported misinformation (rectified post-recording by IV), shows just one reason why LPAs need to receive much greater attention from public policy and how their use (and accessibility) is misunderstood. People with dementia remain at a disadvantage when planning for the future and seeking legal means.

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[84] See https://ukcareguide.co.uk/power-of-attorney-costs/ for an average estimate of costs, cited here as ranging from £400- £1000.

In lines 11-12, Beth gives an approximate cost and extends the numbers with breath particles. She ends this formulation by emphasising the pound and adding a strong upward intonation at the end of her turn. She portrays a strong position of her knowledge by giving the reported personal experience. In line 16 Beth works to achieve positive affiliation using 'you know' which generalises the information to be agreeable. In overlap, Rodney summarises why they have not made any LPAs with 'cannot afford it'. This is met with positive affiliation by the interviewer. In lines 20-22 Beth contradicts Rodney's summary by offering that they would rather go on holiday than spend money 'on a piece of paper', such as an LPA. The monetary value of making the LPA in this extract is constructed as central to why they have decided not to make a legal decision. It is both too expensive, unaffordable and unwanted as an alternative to a holiday.

Delayed and disrupted future plans

Interviewees expressed hesitancy when planning for the future and often perceived the need to delay planning or be flexible with any plans made. The following examples exemplify this uncertainty: 'I don't- don't particularly want to spend my time dwelling on what could be about to happen' (Lesley D), 'You’re quite a living-in-the-present person…since all this’ (Val C) and ‘Take each day as it comes and accept what we’ve got’ (Beth C). These interviewees decline to state what the future might look like for them, or what they would like it to be now that a diagnosis is present in their lives. A future with a dementia diagnosis is silenced in these utterances. Dementia has disrupted their temporality to delay any planning or remove it entirely. These statements recognise dementia as impacting their agency and ability to actualise potential futures and remove the idea of planning completely. Interviewees also used examples of previous planning to exemplify that they had previously been agentic in their futures, ‘I had it all worked out like retirement and the way I was going to work’ (Tim D), but that dementia had disrupted their lives to such an extent that these futures were now entirely impossible (Tim had to leave work before retirement age). Interviewees acknowledge that the future is uncertain and use this to justify a delay in planning or neglecting to make new plans accounting for the presence of dementia.

Extract 5.4 shows how future planning is constructed as disrupted and hence delayed, due to the presence of dementia. It also shows how giving examples of previous plans shows that people acknowledge their previous agency to actualise a plan and with the presence of dementia this agency and ability is affected negatively. This sequence comes after the question ‘what are you plans for the future?’ and is initially met with laughter by Kenan and Sonia. Sonia makes a point of distinguishing between what the plans were (wait for the children to move out and move to the coast) to what the plans may be now. Kenan emphasises the difficulty of employment for both Kenan and Sonia and the financial challenges they have faced.

Extract 5.4

```
Recording: i_09_08_19_WN

Extract Start: 00:30:44

Extract length: 00:00:49

Kd: Kenan, Individual with dementia

Sc: Sonia, Carer and wife of person with dementia

IV: Interviewer
```

Kd: So- really >°as° far as makin< plans
goo
(0.5)=
Sc: =[.h hhh]
Kd: [yu're] quite limited in what
plans: you can actually do [yu t-]
IV: [mm:]=
Kd:
=yu
t'n to live more:: (.) day to day.
IV: m'kay yeah yeah.
IV: .hhh >so with< the: (0.3) >sort of<
.hh
>plan of< (0.3) you know °y- y-° you
wanted tu:: like (0.4) up sticks
a[nd move down to Devon or somewhere]
Sc: [Oh >yeh yeh yeah:<]
That
was it=
IV: =is that kind of (0.3) been:
(1.1)
pushed?
Sc: to one si::de
IV: away- pushed to one side for now?
Sc: [Yeh]
IV: [Unt]il maybe you get used to:: (0.4)
Sc: [Yeh]
IV: [how] you operate [more::]
Kd: [It was]=
IV: =so and
things like that.
Kd: Id still class it as a:: (0.8)
Sc: I'm not [gunney]
Kd: [want] to do thing=
IV: =right=
Sc: =Yeh-
I'm never gunna give up (.) be:cause
if I do: tha:t °.hh hh° like If I
>give up< on tha::t
IV: Mmm
(0.2)
Kd: Mmm
(0.2)
Sc: >uv- s that's:-< (0.3) yu know
[failin]
IV: [Yeah]
Sc: >An I'm not- Im-< I never will.

IV: [yeah]
Sc: [y’know] so it’s still there.

In lines 1-9, Sonia and Kenan both give halted formulations of a dis-preferred response to the question. Kenan uses the impersonal form ‘you’ in lines 5, 6 and 9 when referring to how dementia limits the plans available. In this way, Kenan protects himself as being personally responsible for the limited agency to actualise future plans. He furthers this by using the general phrase in the impersonal form, ‘you tend to live more day to day’. The emphasis on ‘more’ also signifies that Kenan and Sonia previously lived ‘less’ day-to-day, demonstrating dementia’s negative effect. Kenan works to achieve an understanding of why plans are disrupted and delayed.

In the following sequence (line 12-16), with frequent overlap, the interviewer asks if the previously mentioned relocating plan is still relevant or if it has been restricted as Kenan references in the initial utterance. In overlap, Sonia offers minimal agreement. To navigate this the interviewer expands on the ‘for now’ with an optional condition for uptake by Sonia ‘until you get used to how you operate more and things like that’. Kenan describes the plan as a desire, rather than an action to complete or a definite plan. There is a lack of agency displayed in only wanting something, rather than actively planning or taking action to achieve said plan. At line 36 Sonia restarts her turn (started at line 33 and states that she will not give up on this plan. In lines 36-49 she states that to give up on this desire she feels would be a failure. Kenan and Sonia, though acknowledging the limitations for retirement planning from impersonal dementia in the initial utterance, work to position themselves in opposition to the restrictions.

Time is a subtle indicator of the types of agency and control constructed as available (or not available) to Kenan and Sonia. Initially in lines 7-8 Kenan states that with dementia present, ‘you live in the day-to-day’. Living in the present means one is restricted in how far in the future a plan can be made and imagined. Essentially, due to dementia, their agency, the future which can be planned, is restricted by the need to live day-to-day. Anything which requires more extensive planning, such as moving home, is impossible because of the need to live day-to-day. However, their want for previous plans is not restricted and no less important. For Sonia, maintaining their previous retirement plan, while restricted to day-day planning, has moral weight. Sonia ends the sequence with the passive ‘it’s still there’. The plan is described as simply existing in the couple’s lives, not being acted upon in the present. Throughout this extract, Sonia and Kenan not only demonstrate how couples present their agency as being restricted by unwanted dementia and the necessity of living in the present, but show how this rhetoric is problematic for maintaining and taking action for future planning.

This theme addresses how people feel unable to carry out their future plans. The following theme addresses how people with dementia construct their inherent right to carry out desired plans. There is a desire for control that is not met using financial planning tools and I discuss how interviewees acknowledge rights that are accessible and rights that are not, again, partly due to the presence of dementia.

Desired rights and control in the future

In 6/20 interviews, people with dementia referenced a wish to not be alive during the later stages of the disease or if they reached a particular stage; ‘there are methods then we’d rather go to Dignitas…you know, that sort of thing’ (Hugh C)’. Hugh references Dignitas explicitly. Assisted suicide and death were referred to as an alternative to living with dementia in an unwanted stage. However, it was acknowledged that there would be legal ramifications, and dementia’s progression meant the individual with dementia would be unlikely to be able to say when they were in the late stages and put this plan into action. Interviewees used various colloquialisms to refer to the act of suicide such as ‘finish it all’ (Norah D), ‘throw myself under a bus’ (Hank D) and ‘Dignitas’ (Hugh C, Tim D and Mark C). Interviewees did, however, acknowledge the difficulty of suicide and dementia given the disease's progressive nature and the illegality of medically assisted suicide in the UK. Both the unwanted disease of dementia and law are constructed as restraining the ability to plan for desired futures, therefore preventing the actualisation of these futures. Participants did not discuss palliative care and managing dying; a troubling gap in the discussion of future planning and an issue I address in the discussion of this chapter looking at sociological and cultural explanations.

In extract 5.5, a desire for the option of assisted suicide offered by Dignitas is expressed by Tim. This follows the question ‘what are your future plans with the dementia?’ Tim and Courtney have different ideas about how to plan their future. Courtney is a professional carer, as is one of their daughters, and Courtney is adamant that she and her daughter can care for Tim in their home. Tim, however, is resistant to this and states this is due to the traditional roles of a man and wife, with the man providing and being capable. Courtney says she would be happy to continue to care for Tim at home and use local facilities like day centres to have some respite. Tim and Courtney have not made any legal decisions, although they have drafted an LPA but have yet to send this to the Office of the Public Guardian. Tim speaks the most throughout the interview and there is at times tension between Tim and Courtney when asking if they see things in the same way. Tim’s mother also had dementia and was not diagnosed until she had lived with the disease for quite some time. Tim states in the interview that his mother might have seemed odd but that she had managed to hide her dementia for a long time. Shortly before her death, she was very unwell and they found that she had been struggling alone for quite a while. Tim has some personal experience of caring for/witnessing his mother in the very late stages of her disease and he uses this in the following extract as a time marker for the stage of dementia that he does not want to reach.

Extract 5.5

Recording: i_17_02_19_RG

Extract Start: 00:22:18

Extract length: 00:00:51

Td: Tim, person with dementia

Cc: Courtney, carer and wife of person with dementia

IV: Interviewer

```
IV: So- Do you have >sort'of<
    idea:s or plans or are you jus
    >sort'of< [taking it] as it comes.
Td:           [    My   ]
    (0.3)
Td: <what I: inten:d to do (1.3) is:: uh>
    .hh and this is the bit and it
    probably won't happen because of the
    way dementia is, [.hh]
IV:                  [ Mm]
    (0.5)
Td: bu- >when I get to a< poi:nt that I
    think (0.2) .hh #↑nhah↑# I >don't
    wanna< land up like me mum like you
    know.
    (1.0)
Td: .hhh Um hh (0.8) I'll top meself
    #>I'll I'll I'll< uh# (0.7) Dignita:s
    go down that route.
IV: Mm.
Td: You know?
    (0.6)
Td: #Uhr# >but it< of course then you
    think well .hh (1.0) >but if I'm< °>>s
    a<<° in a sou:nd mind to be able to do
    tha:t,
IV: Mm,
```

```
28         (0.8)
29    Td: You know urm:: (.) then I'm probably
30        not ready, .hhu(h) hu(h)h .h(h)u Y(h)U
31        KNOW IT'S A CAT:CH 22 isn' it
32    IV: [Yeah]
33    Td: [  I:]dea:lly it'd be good like be
34        dilly for a week wake up and go .hh
35        Nah time to go to [Switzerland.]
36    Cc:                   [£dilly for a]
37        wee:k£
38    Td: Y(h)U KNo- H(H)UH
39        [H(H)U H(H) A(H)H H(H)A H(H)A]
40    Cc: [     H(h)a he(h)h h(h)eh    ]
41    IV: [  H(h)e h(h)u h(h)uh h(h)uh ]
42    Td: UHM
43    Cc: £Oh dear£.
```

In lines 1-3 the interviewer poses the question to the couple without explicitly referring to the future, but instead using an option question formulation, where the interviewees are given one potential choice to respond to, ‘taking it as it comes’. This line, however, is said in overlap with Tim’s response ‘my’. Tim initiates his answer in a strong possessive format, this is personal to him as it is not positioned in a plural ‘we’ (as the question refers to either a personal or plural you). In line 6, Tim begins his formulation of what his intentions for the future are. He emphasises ‘intend’ and ‘is’ by elongating the words. Tim emphasises the future tense of these plans, matching the initial question formulation. What follows in lines 7-14 is done as an inserted sequence, prefacing his intentions, and working to achieve affiliation when intentions are disclosed at lines 15-16. Essentially what Tim does here is display an active knowledge of the potential upset/disaffiliate responses caused by his intentions and the need to demonstrate knowledge and reason. He works to demonstrate his knowledge of the unlikelihood of achieving his intentions ‘because of the way dementia is’. Tim’s insert sequence also strengthens his position with ‘don’t want to end up like me mum’. Previously in the interview, Tim and Courtney both discussed how distressing it was to see his mum decline so rapidly. Tim uses the agreed-upon negative image of his mum, who also died of dementia, to encourage positive affiliation to his intentions. Time also plays a role in Tim’s intentions; he uses the phrase ‘when I get to a point’. There is a certainty in Tim’s phrasing, speaking of ‘when’ and not ‘if’. However, again, the time suitable for Tim is personal and linked to the image of his mother; it is something which is only known to him, when he deems the time to be correct.

Tim’s idealised future is deemed temporally dependent and constructed as inaccessible to others due to the personal pronouns used and personal timeline, but also unlikely due to dementia and its progression. In lines 17-19 Tim discloses his intention to complete suicide (conditional on the previous statements). After a long pause signifying anticipated trouble with the following talk, he uses the common colloquialism ‘top myself’, followed by repeated personal pronouns in a croaky voice said quickly, before restarting the turn with ‘Dignitas’. This sequence is intriguing as Tim moves from an informal colloquialism of ‘top myself’, an act which, again, is posited as personal and conducted by the self alone, to the formal and impersonal ‘Dignitas’. Long pauses and repetition somewhat halt the utterance, but Tim receives a minimal receipt after mentioning Dignitas. Tim works to achieve positive affiliation by using official terminology and displaying knowledge of such. However, given the topic, he only receives a minimal receipt from the interviewer. Tim seeks further affiliation at line 21 which is not received. The lack of affiliation results in Tim referring back to his understanding displayed in lines 7-9 to restate that this plan, he knows, is not realistic because of the progression of dementia and the time at which he would like to end his life.

Tim’s plan to complete suicide is contingent on having a sound mind, which he is aware is temporally dependent on the progression of the disease. As he put it, it is a ‘Catch-22’; it is the desired plan which is impossible to execute. Dementia is constructed as controlling his ability to actualise his future plans. He states he is restricted by his dementia’s control over his ability to identify when he is ’at the point’ that he would complete suicide. On line 35, Tim also demonstrates a knowledge of the restriction in the UK in being able to carry out his plans. He displays the knowledge that to complete suicide via Dignitas he would need to travel to Switzerland. This hints at the knowledge that if he were to complete suicide in the UK, he would have to ‘top myself’, but in Switzerland he could formalise the process by ‘go[ing] down that route’. The subtleties of how Tim constructs these two different types of idealised suicide hint at the awareness of the legal constraint and the illegality of assisted suicide in the UK.

Finally, in lines 32-40, Tim ends his answer by hypothesising how to achieve his plan. At lines 35-36 Courtney interrupts with a repetition of his idiom ‘dilly for a week’ in a smiley voice, slightly ridiculing his choice of phrase and encouraging a stepwise shift to laughter, which follows at the end of the extract (Haakana, 2010). Talk of death and dying is often a catalyst for laughter, but it is the hypothesis that the seemingly impossible plan could occur that results in laughter here. This laughter encourages recognition by all in the conversation that this plan is hypothetical. This receives the affiliative response from Courtney in the form of repetition and laughter, which they all participate in. The laughter acknowledges the difficulty of talk (evident through pauses and hedging/insert sequences to explain) and achieves affiliation to close the sequence. In the previous talk, Courtney and Tim acknowledge a desired future, acknowledging that they would not have the ability to access this future in the UK. They do not explicitly talk about their rights.

Explicit talk about rights only occurred in 8/20 interviews and there was generally a lack of understanding expressed about what rights were, how to keep them, and how to access them. Rights that were described were a ‘right to care’, bodily autonomy, and anti-discrimination rights. The way rights were described often suggested them as positive rights; an outside figure had control over whether the individuals could access and exercise the right. Generally, the term ‘rights’ was not known to interviewees or not understood. For example, rights were perceived as ‘Too much of an abstract concept for me really’ (Hank D) or something interviewees had not previously considered ‘‘I never thought about my rights’ (Karen C). This controlling outside figure for rights was referred to in the general term ‘they’

(Rodney D). Rights were seen as governed through ‘rules and regulation’ (Pearl D) or simply being ‘legal’ (Val C). Essentially, rights were constructed as subject to enablement or disablement by an external force. They were not dependent on the individual who possessed the rights but rather the outside force which enabled or disabled that person.

Rights regarding the couples were seen as ways to protect and respect the person with dementia (or the hypothetical person who becomes most incapable first). However, this meaning spanned from enabling the person lacking the capacity to make decisions to having absolute power to make substitute decisions. For example, Garth C said, speaking of rights presumed to be given to an attorney using an LPA ‘well it enables me to be able to have total access to anything financial…Legally it obviously gives me the right to make decisions on her behalf’. This shows how rights may be interpreted differently from their legal purpose. These interviews highlight that rights are not generally accessed and understood by people with dementia, regardless of whether they have made a legal decision meant to enable these rights. Extract 5.5 shows how rights are used to propose a potential or ideal future, which is not a reality due to lack of enablement by the controller of those rights.

In extract 5.6 Andrea and Hugh are very prepared in case either person loses capacity, an emphasis which Hugh often adds when talking about anything legal (giving an example of if he were to have a profound stroke). They have both a wealth manager and solicitor, and have made wills, LPAs, and a living will. They had not heard of ADRTs, but thought it was something they would investigate if the living will was not sufficient. Andrea is an ex-judge and Hugh previously ran a business. Prior to extract 5.6, they had been talking about how their assets are divided between them equally and that they decided to make a healthcare LPA and write a personal letter because they have strong feelings that if they ‘come to a point where we have to have our bottoms wiped, we'd rather go to Dignitas'. They also mention DNR orders in the sequence leading up to this discussion. The following extract demonstrates a keen knowledge of the difficulties of having the legal capacity to complete suicide in the UK with medical assistance and the role mental capacity plays in why this right is difficult to implement legally. They frame the wish for assisted suicide as a right to end your life, conditional on when the individual deems it not worthwhile. Analysis of this extract shows how interviewees accept that the 'right to die' is restricted by law and individual agency. Without the means or mental capacity to travel to a country where assisted dying is legal, assisted dying is impossible for people with dementia living in the UK.

Extract 5.6

```
Recording: i_12_07_19_MN
Extract Start: 00:28:16
Extract length: 00:00:47
Ad: Andrea, Person with dementia and wife of Hugh
Hc: Hugh, carer and husband of Andrea
IV: Interviewer

 1   Hc: We both .hh we both feel that we (0.2)
 2       we b:oth feel that >eve'bo:dy< (0.4)
 3       of soun:d mi:nd
 4   IV: Mhm.
 5   Hc: should hh have the right to (0.5) kill
 6       themselves [if] they want to,
 7   Ad:            [mm].
 8       (0.4)
 9   IV: Yeh.
10   Hc: An:d (0.4) >th- i- i-< therefor:e bit
11       li:ke a hor:se or a dog, .hh >yu
12       knowhh it is possible to put-< (0.4)
13        put people to sleep
14   IV: mm=
15   Hc:      =pai:nlessly=
16   IV:                    =mm
17   Hc: And why: not*.
18       (0.2)
```

```
19   IV: Yeh.
20   Hc: Ihf you're profoun:dly unwell, if
21       there's no hope of recovery,
22       [.hh]
23   IV: [Yeh]=
24   Hc:       =and your of and you WANT it and
25       you're of sound mind .hhh you know.
26       (0.4)
27   IV: Yeah.
28   Hc: I understand the safeguards about your
29       chi:ldren wanting you dead or your=
30   Ad:                                  =Mm:
31   Hc: husband or [  wi:fe or ]
32   IV:            [>Yeah yeah<]=
33   Hc:                            =whoever of
34        course but .hhh it ought to be
35   possible to work [it out]
36   IV:              [  Mm  ]=
37   Hc:                          =And the on:ly
38       reason we don't have it .hh I think is
39       because we've got (0.2) bishops in the
40       House of Lords.
41   Ad: <huh(h)h h(h)uh h(h)u
42       [h(h)u h(h)u h(h)u h(h)u>]
43   IV: [  hm(h)h h(h)u hm(h)u   ]
44   Ad: .hhhh .h(h)i h(h)u=
45   Hc:                       =Unelected bishops
46       in the [ Hou:se of Lords ].
47   Ad:        [h(h)u h(h)u[h(h)u]
48   IV:                    [yeah ]
```

In lines 1-3 Hugh begins his talk about rights by emphasising the joint personal thought on the topic, with the repetition formulation of ‘we both’. Hugh restarts his formulation at the end of line 1, moving from the personal ‘we both feel that we’ to ‘we both feel that everybody’. Hugh changes his speech to ‘everybody’ rather than just himself, acknowledging the broader scope of rights. In lines 2-3 the ‘everybody’ however becomes conditional, with emphasis through elongating ‘sound mind’. Hugh is using somewhat official language here, increasing his authority for him to have this opinion that applies to everybody. In other words, Hugh is giving himself and Andrea an epistemic authority to have an opinion which can affect everybody. To warrant this authority and receive agreement, Hugh has to work hard to maintain and demonstrate this throughout the sequence. In lines 5-6, suicide is formulated as a right. On line 5 Hugh says ‘should have’, emphasising the conditional word, implying it is not something that is just possessed but can be taken away or restricted. After this, there is a significant pause indicating some issues with the following talk. In lines 5-6 Hugh uses the term ‘kill themselves’; he continues in the impersonal plural terms, adding the conditional ‘if they want to’. In lines 1-6 Hugh has constructed the right to suicide as contingent on possessing both the traits of a sound mind and a ‘want’ (emphasised by Hugh) to complete suicide. These traits are implied to be personal and belonging to ‘everybody’, contrasting his construction of the right to suicide as being controlled by an external aspect. Andrea offers a minimal agreement or receipt in overlap in line 7, participating verbally in the conversation in which she has already been invoked through Hugh’s use of ‘we’. This is followed by a pause and a minimal receipt from the interviewer.

Hugh then expands upon his initial utterance by invoking an example of where the right to die (and, notably, not assisted suicide) would be administrable by a professional through the comparison of animals. In line 11-12 he uses the phrase ‘you know’ to achieve a stronger affiliative response and follows this with a less-active version of ending one's life. Hugh has gone from the active phrase of 'kill yourself' to the more passive 'put people to sleep'. Importantly, Hugh talks of both suicide and administered death to construct the right to die. The right to die for Hugh is inclusive of both forms of death. Following a minimal receipt from the interviewer, Hugh adds to his example that it is painless, elongating this word. A painless death is considered a right, if it is wanted and if the person has a sound mind. In line 17, Hugh seeks direct agreement, ending with a crisp emphasis on 'not', somewhat finalising his example. This then receives a slightly stronger agreement token from the interviewer after a short pause. Given the lack of affiliative agreement, Hugh continues his pursuit of this in lines 20-25, repositioning this to the pronoun 'you' (rather than the impersonal 'people') and giving a further example, again with the conditional factors emphasised. The interviewer gives only weak agreement after Hugh uses the term 'you know' to achieve affiliation.

In lines 28-35, Hugh displays his knowledge of potential reasons for not enabling the right to die, which, in overlap, does receive a stronger affiliative response. In his construction of the right to die, Hugh demonstrates an awareness of the legal issues (referencing safeguards) and stipulates its conditionality. In line 34-35 there is another reference to the fact that the right to die is not necessarily an accessible right, with the conditional 'ought' and future tense of 'to work it out'. In lines 37-40 Hugh finishes his construction of the right to die by disclosing that he believes the unelected bishops in the House of Lords to be why the right to die is not available ('we don't have it'). Hugh uses the pronouns 'we' and 'we've got'. In this sense he refers to the country and everybody in it, rather than just him and Andrea. At lines 40-42 Andrea laughs at his construction of why the right to die is not available. This may be laughable due to the much more personal construction. He uses the term 'I think', and so he is not claiming epistemic primacy for the reason why the right is not accessible, opening him to the opposition. Andrea does not directly disagree, but the laughter is not affiliative to his formulation. The interviewer joins Andrea's laughter which prompts an expansion and further detail from Hugh. Despite the laughter, the sequence closes with minimal positive response from the interviewer. Overall, Hugh's construction of the right to suicide or a medicated, painless death (if wanted and if the person is of a sound mind) has expanded from his and his wife's right, to the right of all the people in the country. This right, however, is not accessible due to the oppressive third party; the unelected bishops.

Discussion

I will now discuss the ways law could enable people with dementia in England and Wales to plan for their future, accommodating and acknowledging their social world and relationships. As Peel and Harding state,

> 'decision making is shaped and informed by both proximal and distant relational, social, moral, and cultural contexts. Individual life and the perceived quality of that life is generated through relationships with others' (Peel & Harding, 2015, p. 140).

Throughout the themes identified, dementia is constructed as reducing agency to actualise the desired future. Dementia is a negative third party in the relationship, which impedes a person's ability to achieve hypercognitive ideals and be fully valued in neuroculture. It affects couple's perceived future agency. Situating these themes within the society where the people constructing them exist gives insight into how interviewees perceive their social, moral, and legal landscapes I also propose that neuroculture and the Eurocentric death culture of the UK affect the construction of future plans (particularly when observing themes 3 and 4 where participants express a desire to delay or control the end-of-life). Given that most participants had made a legal decision of some kind, having engaged with the law did not mean interviewees expressed security or knowledge that their future (and subsequent end-of-life period) was certain. Through paying attention to discourse, I have shown the limited way in which LPAs, wills, and other life planning tools are used and understood.

Law constructs decision making as an autonomous activity. Interviewees construct future plans as relational. This rift between the two future planning ideas may explain the lack of engagement found with health and welfare LPAs across the UK.[85] Even where a health and welfare LPA has been used (as with some participants in this study) it did not form part of their construction of care planning, suggesting that it is not fully utilised or perceived as useful by people making health and welfare LPAs. If care is to be accounted for and legally enabled, legal practice must reflect that care planning is a relational activity, beyond that of naming a person as an attorney. It must allow the relationship and the support and information provided to become part of the decision making. Furthermore, ensuring full use of health and welfare LPAs could allow for a more relational stance to be taken in care planning, allowing for the often-assumed authority of family members to have legal force (Harding, 2017). Relational construction of future care planning is problematic as law limits family involvement.In the MCA, under section 4, family views must only be ‘taken into account’ (Harding, 2017). If law is to engage with and enable care planning, then health and welfare LPAs should be reframed to account for the relational aspect of care planning, and work with, rather than against, the ideas of people who are likely to use them (that is,

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[85] ONS figures show that from 1 October 2007 (when the MCA came into force) to 11 August 2014, 261,331 health and welfare LPAs were created. (Harding, 2017)

people with dementia and their families). Care planning, end-of-life planning, and the personal, experiential and moral immaterial factors influencing the experience of time (and hence planning for the future) do not match the legal actors demanded by law (i.e. presence of capacity). This may explain why health and welfare LPAs were presented less in these data and why end-of-life care planning was not spoken of in-depth. To enable people with dementia, law must recognise this incongruence and address this through a more relational approach to practice, as well as public policy campaigns to highlight the usefulness of such decisions. This would make them relevant to the relational aspects already present in people with dementia and their carer's construction of care futures.

Although legal plans are constructed as a financial tool, one that enables control over future financial scenarios, making a will and dividing assets enables a couple's financial control while valuing existing relationships (Finch & Mason, 2013; Woodthorpe and Rumblem, 2016). There is an inherent relational aspect to making a will or power of attorney. Enacting valued relationships by making a will, a couple gains a sense of control over the dementia and their future. Wills exemplify how legal decision making and future planning are inherently relational activities, regardless of law's construction of the autonomous individual. Financial plans contrast with care plans, as they are constructed as anticipatory; there is no moral 'right time', they are protective measures that offer control. This allows participants to act quickly within legal frameworks to exert control over the disruption of dementia. This may be because legal constructions and individual constructions of financial planning align when someone has financial wealth deemed worthy of protecting. Wills and financial LPAs aid in preparing for a fixed point in time; either death or loss of capacity. Interviewees construct financial planning similarly to legal time ––wills and financial LPAs temporalize a future where financial capacity might need protecting. Essentially, law and interviewees both construct financial planning as built upon a chrono-normative framework of time where they recognise and coproduce a future where a person is deceased or without capacity (Grabham, 2014, 2016). This co-production creates the legal document and the anticipation of a fixed future that needs protection (Freeman, 2010). There is no moral, incremental shifts required, as with care planning. The types of futures planned for and the way they are planned demonstrates how law encourages a structural binarism to life trajectories, one which does not align with care planning. Therefore, law is absent in care planning. This is an issue because the presumption of desired care and familial influence is not legally binding and desired care futures are at risk of being restricted by legal requirements.

People with dementia posit time and the future as sometimes morally dependant (the 'right time' to take actions); sometimes controlled (with financial protection), sometimes delayed (due to dementia), sometimes restricted (due to law and dementia) and other times entirely unknowable and absent, allowing interviewees to place themselves in the present and neglect the future. As Grabham (2016) states, time consists of multiple interactions between people with dementia and their multiple relationships with: other humans, neuroculture, the Eurocentric death society, the interaction with the immaterial idea of 'law', and the material documents required to make legal decisions (wills and LPAs). This means legal time does not allow for or enable people with dementia to plan for futures that do not align with its construction of time and future. My analysis shows how law must interrogate the multiple 'worlds (including legal worlds) material actors conjure or invite us to access through their conative actions' to enable better practice (Grabham, 2016, p. 27). For legal planning tools to be properly used and appeal to people, they must work to accommodate these multiple worlds and relationships with time. Legal documents demand a certain attention to time, but this attention does not yet account for the multiple actors within a person's time and does not allow for the moral importance people with dementia and their carers place within time. LPAs and wills are constructed as perhaps what Grabham (2016) refers to as 'mobilising' time, they may act like catalysts for some future planning (Financial LPAs, wills), but given the lack of congruence between care planning constructions and legal plans, there is a reduction of potential usefulness.

In theme three, the future is constructed as delayed, or entirely unknowable. The disruption of dementia results in the absence of future planning for some. The lack of agency acknowledged by interviewees to carry out previously held plans, if following structuration theory, removes the ability to actualise the desired future. In short, though a future is referenced and pre-diagnosis plans cited, actual plans and futures are avoided. Stock phrases like 'one day at a time' allow participants to resist the concept of the future with dementia. This rhetoric exists within the relationship where dementia has become an unwanted third party, the legal domain is not present, and legal decisions made do not factor in their construction of the delayed or disrupted future. The absence of held futures gives insight into the society in which interviewees exist and with which they interact. Talking about a future with dementia is not conducive to a society that values the healthy brain and locates death and dying outside of the home. The commercialization of death-care has led to a shame and distance from comfort, intimacy, ritual and discussions of death and dying in Western society (Doughty, 2017; Mohammed, Peter, Gastaldo & Hoqwll, 2020;

Walter, 2017) .[86] Health and welfare LPAs could be used to include instructions dealing with factors such as funeral arrangements and care plans.[87] Law could enable individuals with dementia and their carers to have more agency and control over an unpredictable future, but it must first be recognised and publicised as helpful for this purpose. The issue of death culture in the UK is one too large to address fully in this thesis, but one possible way to address the problems with UK death culture may be to ensure that people making LPAs and wills (which are relatively well known in comparison to ADRT's) are made aware of the full extent of instructions possible through such documents. This may begin to enable conversation about end-of-life decisions for some individuals.

Interviewees express interest in the potential for assisted dying at the end of their lives and propose death as a relational event. However, in the UK, any kind of relational involvement in enabling or assisting someone to access assisted dying could result in a murder charge carrying a 14-year prison sentence.[88] This delineation between murder and assisted dying is fraught and highly contentious, even in states where assisted dying is legal (for certain population groups). Medically assisted dying is illegal in the UK, and in addition to this UK end-of-life planning tools are restricted by the regulatory frameworks guiding them. It is problematic that death and the dying process are not viewed as relational by the legal mechanisms helpful in planning such an event. Regulatory frameworks, such as the MCA

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[86] See Foster et al (2019) for an in-depth analysis of the lack of UK government policies that address death and dying, and how those that do result in inequality in death and dying (particularly in relation to funeral cost inflation and minimal distribution of financial assistance through the Funeral Expenses Payment).

[87] In a 2005 poll of 1,027 people showed that 67% of those aged over 65 years had prepared a financial will, whilst only 8% had completed an Advanced Care Plan document of any kind.

[88] https://www.cps.gov.uk/legal-guidance/suicide-policy-prosecutors-respect-cases-encouraging-or-assisting-suicide

and end-of-life approaches place value on the present dying individual.[89] Therefore, the dying person is detached from the relationships that have given meaning and value in their previous lives, as well as their previous self who held beliefs and wishes regarding their end-of-life. This is a conundrum which I cannot address fully in this thesis, nor do I believe I can argue for or against assisted dying based on my findings. However, death is a social and relational phenomenon, and to properly enable people with dementia to die without disadvantage means changing the regulatory frameworks relating to how planning for death is allowed and how social actors treat their dying process (Borgstrom, Ellis & Woodthorpe, 2019; Peel & Harding, 2015). To summarise, Borgstrom et al (2019) state, 'The end-of-life, as with all phases over the life course, is thus not simply a series of individual experiences, choices and responses; it is something that is creatively enacted between people' (p. 1128). Law must simply acknowledge and enable relational reality in practice. Debates will and do continue where states have and are considering legalizing assisted dying for people with psychiatric disorders and/or dementia. Currently, people with late-stage dementia who have not made an advanced decision about their death, are essentially without access to assisted dying globally, apart from the minority of cases cited in Belgium.[90,91] To properly respect the rights of this population group we must listen to their wishes and seek ways to enable the control desired at the end of their lives.

Newtonian laws and linear interpretation of time are not helpful for people with dementia, nor conducive to time, which is influenced and constructed from materiality, morality and

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[89] This excludes palliative care which is largely inaccessible to people with dementia due to the proposed 6 month pre-death time period in which palliative care is prescribed.

[90] See page 214 of this chapter for the discussion of Belgian euthanasia law.

[91] Medically assisted dying is available, with restrictions, in Switzerland, Netherlands, Belgium, Luxembourg, Canada and Columbia, some USA and Australian states and Spain. See https://www.bma.org.uk/media/4402/bma-where-is-pad-permitted-internationally-aug-2021.pdf for a comprehensive map of assisted dying legality and progress globally.

meaning (Beynon-Jones & Grabham, 2018). Interviewees place a moral weight on 'the right time' to make changes and achieve futures. LPAs place a similar emphasis on deciding 'at the time it needs to be made'. Nonetheless, possible decisions are limited and constrained. Firstly, people are constrained through law's linear perception of time and the binary construction of a person with or without capacity (and hence agency), to actualise a future which is anticipated and possible. Secondly, the illegality of assisted suicide or euthanasia restricts perceived rights and control desired at the end-of-life. This second point is reflected by interviewees' acknowledgement that 'the right to die' is not enabled through medically assisted suicide in the UK, and if desired they would have to travel to 'Dignitas' (a financial cost not feasible for some interviewees, regardless of capacity to travel and consent).

The value placed on activity and maintaining agency in later life is partially due to the neurocultured society of the UK, but also the more global rhetoric of 'active ageing' (Romaioli & Contarello, 2019) .[92] There is the expectation that agentic individuals live productively (and conform to hypercognitive ideals), while those who cannot meet this expectation are dependent (Romaioli & Contarello, 2019). In theme four, the discourse of the dependent body is relevant.[93] The discourse of shameful body and bodily integrity is used to reason for wishes for ending life at 'the right time'. The 'right time' is often constructed as a time prior to an unacceptable breakdown of bodily integrity (Street & Kissane, 2001; Tagney, 1996). The moral equation evident in care planning is reflective of neuroculture and larger discourses on health and illness, whereby illness affects personhood

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[92] WHO used this term in their 2002 Policy framework and it continues to be used at time of writing by the organisation, as well as being used globally by national organisations and health institutes

[93] See chapter 4 for an overview of the dependent body

to the extent of damaging and invading a person’s agency(Sontag, 2001). In this chapter, the presence of dementia invades the relational and future-oriented planning of the interviewees, preventing agency and removing control to actualize desired futures.

Dementia is not the only barrier for persons actualizing their futures. As highlighted in theme four, interviewees express a desire to exert control over the point of death but acknowledge that legally this is not possible in the UK. The British Medical Association (hereafter BMA) guidance on potentially legalizing assisted suicide included the criteria that all adults accessing assisted suicide must have mental capacity, possibly because their survey is the result of consulting BMA members (British Medical Association, 2020). Debates must continue and include people with dementia to ensure their desires are accounted for in any progression in this legal landscape. Moving outside of the UK context, in Canada recent legislation means people with dementia can only access assisted dying at the early stages of the disease, and even then, where an advanced request has been made. If the person at the point of administering medication refuses or expresses opposing wishes these will be upheld in contradiction to the advanced request to access assisted dying (Bravo, Trottier & Arcand 2021). Belgium is one country where euthanasia has been carried out for people with late-stage dementia, but these cases are fraught and doctors are reluctant to carry out euthanasia on persons with late-stage dementia (Bolt, Snijdewind, Willems, Van der Heide & Onwuteaka-Philipsen, 2015). Requests for euthanasia in Belgium from people with dementia (rising from 12 requests in 2009 to 162 requests in 2019), shows the urgent attention needed to this ethical question (Jakhar et al, 2021). These figures do not indicate the number of authorizations, but given that only two of these requests were made by people with late-stage dementia, it is still highly unlikely for people with late-stage dementia to be able to access euthanasia in this state, which has one of the longest standing histories of legal euthanasia (Jakhar et al, 2021; Van Den Noortgate, 2021).

Legal actions in the UK can include ADRTs, a medical statement in which specific scenarios are predicted and understood by the individual and treatment options are specifically addressed. When asked in interviews, one couple had heard of ADRTs and one couple, although they had not heard of these, had made a living will document. Internationally, fewer than 40% of people with dementia make any advanced care plan (Sellars et al, 2019) and in the UK only 5% of the population report making any kind of advanced end-of-life care plan (Shucksmith, Carlebach & Whittaker, 2013).[94] The lack of knowledge and clarity is evident through the construction of the improbability of rights-based end-of-life plans and lack of awareness of the range of decisions which can be made. Furthermore, there is a contrast between the negative action of refusing treatment (legal in the UK but undiscussed by interviewees) and the positive action of completing suicide or seeking euthanasia (illegal in the UK but constructed as an ideal plan by interviewees). This is where policy and debate need to recognise the difference between allowing death following a lack of medical intervention and the idealised active participation and decision to end life. Peel and Harding (2015) highlight the example of Sandra Bem, who completed suicide citing her dementia diagnosis as a reason. For people with dementia, choice for end-of-life is only a possibility in the current interpretation of the legal framework as being taken through pre-emptive decisions, such as premature suicide, before reaching the stage that the person wishes not to be alive. The disease's progressive nature, coupled with law's insistence on capacity,

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[94] Medical practitioners also demonstrate a lack of awareness of the different types of end-of-life decisions legal in the UK, as well as a reluctance to carry out advanced decisions made by someone with dementia.

places people with dementia in a disadvantageous position for end-of-life planning and the consequences of such can be seen in the case of Sandra Bem. In these data, interviewees describe the impossibility of planning for a future at all and choosing a ‘right’ time to die and accessing the ‘right to die’. Some explanation for the dilemma of the ‘right to die’ and the debate surrounding it can be understood when looking at the general legal position;

> ‘According to the European Court of Human Rights (ECtHR) in Strasbourg, an individual has the right to decide how and when to end his [sic] life, provided that said individual is in a position to make up his own mind in that respect and to take the appropriate action. There is, however, no legal obligation on EU Member States to provide the means to enable a person to take their own life, nor to assist someone to do so.’ (Peel & Harding, 2015, p.138)

Given the insistence on the individual agency required to complete the act of suicide, as well as the position of capacity (make up his own mind), one can see why dementia has thus far been excluded from UK debates regarding legalising assisted suicide and is difficult to access in countries where assisted suicide and euthanasia is legal. These data contribute to the argument that there must be a more nuanced understanding of rights, death, and dementia to tackle the issues faced and create policy that reflects people with dementia’s equal status as legal actors and respects their rights (Hayes, 2021; Wright, 2019). This understanding shifts focus away from suicide towards enabling a person’s agency and control in their end-of-life through all means, including legal decision making. I cannot, based on these data, make a strong argument that all persons with dementia desire or should have access to assisted suicide or euthanasia. However, it is clear that people with dementia feel unable to plan for and exert control over their end-of-life stage, and focus on the instance of death, rather than the process of dying and how and where they would like this to happen. Viewing dementia as a terminal illness may encourage palliative care planning to become a more widely used instrument for those with dementia. Musa et al. (2015) found in their survey of people over the age of 65 that the most crucial predictor of completing an advance statement or an ADRT was being offered the opportunity to discuss the issues in the first place. Framing dementia as a terminal illness may enable clinicians to propose end-of-life and palliative care plans. In this stage where there is debate about a right to die, we need to use advanced care planning to its absolute maximum benefit for people with dementia (Kitzinger, 2015; Peel & Harding, 2015; Harding, 2017). Indeed, a systematic review of largely USA based studies shows that, generally, using advanced care plans is associated with better end-of-life experiences (Dixon, Karagiannidou, Knapp, 2018). We must recognize their importance and further research how we can encourage their use in the UK and therefore improve people with dementia's end-of-life experience.

Conclusion

This chapter has shown that people with dementia and their carers use different interpretations of time and future for different types of planning. I have identified how time and agency are essential for people with dementia when making (or not making) future plans. The care planning gap could be addressed by better understanding and engagement of health and welfare LPAs. By making care plans and using an LPA, interviewees could increase their sense of agency and control over the unknown future, addressing issues raised by themes three and four (Birchley et al, 2016; Hawkins, 2015). Rights-based plans were differentiated by the acknowledgement that, to some degree, this future is unlikely. This theme demonstrates the discord between legal options for end-of-life care in the UK and the desire to access end-of-life rights for people with dementia (with a mixed understanding of what these rights were and if they were or were not legal). The data in this theme raises concerns about suicidality among people with dementia, end-of-life care options available to people with dementia, and how rights are perceived as enabled or actively disabled by the state. The ongoing debates around assisted suicide legalisation in the UK must acknowledge people with dementia. Additionally, we must seek to address the discord between the use of legal planning tools and people's desire for control. Achieving some harmony between what people wish to control and what is legally available and used may make future planning more accessible for people with dementia and their carers.

Chapter 6: Capacity in practice, findings from observations of a solicitor and their client

Introduction

In this chapter, I use CA to understand how capacity is constructed in practice in a solicitor's office with clients, and how these constructs relate to themes of capacity discussed chapter 3. Here, legal decisions and concepts of capacity are de-constructed by paying close attention to the conversation in which the legal decisions are co-produced by the client and solicitor. As discussed in chapter 3, CA allows for an in-depth, micro-level analysis, resulting in the long extracts used in this chapter. With these longer extracts, attention can be paid to the minutiae of talk.[95] There are two main themes identified in this chapter: 'Clients presenting information as knowledge' and 'Statements of legal obligation'. Both of these themes pay close attention to capacity. Overall, this chapter shows how epistemics play a vital role in this institutional interaction.

The solicitor has a social role of authority and possesses superior expert epistemic rights. Meanwhile, the clients have superior experiential epistemic rights (Heritage, 2013b). There is a balance to be navigated around who has the right to assert expertise and when, and how this is and is not conducive to a successful interaction (Lehtinen & Kääriäinen, 2005; Lindström & Weatherall, 2015). As stated in chapter 3, there has been little (if any) interrogation of this dynamic between solicitor and client, therefore I draw from medical interaction research (Lindström & Weatherall, 2015). There are similarities between the power dynamics at play, however my data presents a unique social situation. The solicitor's role differs from the role of a medical practitioner; their status is reliant on adhering to

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[95] The extracts here may have long gaps and hearable 'writing noises' have been transcribed to indicate where a long pause may be explained through non-verbal actions in the meetings.

legalities and making clients aware of them. The testamentary capacity assessments occur through and within the conversation. Testamentary capacity follows the *banks v goodfellow* test and the subsequent 'golden rule'.[96,97] In combination, these stipulate that capacity is potentially affected by age and mental disability/mental health, but not solely dependent on either.

In section two I show how the solicitor draws attention to the relevance of capacity, while not explicitly assessing capacity. The subtleties captured by CA give new insight into how capacity assessments happen in legal practice. A comprehensive review of guidance for capacity assessments has shown the practical 'doing' of the capacity assessment is left un*prescribe*d by law. Due to capacity being time and person-specific, there could be significant issues in creating a definite step-step assessment of capacity to make a legal decision, as stated in chapter 1, psychological assessments of capacity have their faults.[98] In both the themes interrogated in this chapter, there are notable absences which have been observed in medical settings and counselling settings to assess clients/patients, while adhering to institutional roles. These data only come from one solicitor (though their approach to each client's capacity differs), therefore I approach the data as a limited dataset. The multiple approaches and clients prevent this dataset from being labelled a case

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[96] Testamentary capacity refers to a client understanding; the act of will making, the amount that can be and is disposed, and the consequences of this decision. Additionally, 'no disorder of the mind shall poison his affections, pervert his sense of right, or prevent the exercise of his natural faculties' (per Cockburn CJ).

[97] 'The making of a will by an aged or seriously ill testator ought to be witnessed or approved by a medical practitioner who has satisfied himself of the capacity and understanding of the testator, and records and preserves his examination or findings' (per Re Simpson [1977] 121 SJ 224)

[98] I reviewed 90 information and guidance web pages for capacity assessments, including the MCA code of practice, as well as multiple solicitor firm and law society guidelines and YouTube videos from law firms. None contained a prescribed way to assess capacity (some use hypothetical fictional scenarios to highlight potential good practice). Instead, they give advice on how to enable capacity, and what 'lacking capacity' may present as. Neither testamentary capacity nor the mental capacity act provides strict guidance on the practicalities of how to assess capacity. For a full list see appendix R.

study, but as stated in chapter 3, further research is needed with solicitors to ensure all different practices are captured.

Clients presenting information as knowledge

This section shows how clients work hard to demonstrate their epistemic value in the meeting where the solicitor is the authoritative professional. I have selected one extract from each of the client's meetings that best exemplifies the phenomena, and I use CA to show how the clients work to increase their status using various methods. Clients can increase their epistemic primacy through physical presentations of information: 'SO: do you have anything of any value… CL: well I mean (presents rings on fingers)' (Clara), 'so that's a bill with our address on' (Alana). Also, clients provide personal information to assert their knowledgeable position: '(on full names) it's just that we always call ourselves Nas and Flor yes although for example I always sign as Flora' (Flora). I also examine how this can sometimes cause trouble in the conversation, evident through a subsequent challenge of the information or presentation by the solicitor: '(on council tax bill for ID check) AL: that would be in my name… SO: no… it should have both of your names on the council tax bill' (Alana). The solicitor often has to work hard to move the topic forward after a disaffiliate sequence.

The single instance where a client makes a strong epistemic claim through disclosure of personal knowledge and successfully maintains the relevance of said knowledge is with Flora and Nasirah. Flora is explaining why she wishes to change the executor of her will.. She refers to her brother's previous status as a senior legal professional, and the solicitor's mutual knowledge of his reputation among the legal community. Flora uses a disclosure of potentially shared knowledge (of her brother's status), which can bridge the gap between knowledge through experience (in this case family relation) and knowledge of expertise (the family relation is a retired solicitor). This instance is unique but worth mentioning to demonstrate how displays of knowledge can work in favour of the client and receive little rebuttal from the solicitor. In the following extracts (and the rest of the data), displays of knowledge by the client, though necessary for the task, were often a source of trouble, as I discuss below. In my analysis I pay close attention to pitch, overlapping talk, and emphasised syllables.

Clara is the only client who requested to attend the meeting alone, without the accompaniment of her son's partner (to whom she refers to as her daughter-in-law). Clara is hard of hearing and in a wheelchair. She states that she has no mental disabilities. In the first meeting, Clara is initially hesitant to accept the solicitor's request that she be alone for the meeting, and it is her son's partner who initially provides all the paperwork for the solicitors.

Extract one is at the start of the second meeting with Clara. This is after taking home the written advice of the solicitor and the solicitor making it clear that, during the first meeting, she was unsure of Clara's capacity to make the will she described due to her recent bereavement and emotional state.[99] Clara returns just over a month later, and still wishes to make the same will where her daughter is excluded. Clara has stated that she and her daughter (who lives overseas) have 'never got on' and it is her son and daughter-in-law who have cared for her. Her daughter would, in Clara's words, 'just put me in a home'. Clara repeats her sentiments toward her daughter throughout both meetings. She makes it clear that she does not want her daughter to benefit from her will and articulates her reasoning

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[99] See extract 6.3, pages 234-235 of this chapter

for this. The solicitor offers some comments on the decision, such as: "she might change". The solicitor goes on to state the fact that, in her husband's will, if he had died after Clara, all money would be split equally. The solicitor must ensure that this is the client's own decision, but she also has a duty to reduce the likelihood of the will being contested in court. This contextualisation is relevant to this extract as it foregrounds why this repeated request for information may be a question of capacity, and why Clara works hard to claim her epistemic status in this sequence. The analysis focuses on the minutiae of the conversation, and the broader context informs the overall analysis and purpose of what is otherwise an odd interaction.

Though Clara does not have a mental disability or dementia, this extract gives insight into how professionals speak to people with questionable capacity where abnormal conversation practices occur. In the initial meeting, the paperwork provided was insufficient to determine Clara's estate and she mistakes the name of her bank for her husband's bank. In this initial meeting Clara is clear about what she wants to leave and is sure of what funds she has. In the second meeting, the solicitor, despite having already taken all of Clara's details and family history, asks to retake her details for the new will she is writing up. This is interactionally odd, as both Clara and the solicitor already have access to this information. This may explain some of the difficulties in the following extract. It is worth noting that the reason behind this may be to check Clara's capacity to make the will and so she is checking her knowledge of basic details which should be in her epistemic domain. I will now demonstrate how Clara takes this opportunity to demonstrate her utility, knowledge and capacity:

Extract 6.1

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Extract Start: 00:06:17
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Extract length: 00:01:04

Pseudonyms:

SO: Solicitor

Cl: Clara

SO: .hh righ:t=>can we take< som:e (0.3)
basic [infer]
Cl: [>sorr:y<]=
SO: =↑no don’t keep
a↑p:ologising.
(0.3)
SO: some basic in:form:ahhtion from you:
again=>cause I’m gunna< star:t it
<again>?
SO: .hh (.) so- y:our: full <na:me>.
(0.6)
Cl: Cla:ra Moor.
(0.2)
SO: No: mi:ddle na:me at all.
Cl: no.
(0.5)
SO: ahhnd your date of bhhi:rth.
(0.9)
Cl: twhhenty sehhcon:d (1.1) te:nth: (0.5)
for:ty three.
(0.7)
SO: and your: a:ddress:.
Cl: .hh un:dred seven, (0.6) Ihhp:swi°sh°
Roa:d,
(0.8)
SO: y:ehp.
(1.2)
Cl: Nor:th >Green:wich:<,
(0.3)
SO: yehp.
(0.3)
Cl: >>A three<< one (0.6) four G M.
SO: °.tch .hhh° ↑do you know your
tele↑p:hone num:ber there.
(1.0)
Cl: four oh- (.) owh (.) oh:
(0.3)
SO: w-oh four three four.
Cl: yeh four oh one (0.6) s:>even< nine
five four.
(0.2)
SO: lovely: .hhh (2.2)
Cl: s:e[e I k]now
SO: [>and you-<]=

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45   C1:                   =all: tha.
46   SO: °↑y:eah:↑° >>no: ↑no no no↑<< (0.3) e-
47       (0.4) a::bs:olutely fi:ne.=.hh
48       (0.5)
49   SO: >h:ow many< chil:dren have you (0.3)
50       h:ad.
51   C1: two.
52   SO: >you've< o:nly >ever had< two
53       °children°.
54   C1: yeh.
55   SO: oh:kay.
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In line 1 the solicitor presents a new topic, ‘right’, and latches the question to swiftly move the conversation to the business of taking ‘basic information’. This follows on from the previous conversation where Clara asked the solicitor and the researcher in the room to pass judgement on her daughter’s recent behaviour (an institutionally inappropriate topic of discussion). On line 2 the solicitor emphasises the ‘basic’, signifying its relevance to the meeting. However, the strength of the topic shift makes it clear that Clara's previous sequence was inappropriate. This causes Clara to interrupt with a quick, elongated 'sorry'. The solicitor latched her turn at line 4 in a high-pitched voice, then produced a directive to Clara: ‘don’t keep…’. This is softened by the higher pitch and immediacy with which it is produced. In line 6 there is a pause. Clara is not *asked* to stop apologising, she is *told*, so only a minimal receipt would be appropriate. Additionally, the request at lines 1-2 was incomplete. As the client in this setting, Clara, through her silence, is deferring to the solicitor’s authority to continue with the new task and complete her request, which she does in the following sequence. The solicitor reproduces the initial turn in line 2, emphasising the ‘basic’ but inserting an explanation of why the activity is being repeated here. Importantly, the solicitor places the reasoning on herself, ‘I’m gunna’, not the client; initially avoiding any epistemic degrading of Clara’s position to give this information. The rising intonation in the word ‘information’ at the end of this turn indicates that the solicitor, though not syntactically, uses pitch to invite a response from Clara, which is not given.

The solicitor then begins taking Clara’s basic information. In lines 10-30 we can see Clara giving her information to the solicitor. The solicitor checks the legitimacy/accuracy of her answers through follow up questions (line14) and offers no verbal receipt of the information. This interaction is like a teacher-student interaction, where the teacher asks a question to which they already know the answer but expect the question to be taken seriously by the student and for them to provide an answer (Seedhouse, 2005). The questioning in line 14 is done through a declarative question, with Clara's preferred answer of ‘no’. This somewhat lessens the solicitor's checking the information that belongs in Clara’s epistemic field is correct (Clara ‘should’ know if she has a middle name, it is information that belongs to herself not the solicitor). Through her affiliative response on line 15, using the preferred answer, Clara aligns to the notion that this information is within her epistemic field, and she is competent and able to give it.

In line 26, after giving the date of birth and part of her address, the solicitor does offer a verbal confirmation of having received the information and a continuer, legitimising Clara’s position as the epistemic authority. However, this comes after several pauses where no confirmation is given. In line 33 the solicitor asks the client if she knows her phone number in a high-pitched voice. Despite the previous competency displayed by the client in producing information, the solicitor again questions her knowledge by asking: ‘do you know. This is followed by a 1 second pause at line 35, signalling trouble with the question posed. Clara then struggles to complete the request in line 36. She answers by beginning to say her phone number, demonstrating she does know it, but doing so with some difficulty, evident through the pauses and cut off syllables. The solicitor offers a correction (line 38) in her following turn by initially offering the area code, Clara then replies. Despite initial difficulty, Clara produces her telephone number in response to whether she knows it, showing through her response that she can provide it.

Clara is working hard to construct her turns to demonstrate her knowledge, ability, and her epistemic right to this information. In line 42 the solicitor gives a positive receipt of the information. The solicitor does not offer a topic-closing utterance, and the silence leads Clara to insert into the project of collecting basic information, a statement of her knowledge (lines 43-45). Clara places emphasis by elongating ‘see’ and ‘all’, where the ‘see’ acts to invite praise or confirmation of the receipt of the amount of information she has given. Clara’s emphasis on ‘all’ also strengthens her epistemic stance, explicitly stating that she possesses ‘all that’ basic information, which is her epistemic right. The specificity of ‘that’, regarding the request for basic information, also works to demonstrate Clara’s right to knowing information about herself (and placing ‘other/legal’ knowledge outside of her epistemic domain). In lines 46-47 the solicitor offers a troubled (multiple pauses), affiliative response. However, due to the pauses, multiple repetition and high pitch, though sequentially affiliative (agrees to the previous statement by Clara), the way it is uttered proposes there is trouble in agreeing with the statement. Additionally, in line 47, the solicitor offers a neutral comment of ‘absolutely fine’, receiving no response. The following sequence shows that the solicitor continues the project of collecting basic information. Again, on line 52-53, she checks information that Clara has previously stated she has a strong epistemological right to know. Clara’s demonstration of her own knowledge in the previous sequence, followed by her explicit statement of it, does not work to reduce the solicitor’s checking. Lines 52-53 work as a declarative question, which the client answers with preferential agreement.

This extract shows how the client can work very hard to demonstrate their knowledge and increase their epistemic position in the conversation. However, the solicitor can maintain their epistemic superiority, not through the social status of ‘being the solicitor’, but by checking information that belongs to the client and consistently questioning and offering few receipts or positive acknowledgements of the information. The function of this sequence is concluded by line 55 and the basic information is collected. Although the client is demonstrating knowledge throughout, the solicitor’s atypical, non-verbal receipt of information could be construed as checking the client’s ability to retain information; a condition of capacity as set by the MCA.

Similarly to extract 6.1, extract 6.2 demonstrates the client’s use of physical presentations of information to demonstrate their knowledge of their personal affairs and legal choices. However, unlike extract 6.1, where the knowledge belonged in the client's domain, this extract shows how the solicitor can challenge a demonstration of knowledge if it pertains to the legal domain. Within this domain, it is within the solicitor's epistemic rights to make such a challenge, as her role is that of an expert on legal matters, whereas the client's role is that of an expert on personal matters. This extract is from the beginning of the meeting where the solicitor establishes what the clients wish to discuss. The clients have previously spoken about why they have chosen this solicitors firm. The extract begins when the solicitor starts the new topic of establishing what decisions have been made previously and why they have decided to change these now.

Extract 6.2

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Extract Start: 0:02:51
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Extract length: 0:01:09

Pseudonyms:

SO: Solicitor

SA: Solicitor's assistant

Al: Client, Alana Jean Bryce (wife of Stuart)

St: Client, Stuart Andrew Bryce (husband of Alana)

1

SO: S:o (.) you've had a will made
↑bef:ore↑.
AL: .hh [ye:s]
SO: [I c][an ↑see↑]
ST: [we have] (.) ye:s.
(2.1) ((paper/writing noises))
AL: in two thousan an eigh:t ↑.h(h)u h(h)u
.h(h)u-↑
SO: °ok:ay° sometimes >we look at them<
(.) £.hfrom nineteen seven:tyhh
[.hy(h)eh]
ST: [yeh.]=
SO: =£so: um£
(0.8)
ST: °ri[:ght°]
AL: [s:'in:th]ere's a
fe[w things that (have)]
SO: [SO THAT'S YOUR:S] (.) have you:
got your[:s as well?]
ST: [yes °I've got°] mine as well.
(0.2)
AL: [the things tha-]
SO: [↑whhooh↑] MY: goodness .hh
AL: u-
SO: s:omebody's mar:ked thee ↑.h(h)u
.h(h)u hh £ori:[ginal£]
AL: [the pink]
(0.2)
AL: n- TH[at's]
AL: [yeh]
ST: yeah.
AL: NO: >that's:< (.) >what's got to be<
cha:n:[ged]
SO: [I]IKN(H)O(H)W £but >this is
an< original [copy£]
AL: [OHW] RI:GHT
[S:ORRY]
SO: [(that's alright)]

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AL: that’s mine mine hasn’t bin
    mar:ked=
SO:         =o[kay   ]
AL:           [so:rry]
SO: no it doesn’t matter=if you were to
    die:=
AL:      =yeh=
SO:           =now:: (0.4) um be:for:e
    you’d signed your new will.
    (.) ((paper turning sound))
SO: this will would be effect:iv[:e.]
AL:                             [ oh]w
    r[ight yeh-]
ST:  [   yeah: ]
SO:  [   okay  ]
ST: [ri:ght]
SO: [ u:m s]o the fact that you’d actually
    (0.2) high:ligh:ted it (0.9) °>we:’d
    have to do a sta:tement to say why:
    you’d highlight[ted it°<]
ST:                [  yeah  ]
    [no thas ]
AL:                [  ohw   ]
    [right oh]:kay?
SO: okay >but it’s< [  its  ]
AL:                 [>sorry<]=
ST:                           =yeah: no
    >its no it’s< fi:ne=
SO:                     =>>doesn’t<<
    >doesn’t< inva>lidate it< because yu
    can still: read what’s
    un[derneath][(h)£.hh hh£]
AL:   [  yeah  ]
ST:             [    yeah   ]=
SO:                           =bu[t so
      ]
ST:                              [don:’t
    do] that next time.
SO: °uh.h(h) [.h(h)u h(h)u°]
AL:          [°m(h) h(h)m° ]
SO: £.HHH£ um: (0.4) goo:d well you have
    (.) >actually< revisited your will a
    lot sooner than many people.
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The solicitor begins the sequence through a declarative question, made clear by the increased pitch on the final word and rising intonation in the middle of the word 'before'. The declarative format presupposes the need for a rising intonation at the end of the turn.

The solicitor uses this declarative question to confirm that the document presented is a will. She makes the physical presentation relevant to the purpose of the meeting. On line 3, Alana gives the preferred affiliative response in overlap with the solicitor's confirmation on line 4. Through this confirmation she increases her status in the meeting; the declarative question is lessened to a statement of knowledge in her follow up utterance. The solicitor goes from checking that they have made a will before, to stating that she knows they have. This is a strong epistemic stance to take, claiming knowledge that belongs to the clients, and sharing it with them through the presentation of the document. This prompts Stuart to return to answer the initial query in lines 1-2 in overlap, by producing the affiliative response of: 'we have yes'. Stuart places the action (having made a will), and knowledge, in their plural relational domain. The clear end of turn marker, after yes, emphasises this affiliative, positive answer.

In lines 1-5, the solicitor initially produces a declarative question, which the clients answer as such. Then, she moves to strengthen her epistemic primacy by changing the utterance to a statement in post on line 4. However, as this is done in overlap, and is regarding information in the clients' domain, the clients still answer the question, equalising the epistemic field. All parties have access to the same knowledge, because the clients have allowed it through presenting the document. In line 6 there is a long pause with writing sounds. This extended silence while the solicitor writes (evidenced through field notes) is followed by a depreciative comment by Alana on the will Alana emphasises the date when the will was made. This is followed by laughter, which minimises the credibility of Stuart and Alana's previous will, and their 'legal' status for having made it. The solicitor does not affiliate with Alana's negative statement about the will or themselves; it would be atypical to do so given that an agreement with a negative self-statement could result in negative consequences for the following conversation and meeting. Instead, the solicitor offers an alternate scenario to demonstrate the clients' wills' superiority over others.

In line 16, Alana proposes a new topic after the sequence closing 'right' by Stuart. She refers to the current will, emphasising the 'few'. This signals multiple elements which need to be discussed, and her knowledge of these elements prior to the solicitor asking about them. There is discord and overlap in the following sequence, as Alana and the solicitor pursue different topics. The solicitor interrupts in a loud voice with a declarative: 'that's yours'. After a micro pause, she follows this up with an explicit question, asking if Alana has brought/got her will as well. Alana is highlighting what it is that needs to change in the current wills and works towards the broader goal of the meeting (making a new will). Meanwhile, the solicitor is working towards establishing all the relevant information (a pre-requisite of her being able to draw up the new will). This creates a fissure in the conversational flow, and overlap continues throughout the sequence as each participant attempts to assert dominance to pursue their individual goals.

Alana begins to reformulate and restart her project on lines 22, 29, and 32-33. In line 23, the solicitor asserts herself as superior in the meeting through the 'oh' surprise token (Wilkinson & Kitzinger, 2006) and exclamation, signalling something is wrong. This is followed by high-pitched laughter particles and a smiley voice in lines 25-26. In this disfluent sequence, the solicitor indicates that marking the original is not a positive action, and her knowledge of this means she has superiority in the epistemic field. The solicitor, being the only one party to this information, is in a K+ position, and has managed to assert her dominance (Heritage, 2012a; Heritage, 2012b).[100] Also, she does not acknowledge Stuart's answer to her question and speaks in overlap with Alana. She highlights her role as the legal professional and the clients' lack of knowledge through the exclamation at the marking of the will.Alana's acknowledgement of marking the document and subsequent explanation evidence this, there is clear evidence of discord as the laughter and smiley voice are not matched by Alana.

On line 32, Alana starts her turn with the loud and extended 'No', strongly asserting it is her turn to speak and offer an explanation on the reformulation of her project, 'what's got to be changed'. She does not align to the solicitor's appraisal that marking the will is wrong, but instead offers an explanation to demonstrate why it is relevant. The solicitor interrupts with the loud 'I know', continuing her volume from her previous turn and with laughter particles in the 'know'. This indicates that the explanation given is not sufficient to change the issue. The Solicitor's strong claim of knowledge about something which they does not have the clear epistemic right to claim is followed by explaining the issue, which though she has stated has not yet been affiliated to as an issue. She does so in a smiley voice which is not matched by Alana's reply of understanding and emphatic 'sorry'. This is not conducive to the meeting's purpose. The different forms of knowledge, legal and personal, make for poor epistemic brokering and creates friction in the conversation (Raymond, 2014).

In this epistemic struggle, Alana attempts to concede by offering her own reason for marking the will. However, this is not accepted by the solicitor, which leads to the 'sorry' at line 42. How Alana replies, in a loud voice and in overlap, works to reduce some of the

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[100] K+ refers to Heritage's epistemics framework, where people can claim to have a positive right to knowledge (K+), and interactionally make their claim to know with a strong stance. This forms part of the 'epistemic field', where parties can either have a K+ position or a K- position. The field can be equalised when people with K+ impart knowledge to people in the K- position.

epistemological downgrading done by the solicitor’s rebuttal and works similarly to statements of not knowing. Alana has stated her reason for making the original clearly, but this is insufficient, so she has had to apologise. Her emphatic apology also draws attention to the fact that the solicitor is referring to legal information not in Alana’s domain, and thus she should not be expected to know this. This reflects Raymond’s (2014) work, which shows the issue of presupposing common knowledge that belongs to the expert, and thus the expert can risk undertelling or patronising the non-expert. In this extract, the undertelling is addressed in the following dialogue by the solicitor, giving further, detailed explanation. However, Stuart complicates this by returning to the issue of Alana’s lack of knowledge at 75-76. Stuart’s admonishment is somewhat inappropriate for the setting and is treated as semi-serious by the solicitor who produces laughter which Alana reciprocates. The sequence closes, after much difficulty, with the solicitor giving praise and using a comparison to other people to emphasise how legally savvy they are.

This sequence shows how presenting physical information is not always beneficial to the client’s knowledge demonstration. The solicitor must validate the knowledge as relevant and useful for the client to maintain epistemic equality. Here, the physical presentation of knowledge and the pursuit of different tasks create discord in the conversation and enforce an epistemological imbalance. As a result, both solicitor and client are attempting to increase their status in the conversation. But, as the knowledge is deemed to belong to the legal domain, the solicitor maintains her epistemological superiority. Her knowledge of the will and its marking is maintained as relevant, while the clients’ knowledge of the will and why it has been marked is deemed to be irrelevant.

The solicitor’s role here is to create a new will according to her clients’ will and preferences. She also has a responsibility to ensure the legality of such documents. In this sequence these two tasks conflict with the clients' demonstration of their knowledge and wishes. The client attempts to demonstrate knowledge through physical presentation of what they want to change in the will, but the solicitor is privy to legal knowledge which means the physical presentation is troublesome. The clients' epistemic primacy is challenged through interruptions, exclamation, and laughter. However, none of this is matched by the client, demonstrating a discord in the conversation which is only resolved when the client apologises and states a new understanding of the issue.

Extract 6.3 is a contrast to extract 6.2. The presentation of the previous wills acts as a physical demonstration of what is helpful to make a new will. This, combined with the deference to the solicitor's authority, means the sequence of conversation is fluid and ends quickly with the epistemic balance maintained. I have chosen to include this extract to show the importance of the social environment when claiming epistemic primacy or demonstrating knowledge on a topic. The solicitor works to gain information not in her epistemic field and uses the opportunity to check for aspects of capacity (as seen in extract 6.1), whilst maintaining her epistemic superiority of legally relevant knowledge. This extract shows that a straightforward demonstration of knowledge by the client can occur, where that knowledge is legally relevant, without challenging the epistemic primacy of the solicitor.

Extract 6.3

`Start of extract: 00:00:01`

`length of extract: 00:00:23`

`Pseudonyms:`

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SL - Solicitor
FL – Client, Flora, wife of Nasirah
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Also Present:
NM – Client, Nasirah, husband of Flora
SA – Solicitor’s Assistant

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 1   SL: £ri:ght so uh£ (.) >you’ve< (.)
 2       >obviously< brought your ↓previous↓
 3       wills [with] you:.
 4   FL:       [yes:]
 5   (.)
 6   SL: .hh that’s grea:t=now do you want to
 7       use those’as’a start:ing point or do
 8       you want to use tho:se as a >sort of<
 9       .hhh HHUh- (.) jus- (.) ↓you’ve got
10       them↓ (0.2) an:d
11       (0.7)
12   FL: .hhh >>well: whatever I mean I<<
13       think: (.) >>I mean I’ve I’ve brou- a
14       copy for<< you: that you’re wel:come
15       to have::
16   SL: okay [>let’s let’s<]
17   FL:      [      Umm:   ]=
18   SL:                     =>lets h- if I
19       have
20       a< quick loo:k
21   FL: yeah sur:e.
22
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In this sequence, Flora demonstrates her knowledge of the legal procedure and uses the aid of producing the physical will. She maintains her role of ‘client’ and defers to the solicitor as the ‘expert’ in this social situation. The solicitor begins the new topic (‘right so’), by bringing attention to the relevance of the previous wills which Flora has presented. In lines 4-7 the solicitor takes several actions. She initially praises the presentation of the action ‘that’s great’, with emphasis, but latches this to the next turn of the business of the meeting (making new wills), where she gives two alternate options for either client to select. The ambiguous end of turn and slightly elongated ‘and’ results in a long pause. This is a result of the ambiguity and indicative of a non-conforming answer given by Flora in lines 12-15. Flora declines to select the options given, and instead emphasises her ability to provide the tools to enable the solicitor’s role. Flora uses five personal pronouns (I’ve/I) in her turn, taking strong ownership of the action of providing a useful piece of information for the solicitor (which is again emphasized by the lengthening ‘you’ and ‘have’). She uses similar phrasing to the solicitor, matching the elongated sound and ambiguous end of her turn (line 15). Flora has successfully turned the conversation from making a binary choice put forward by the solicitor, to demonstrating her own knowledge that providing a past will is valuable, and giving the solicitor the option of having this useful document.

These extracts show how clients work hard to demonstrate their own worth and knowledge, and how the solicitor can attempt to rebut the epistemic primacy of the client by asserting their own expertise. Clients may be working to demonstrate their own knowledge as a way of demonstrating their ability. Though knowledge of procedure is not required for capacity to make a decision, clients use knowledge of procedures (with mixed success) to demonstrate their utility and ability within this legal setting. Essentially, the clients enter the solicitor’s space, and therefore must work hard to demonstrate worth. However, knowledge of procedure cannot be directly related to capacity stipulations, as this is not an explicit (or particularly relevant) aspect of capacity to make a decision (as stipulated by testamentary capacity and the MCA). The following section shows how capacity is explicitly referenced by the solicitor, and what purpose this serves within this setting.

Statements of and references to capacity

In this theme, I have chosen extracts that highlight how the solicitor’s role and duty as a ‘legal professional’ result in discussions and descriptions of capacity. The solicitor is required by law to assess whether the client has the capacity to make the legal decision prior to legalising the desired document. Testamentary capacity is the most relevant to the documents that are being created (wills). However, the solicitor does suggest to several clients that Lasting Powers of Attorney may also be relevant, and in these instances, she often offers the reason for their usefulness as protecting against a loss of capacity. Given the subjective nature of assessing capacity, the solicitor does so in subtle ways. Capacity itself as a term is used in three of the four observations. The solicitor tends to refer to capacity during explanation of law and potential challenges, rather than interrogation. The extracts below are key examples of how the solicitor may use certain phrases/references to fulfil her institutional role of 'capacity assessor', and how she comments on client capacity.

As discussed in the previous section, the solicitor uses her epistemic primacy, laughs and requests information she already knows as ways to potentially demonstrate an adherence to the legal requirement of checking testamentary capacity.[101] The solicitor uses explicit statements of legal obligation to refer to capacity and, as is encouraged by the 'golden rule' for making wills, conflates old age with potential lack of capacity. This section shows how the legal obligations and needs being highlighted by the solicitor can make the interaction difficult and increase the authority of the solicitor. In this section, I conducted an informal content analysis to collect examples of capacity statements, and these can be seen in the tables which precede the larger extracts. These tables show how there is some uniformity in the way the solicitor references capacity, and how she does so in distinct ways for different purposes throughout the meeting with the clients. I use TDA to explain why quotes have been selected as referencing capacity and the function of this reference.

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[101] See page 252 of this chapter for an explanation of testamentary capacity, its conditions and the 'golden rule'

Table 6.1, brief Discourse Analysis of quotes where the solicitor uses capacity to state her legal obligations to the client

Observation code	Example	Function/context
O_30_07_19_2	you need to just be absolutely sure you've thought through the consequences of what you're proposing to do	Referencing stipulation of capacity, making relevant own legal knowledge for client's decision.
	make sure you understand everything	Referencing stipulation of capacity and own responsibility.
	and we need to be very careful in situations like this to make sure that y-you're considering everybody and that you understand the implications of what you are telling me you want to do	Referencing stipulation of capacity, highlighting potential 'risk' of client's situation and request, and solicitor's legal obligation to do so.
	that you are thinking straight and that your reasons for doing it are clear and they're well-thought out and you understand the consequences	Referencing stipulations of capacity and individual nature of decision making
	when somebody's making a will, we have to check that they're your instructions and that you understand what you're doing and you're making those decisions of your own free will	Demonstrating solicitor's duty and stipulating client is free of undue influence, and meets several requirements of capacity.
	the first one would be that you didn't understand what you were doing and you didn't understand you were making a will that would dispose of your property and assets after you died…	Demonstrating solicitor's duty to prevent a successful claim on a will, and stressing importance of aspects of capacity.

	which is why I'm going through what you do own…okay to make sure you understand and you understand that your will can give all of that away	
	well yes it would say you're invalid you didn't actually have the mental ability	Explaining how a will can fail and why that may rely on capacity.
O_12_09_19_4	which is why I'm talking to you at length so why Holly's here recording it all as well	Referring to legal responsibility as an explanation for inquiry of capacity and referring to research record presence.
	suddenly or gradually you lose the ability to make decisions or to understand and process information	Describing how a loss of capacity could lead to difficulty in making further legal decisions, referring to different aspects of capacity loss.
0_10_09_19_3	because if one or other of you became mentally incapable…of managing your own affairs then you would be stymied	Highlighting potential future issues with capacity to encourage further legal decision making.
	None of us know if we might suffer…RTA or something…and you've not prepared for that eventuality	Encouraging clients to make LPAs with the solicitor's firm, uses hypothetical scenario to highlight usefulness.
	he could speak for himself [laughing]	Identifying professional obligation of hearing both clients' perspective.
	if you are happy to take that risk please please please look at the situation you can only make a will if you've got capacity so if you lose capacity you can't change your will without	Regarding how the clients want to leave money, a gift to one partner's sister could later be rescinded after one death, or children may receive very little if cash is used to care for one or both partners.

	the formal application to court	

Table 6.1 gives short quote examples of how the solicitor references capacity to make her clients aware of its significance, and her legal obligation to 'assess' their capacity to make the decisions proposed. She also uses references to capacity to encourage clients to make further legal decisions in preparation for potentially losing capacity in the future. The solicitor identifies and draws attention to several different elements of capacity and testamentary capacity as set in the MCA without explicitly referring to legal statutes. Here we see how the solicitor skilfully introduces knowledge in her domain to clients who may not have the legalese to understand 'official terminology'. There is a risk associated with this of potentially over or under assuming client knowledge, but through focusing on her legal obligation, the talk is centred not on the clients' knowledge of capacity, but on her duty to assess and make them aware of any potential issues. I insert this table to contextualise the solicitor's talk in the following extracts which show how highlighting professional status can allow the solicitor to question the knowledge of clients, and how this is not always successful given the present struggle between the clients' status as experts of experience and the solicitor as a professional expert.

In the following two extracts, we see examples of how the solicitor explains the legal procedure to justify her actions. She does this throughout her meetings with Clara. The solicitor questioned Clara's capacity without directly proposing that Clara does not have the capacity to make the decisions she has discussed. In these two extracts, we see how the solicitor works hard to demonstrate her legal obligation and reason for proposing other actions (asking support to leave when the client would prefer them to be present, not making a will when a will has been requested). Extract 6.4 occurs at the very start of the first meeting with Clara. Clara attends the meeting with her daughter-in-law who initially produces all of Clara's paperwork and documents. In this extract, the solicitor references the individual nature of capacity and focuses on the need to avoid potential claims that the presence of the daughter-in-law may give traction to the claim that Clara has been unduly influenced. However, asking the daughter-in-law to leave removes a support system of Clara's and conflicts with the guidance in the MCA code of practice (2005).[102] Evident here is the duality of paternalistic values in capacity law that aims to protect from undue influence, potential assumptions of ageism and family dynamics (which I discuss further in chapter 7). Tis is coupled with attempts at ensuring the MCA moves beyond the medicalized narratives of competency and acknowledges enabling criteria for people with mental disorders (as discussed in chapter 1). This first extract demonstrates largely how the solicitor treats Clara differently from the other clients observed (who were married couples attending with their spouses) and how she uses legal justification to manage the meeting and propose actions that are different to those requested by the client. The analysis focuses on the use of emphasis, latching, overlap and hypothetical reports in the interaction to achieve epistemic primacy and agreement by the client.

Extract 6.4

Start of extract: 00:00:01

length of extract: 00:00:53

Pseudonyms:

SO: Solicitor
CL: Clara, Client
AN: Andrea, daughter-in-law of client (unmarried to son but described as such by CL)
SA – Solicitor's assistant

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[102] See MCA Code of Practice (2005), chapter 3, p.37, 3.15

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SO: You’ve come in to:day to make a will
    is that ri[ght]
CL:        [yeh]=
SO:             =ok:ay >an is this your<
    daugh:ter.
CL: >daughter in law<
SO: £dauhhghter£ ihn lhaw (.) right .hhh
    be:cause(0.2) >the wa:y we do it we
    have a< prot:o:col he:re, .hh >when
    we’re dealing with< cli:ents we see
    them on their o:wn,
    .hhh so that we: (.) can check that
    the in:stru:ctions and that the
    information you
    give us are done without any- body-
    (0.3)
CL: [mm]
SO: [in]fluencing: you or affecting it-
    .hhh an
    it’s (.) t’ pro:tect you: >but it’s<
    al:so to pro:tect those people who
    mi:ght benefit (.) under your will.
    (0.6)
SO: .hh so hh if you’re happy we’re going
    to as:k your daughter-in-law to just
    step out:side and wait in reception=
CL:                                    =I’d
    ra:ther
    her here [if im honest]
SO:           [    .hhh    ] >yes< d’you
    understand the reasons why we ask her
    not to be he:re.
    (0.6)
CL: not really (.) no
SO: nho .hhh ohkhay .hhh when >somebody’s<
    making a wi:ll (0.3) we: have t’ check
    (0.2) .hh that they’re your:
    in:structions .hh an:d that you
    under:stand what you’re doing .hhh
    ahnd you’re making £those decisions£
    <of your own (.) [free will>]
CL:                  [ oh ohkay]
```

In this extract, the solicitor links the two legal concepts of undue influence and capacity.

This is interesting when looking at the relational approach to decision making and relational analysis (see chapter 7). In this extract, the solicitor begins by establishing the purpose of the meeting (line 1-2), and immediately follows this by asking who is accompanying the client. These data are unique among the collection as it is the only occasion where the solicitor is dealing with a single client. The 'daughter-in-law' is not also a client of the solicitor unlike the married partners who are both clients. The solicitor's questions in lines 1-2 and 4-5 are designed to encourage positive affiliative responses. Her question format assumes that the information requested is already known. In line 6, Clara offers a quick correction, stating it is not her daughter but her daughter-in-law. In line 7, the solicitor addresses this non-affiliative answer, using a smiley voice for 'daughter-in-law', suggesting an issue with Clara's correction and follows this with a pause and 'right'. This signifies trouble and acknowledges that there may be an issue with what she is about to say.

After a long in-breath, the solicitor begins her explanation of the issue with the daughter-in-law's presence. She uses the somewhat official term 'protocol' and the plural 'we', referring to the solicitor's firm rather than her individual self, making her statement broader in meaning. She defers responsibility of the issue to the protocol and the solicitor's firm, discouraging an issue with her statement of seeing clients on their own. The client offers a minimal receipt of the information, and the solicitor responds with further explanation, referencing the legal concept of undue influence (lines 12-18), which does not receive agreement. The client is signalling that she does not affiliate with (either through understanding or agreement) the solicitor's explanation of the issue with the daughter-in-law's presence. The solicitor, however, continues her pursuit of Clara being alone for the meeting. In lines 24-26 the solicitor formulates the question. She begins in the weak format of 'if you're happy' but strengthens her request by changing to the declarative form 'we're going to’. After this switch to the declarative format, Clara latches onto the solicitor’s talk with a disagreement to the request.

After establishing that Clara does not understand why her daughter-in-law is being asked to leave, the solicitor begins a new explanation of why her presence may cause issues and in this explanation, she combines the concepts of undue influence with capacity. In line 35, the solicitor begins her turn by acknowledging the client’s lack of understanding in a breathy voice. Her extension of ‘okay’ signifies a further explanation, which follows a long in-breath. In lines 36-41 the solicitor emphasises key aspects of her explanation through elongation or extra emphasis on sounds. Emphasis occurs when the solicitor refers to persons; ‘we’, ‘your’ and ‘own’ and actions; ‘check’ ‘instructions’, ‘understand’, ‘making’, and ‘decisions’. The solicitor this time refers to the client explicitly, making relevant the ‘protocol’ from line 9. The solicitor states that ‘we have to check’, referring to her status as ‘legal professional’ and her legal obligation. The solicitor refers to the individual nature of will making as ‘your instructions’ and the requirement of capacity to ‘understand what you’re doing’, and then returns to the issue of undue influence as ‘free will’, all in one succinct utterance.

The solicitor uses her professional status and legal obligations to make relevant three legal concepts in one succinct explanation, as she wishes to see Clara alone rather than with the daughter-in-law. This is one example of how the solicitor combines references to legal concepts (e.g. capacity) and her own status as a legal professional to encourage understanding from the client.

Table 6.2 contains short quotes where the solicitor uses metaphor or other descriptions to refer to the mental capacity, without using the legal language of mental/testamentary capacity. She uses these statements to divulge her opinion of the client’s capacity status without referring to the official term itself. The solicitor translates the legal concept into more ‘agreeable’ terms which achieve understanding with the client. The following extracts show how offering statements of capacity are useful for the solicitor.

Table 6.2, table showing alternate word choice for capacity

	Example	Function/context
Observation code		
o_12_09_19_4_2cont	probably got your headspace a bit better	Metaphor, explains why solicitor did not draw up will in first meeting, but is now
	you’ve got the mental wherewithal to do it	Descriptive, explaining what capacity is
o_30_07_19_2	thinking straight	Metaphor, explaining what capacity is
	there are some little warning bells going on in my head at the moment about whether this is a really good time to do it	Metaphor, referencing temporal nature of decision making and capacity, explaining why solicitor will not draw up will in this meeting
0_10_09_19_3 (1)	I mean neither of you are suffering from anything terminal that you know well– you know apart from life issues…	Conflates terminal illness/disability with capacity loss, as opposed to ‘life issues’.
	it’s gone you can’t bring back and you can’t rewind the clock	Idiom, explaining why LPAs may be of interest to clients, capacity framed as ‘definite’.

Extract 6.5 occurs at the end of the meeting observed in extract 6.4. Clara has been upset throughout the meeting; her husband died a month ago. She has come to make a will that excludes her daughter, as she says they have never got on, and since her husband’s death, she has not spoken much with her. She is in a wheelchair and is hard of hearing but has no other disabilities. Clara’s son and daughter-in-law have been called back into the room to go

over what has been discussed, and why the solicitor will not be finalising a will today. The solicitor refers to her knowledge of potential issues and an anonymous external example of why she is not making the will today. She does not directly state she believes Clara is ‘traumatised’ or unable to make a will, but that instead there may be issues if she did. The solicitor avoids referring directly to any doubt in capacity, and subtly highlights reasons why she cannot, at this time, make the document proposed. This is the only meeting where the solicitor does not draw up the will requested and does not follow the client’s instructions.

Extract 6.5
Extract Start: 00:58:10

Extract length: 00:01:12

<u>Pseudonyms:</u>

SO: Solicitor

CL: Clara Moor, Client

CS: Client’s son

DL: Daughter-in-law

Context:

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SO: what I’ve s:aid (0.7 ((paper
    rustling))is (.) I’m happy to take
    (0.8 ((paper rustling)) ur: (0.2)
    >your moth<er’s:(.)in:structions which
    Ihh’ve done (0.3) .hh (.) >the
    pro:bLem is< it’s very s:oon
    a:fter your father has passed [ away ]
CS:                               [(°mm°)]
CS/DL: °°hhohhkay°°=
SO:                =there’s >been a- r<
    cas:e
CS: (°yuh°)=
SO:         =>thut was:< (0.6) the Will
    was thro:wn out.
    (0.2)
SO: because it was made so soon=
CS:                            =oah.
SO: aft:er somebody had- (0.3) passed
    a:way: (0.2) .hhh on the bas:is: that
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20      they were too em:ohhtionally (0.3) uh
21      trauma:tised by the whole thing .hhh
22      (0.3) um: (1.2) >so I'm< (.) >very<
23      con:scious of tha:t,
24  SO: .hhh I'm conscious of what your mum
25      has as:ked me to do:,
26      (0.2)
27  So: I'm going to wri:te er a letter (.)
28      and (0.8) s:et it all: ou:t .HHH (.)
29      I'm asking her to just <wai[t>]
30  CS:                            [ m]m:.
31      (.)
32  SO: On: that lett:er (0.4) .hhh an to
33      rea:d it through ca:re:fully (0.2) and
34      to think <car:efully> about what it
35      says >and whether it< is: what she
36      wants:.
37      (.)
38  SO:.hhh u:m (0.3) now (.) ov:iouSOy (.)
39      what I don't want you to do ihhs (0.4)
40      to ↓not have a will↓.
41      (.)
42  SO: .hh so plea:se >don't< lea:ve it (0.6)
43      too long: (0.2) .hh (0.2) >but what I
44      want you to do is to be absolutely
45      sure=and I've said if she< cha:nges
46      [her m]i:nd=
47  CS: [ mm: ]
48  SO:            =(.) that's a:bso:lutely
49      fi:ne .hh (.) we'll: we'll see her
50      a:gai:n .hh (.) >we'll see her again
51      a[nyway to<]
52  CS: [    mm:  ]=
53  SO:             =get it si:gned=.hhh uhm
54      >but I'm going to do< tha:t.
```

In this extract, the solicitor is explaining why she has not made the will for Clara today. Clara is still present in the room, but she does not speak in this interaction and is spoken about. In lines 1-7 the solicitor informs the client's son and daughter-in-law of her actions for the client. She works to mitigate the trouble of not fulfilling the request of making a will at this time. In lines 2-5 there is emphasis on the fulfilled action of taking Clara's instruction. She demonstrates her usefulness and role fulfilment as the solicitor, before beginning the problem formulation on lines 6-7. She quickly states there is an issue, before emphatically stating it is ‘very soon’ after Clara’s husband’s death. The solicitor addresses the timeliness of capacity to make decisions and the requirement that if the decision is better made at another time, it can be. She moves this focus away from the client by using the terms ‘your father’, distancing the issue directly from the client to the familial grief. This is responded in overlap with ‘mm’ and ‘okay’, which act as continuers. The solicitor is still in the position of knowing why the death poses an issue for the making of the will, and the clients’ minimal receipts act as continuers for the solicitor to carry on with her explanation, giving her epistemic authority in this sequence.

At line 10-11 the solicitor distances further from the client's situation by referencing ‘a case’. As well as depersonalising the explanation, the solicitor can use language that belongs in her domain as ‘legal professional’, there is no invitation for questioning her legal expertise and her authority. On line 13 the solicitor emphasises ‘will’ making relevant this new information she is giving, which is furthered in lines 16-21*. Re Key (Deceased)* involved a man whose wife of 65 years passed away, and one week later changed his will accompanied by one daughter.[103] In the previous will, everything would be left to his two sons after his death, excluding his two daughters (who lived abroad but kept in contact). In the newly made will, everything would be left to the two daughters, excluding the sons. The claimants were successful in their case that their father was too recently bereaved to have the capacity to make a new will, and the previous will with the original wishes was instead upheld. There are similarities between this case and Clara’s, however details do differ (for example the new will did not state the daughter accompanied him). With this context of the

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[103] Key (Deceased), Re, [2010] 1 W.L.R.

case in mind, I continue the analysis, recognising the contextual significance of the solicitor's reasoning for not carrying out what the client has attended for.

In line 16, the solicitor emphasises the link between the 'case' and the issue of the recent grief for Clara by emphasising the 'because' and reiterating the timeliness issue. In line 6, she states that for Clara, it is 'very soon', and for *Re Key (Deceased)* it was 'so soon'. The mirrored formulation again works to make this information relevant to Clara, without naming her directly. At line 17 the client's son produces a minimal token of understanding latched, recognising the similarity between the issues. The solicitor uses this mirror formulation again on line 18, with depersonalisation referring to 'somebody' in this case, and 'passed away'. She works to draw attention to the similarities to justify her inaction. This depersonalisation works to soften line 21, that a person recently bereaved is too 'emotionally traumatised' to make a will. This statement is followed by pauses and 'um' signalling the solicitor's acknowledgement of the sensitivity of her previous utterance. At line 27, the solicitor moves back to the original project of justifying her inaction, emphasising her consciousness of the issue.

Given her retained epistemic authority in the sequence and her undisputed position of 'legal expert' and authority figure, the solicitor, through her turns, has managed to highlight how making the will would be a disservice to Clara. The solicitor owns knowledge that the client and family do not, knowledge that indicates making a will at this time would be a potentially futile exercise (it would be 'thrown out'). The other persons in the interaction do not respond to this, so the solicitor produces more information pertinent to Clara's situation. In line 24, she makes vague reference to the discussion they have had, emphasising the 'what'. This highlights that the 'what' of the discussion and the recent bereavement are the potential issues for the solicitor. Furthermore, the solicitor takes ownership of what the client has 'asked' with the personal pronoun in ‘I’m conscious’. The elongation of ‘ask’ emphasises that the client has asked for something, which the solicitor must be ‘conscious of’. The ‘what’ is problematic, and it is the solicitor’s duty to treat the client’s request cautiously. The solicitor does not state that this is what Clara wants, but what she has asked, giving less certainty to Clara’s request.

Having finished her explanation, the solicitor states what she is going to do instead of drawing up the will as requested. The solicitor is non-specific in the ‘it all’ in line 28, potentially due to the weight she has given at the start of the meeting to Clara’s client confidentiality. At line 29, the solicitor addresses the fact that Clara is still present, although not involved in this interaction. The solicitor explicitly addresses this with the use of the pronoun ‘her’. The son offers a minimal receipt. In lines 32 onwards, the solicitor does address Clara through the instructions which follow her request. Clara is asked to ’carefully’ consider what is written in the letter. This letter reflects what Clara has said throughout the meeting, but the way the solicitor formulates it suggests there may be disparity between what the letter will state and what Clara wants, evident through the differentiation of ‘what it says’ and ‘what she wants’. The solicitor then states her desire for the client to have a will, but, with the context of the previous formulation, potentially not the will that Clara has stated she would like to make. The solicitor emphasises that she wants Clara to be ‘absolutely sure’ in lines 44-45, which, along with the previous sequence explaining her inaction, indicates that Clara is unsure. The solicitor also offers the alternative option for Clara to change her mind. The solicitor has not referred directly to capacity once, but instead uses displays of legal language knowledge, her authoritative position, and depersonalisation to encourage agreement to not fulfilling the initial request (making a will).

The extract ends with the solicitor completing her explanation with the definitive and abrupt ‘I’m going to do that’. Again, she draws attention to her legal usefulness.

This extract, along with the referenced case, shows how the conflation of age and testamentary capacity can lead to institutional ageism. The judgment given for the case that the solicitor references uses the ‘golden rule’ to justify the ruling and the comment that mental incapacity may be difficult to detect for solicitors. This is because of clients that

> ‘seek to conceal what they regard as their embarrassing shortcomings from persons with whom they deal, so that a friend or professional person such as a solicitor may fail to detect defects in mental capacity which would be or become apparent to a trained and experienced medical examiner, to whom a proper description of the legal test for testamentary capacity had first been provided.’[104]

The solicitor, like the judge in this case, uses the golden rule which calls into question elderly testators as one reason to doubt capacity.

Extract 6.5 serves as an example of how the solicitor uses her status as ‘legal expert’ and draws from impersonal knowledge to raise the issue of capacity, without being explicit and potentially causing discord by refusing to fulfil a request due to doubts in capacity (and delusions of the mind or brain). Due to the small dataset, this meeting is the only instance where capacity is called into question. This observation acts as a case study of how solicitors may avoid explicit capacity discussions by using their position as legal expert to justify not carrying out a client’s wishes. The solicitor refers to several elements of capacity, time and reasoning. She accounts for her decision by using terms relevant to capacity. However, her

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[104] Key (Deceased), Re, [2010] 1 W.L.R [39]

assessment of capacity is somewhat absent in this meeting; she offers explanations of what capacity is, but misses opportunities to check her clients' understanding of capacity.

Table 6.3 (below) and the subsequent extracts demonstrate how the solicitor can draw attention to capacity as a part of her legal status and obligation to assess clients. In doing so, she highlights several different aspects of mental and testamentary capacity, again without mentioning the official legal concepts. The solicitor works to assess the client's capacity and inform clients that they must be in possession of said capacity to make these decisions.

Table 6.3, table of statement of capacity requirements

Observation code	Example	Function
0_10_09_19_3	he could speak for himself [laughing]	Drawing attention to importance that both parties act as individuals
	I'm disabled but nothing … a disability doesn't S:[laughing]… sorry it's no– it's nothing that's going to not have a rapid advance	Highlighting how disability 'could' but does not mean a person lacks capacity. Draws attention to the timeliness of decision making and capacity
	we need to watch you, you do all the speaking yeah I'm assessing both	Drawing attention to importance that both parties act as individuals for purpose of capacity assessment
	I don't doubt your capacity but I think you've got other things on your mind [laughing]	Acknowledges potential 'questionable' capacity, lack of doubt, and gives reason for this.
O_3-_07_19_2	it's easy to get confused particularly you've only just lost him…do you feel up to doing this today	Excusing client's behaviour/lack of knowledge, gives reason for potential questionability, interrogates questionability further.
	SO: yeah that's fine right okay that's fine all right now how's your ability to write CL: a bit shaky	Refers to 'reasonable adjustments/support' aspect of enabling capacity, in terms of physical abilities.

	SO: shaky okay that's fine what about reading do you need large print CL: yes I need glasses as well SO: but you can read CL: yeah	

During the meeting of extract 6.6, the solicitor has used phrases like 'he can speak for himself' and 'both speak' prior to the meeting to encourage SB to speak as well as his wife. They wish to update their wills to exclude their son and the grandchildren that they are not in contact with. They state that their son is irresponsible and was fired from the family business. At no point is either person asked to leave the room. In this extract, the solicitor has just run through all the assets the couple can leave in their wills. Ensuring both parties speak could be a 'technique' to determine if they do have the capacity to understand and to ensure both parties want the same in each of their wills.

Extract 6.6

Extract Start: 00:28:55

Extract length: 00:01:41

Pseudonyms:

SO: Solicitor

SB: Stuart Andrew Bryce, Client, Husband of Alana

AB: Alana Jean Bryce, Client, wife of Stuart

```
 1   SO: oh:kay .hh so ↑tell↑ me: (0.9) >in
 2       your own words an you-< (0.3) each >of
 3       you:< (.) must speak .ih(h) h(h)u
 4       h(h)u .hhh £what d'ya wanna do:£?
 5       (1.2)
 6   AB: °mm°
 7       (0.8)
 8   SO: whe:n: yu di:e what do you want t'
 9       h:app:en.
10       (2.0)
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11  SB: thee: >bus:iness and everythin ull<
12      go: to:  (0.6) me dau:gh:ter,
13      (0.9)
14  SO: your: share a the business.=
15  SB:                             =yeh.
16      (0.7)
17  SO: y:uh.
18      (7.3)
19  SB: the bung:alow will go to (0.7) th’
20      daugh:ter,
21      (3.3)
22  SB: .tch or: she’ll move into it an sell
23      ers.
24      (0.6)
25  SB: (>d’y[know<)]
26  SO:      [    ye]ah.
27      (1.8)
28  SB: any ass:ets >that are< left (0.8)
29      >all< be: >handed down< to: (.)
30      prob’ly the grand:chil:d:ren,
31      (3.3)
32  SB: °↓u:m↓° (0.3) that’s it for me.
33      (0.6)
34  SB: I don’t (0.3) >I duno’I< (0.2) .hh
35      ni:ce and sim:ple.
36      (0.2)
37  SO: .tch (.) so you: n:othing >to the<
38      son.
39      (0.6)
40  SB: not at mo:m:ent no.
41      (1.0)
42  SO: kay (0.2) we’ll come ↑back to that↑.
43      (0.2)
44  SO: .hh (0.3) what do you: want to
45      happ:en.
46      (1.2)
47  AB: my: share a the business to my
48      daugh:tah,
49      (2.1)
50  AB: the h:ouse to my daugh:ter,
51      (0.5)
52  AB: an: (.) any:thinc (0.2)=
53  SO:                         =you mean the
54      bung:a:low=
55  AB:            =ye[h ]
56  SO:               [°r]i:gh°.
57      (0.3)
58  AB: an anythin else to the gran:chil:dren.
59      (5.0)
60  SO: (now [your-)]
61  SB:      [  gran][childre]
```

```
62  AB:              [a:pa:rt] >from the<
63      four: that we don’t [see    ]
64  SB:                     [I’s gu’] say the-
65      (.) na- [°is°]
66  AB:         [ mm:]=
67  SB:                =°yeah° not five.
68      (0.3)
69  AB: well yeah: the f:ive don’t
70      [re- (.) d’ont    ]
71  SB: [that’ll that gran]hil:dren will have
72      to be na:med >up< wo- we-s:
73      [we see]
74  SO: [ yeah ]=
75  SB:          =the’s half (0.7) only.
76      (0.6)
77  SO: .hhh ohkay: and again no:thing to your
78      son?
79  AB: nho.
80      (1.7)
81  SO: .hh o:kayhh.
```

In this extract, the solicitor vaguely references the individual nature of legal capacity through their insistence in lines 2-3 that each person must speak. What follows are the two accounts given of what each person would like to be in their wills. The solicitor in this extract is filling out a form where she records the information to be written into the will, which may explain some of the long pauses. This also potentially provides a reason why the solicitor asks for information that has, at least in part, already been given in the first half of the meeting. This practice is again typical in medical interaction, where there is an institutional requirement for practitioners to ask patients to repeat information they already know. However, in this interaction, it also works to draw attention to the fact that the wills being provided are two separate legal documents, and though the couple has attended the meeting together and are being asked these questions while the other is present, each will is treated as being made by someone with individual capacity to make the decisions set out.

In line 4, the solicitor asks the broad question, ‘what do you want to do’ in a smiley voice. The lack of specificity and smiley voice produces a long silence, indicating an issue with this utterance. At line 6, a quiet ‘mm’ is followed by another long pause. At line 8-9 the solicitor changes the tone of her question, it is specific, and the slow elongated words recognise the topic's sensitivity. This is (after 2 seconds) followed by an answer from Stuart, who gives his account of what he would like to happen. Stuart’s account is given in list format and allows time for the solicitor to write his instruction. The solicitor asserts herself when deemed legally important on lines 14 and 37, using declarative interrogatives (which are treated as further questions by Stuart who gives affiliative responses when answering). At line 42, the solicitor uses a high pitch to draw attention the legal relevance of ‘nothing to the son’, while staying on the current topic ‘come back to’. She continues with her current project at line 44, emphasising the singular ‘you’, directly addressing Alana with an explicit request for Alana’s account of what she would like to happen after she dies. Alana then gives her account, mirroring Stuart’s account beforehand, with the same order of assets.

At line 47, Alana uses the solicitor’s specification with ‘my share’, demonstrating attention to the solicitor’s previous declarative question to Stuart. The solicitor offers a correction at line 53-54 of ‘bungalow’, which Alana treats as a question, answering ‘yes’. After near repeating what Stuart has said in his formulation, Alana then offers further information about which grandchildren she is referring to. There is an interesting epistemic dynamic between Stuart and Alana as each speaks in overlap with the other to offer the solicitor the clarifying information about which grandchildren will be included in the will. The solicitor somewhat disregards this information, which follows the same pattern of questions as with Stuart, and questions with rising intonation ‘nothing to your son’. Alana affiliates to this statement in her response ‘no’. This is responded to after a pause by the solicitor at line 81 with a topic closing ‘okay’. This extract ends here, as the solicitor then swiftly moves on to her next project.

In this sequence, the disadvantage of having both parties present when asking for their individual wishes is evident. Though the solicitor insists on each person speaking, their formulations and accounts are very similar. Although the law insists that the will should reflect their individual wishes free of influence from others, the solicitor is faced with the issue that this married couple are attending together, and she does not ask either party to leave at any point. She must attempt to ascertain their individual wishes while they attend as a unit. The solicitor's tactic to insist that both parties must speak does little to individualise the accounts given. This extract shows how the solicitor is constrained by the legal need to ascertain individual wishes. Throughout the meeting, the couples (in both observations where a couple was observed refer to themselves as a unitary ‘we’, assets are often joint, and decisions are referenced as being discussed beforehand between themselves and with family. The solicitor is then required to untangle the relational nature of making a will. It is difficult, as we see here, for clients to switch from referring to decision making and will making as a relational act, to being required to individualise their decisions. In contrast, in the next extract, the solicitor refers to capacity explicitly so that they are clear in their judgement (this extract occurs at the end of the meeting after lengthy discussion).

Extract 6.7 occurs the end of the meeting and the solicitor asks, ‘have you ever thought about making powers of attorney’, she suggests making a business power of attorney and financial power of attorney. She cites reasons that financially they would be ‘stymied’ without one, and that none of us know if we suffer a stroke or car accident. She then runs through the costs of doing the LPAs with them (from £600 up to £1200) and gives them a leaflet on how to make an LPA with this solicitor firm[105]. LPAs are individual documents for each person (but often include the spouse as the attorney). What follows is an explicit statement of the solicitor's belief in Stuart's capacity, and an account as to why he may not attend to the information that she is providing about LPAs.

Extract 6.7

```
Extract Start: 00:55:23

Extract length: 00:00:24

Pseudonyms:

SO: Solicitor

SB: Stuart Andrew Bryce, Client, husband of Alana

AB: Alanna Jean Bryce, Client, wife of Stuart
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 1   AB: alrigh have a read it- we'll have a
 2       ~read~ a the leaf:let=
 3   SO:                        =y:eah: an I can
 4       send you out some more stuff in >in
 5       the <post as [  w:ull:   ]
 6   SB:              [>w you can<] read it
 7       then you can sit there and tell me
 8       a:boud it=
 9   AB:           =well yeah:.
10   SO: ↑.mhi(h) [mhi(h) mh(h)] h(h)m↑ =
11   AB:          [°hu(h) h:m° ]
12   SO:                                 =.hhh
13       £I DON'T DOUPT YOUR CA:PACITY BUT I
14       THINK YOUVE GOT OTHER THINGS ON
15       [  YOUR MHIND£  ]
16   AB: [.H(H)EH HH(H)uh]=
17   SO:                   =.AH(H)A H(h)a.
18       h(h)a .hh=
19   SB:           =got a lot on my mind at
20        mo:me[nt (y'know)   ]
21   SO:       [>yeh< have you] got anything
22       that you feel I h:aven't covered or
23       you'd like to dis:cuss with me
24       todayhh.
25       (1.7)
26   AB: no not rea:ll:y.
```

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[105] it is not a legal requirement to make LPAs with a solicitor, you can make an LPA for £82 without professional help

On line 1, Alana uses the typical sequence closing formulation ’alright’ to begin her turn. This turn comes after an explanation, by the solicitor, of why powers of attorney would be a good idea. The topic close may be due to the fact that the powers of attorney being discussed will not be made in this meeting but will need to be made in a subsequent meeting. Alana uses the plural ‘we’ as she restarts her turn on line 1, reading the information as a relationally important activity. This demonstrates knowledge that the information is for both parties in the couple and is relevant for both people. The solicitor latches on to Alana’s topic-closing statement with the addition of a further demonstration of her own usefulness as the information provider and authority. This statement is somewhat ignored as Stuart does not pick up on it as he begins his turn in overlap at line 6. He refers to Alana’s utterance and reformulates the receipt of information from reading it to ‘being told’ about it. Alana treats this as serious, agreeing to his assessment of what will happen when the information is received. However, the solicitor treats this as a semi-serious statement and invites laughter in line 10 by producing high-pitched laughter particles.

This also indicates something wrong with the couple’s reformulation of how the information is to be treated. The fact that Stuart has received this information via his wife, is treated as a laughable statement, as semi-serious. Legally, it is not entirely inappropriate for an explanation of power of attorneys to be given by someone who is not a legal professional and, as is evident in the interview data, legal decisions are often initiated by one person in the couple and explained to the other. Yet, this is treated as problematic by the solicitor, and her following utterances suggest there is a potential capacity issue if a person receives information in this way. In the following line Alana does affiliate with the laughter, Stuart however, does not. In lines 12-15, the solicitor makes a strong statement, indexing her institutional position, and taking a strong epistemic stance and high epistemic primacy (as a solicitor, she has the right to make comment on her client's capacity). In this single turn, in loud speech and a smiley voice, she works to draw attention to her official responsibility as a solicitor and provides an account (which she can affiliate with) as to why Stuart may not read the information himself.

This is somewhat like clinical interactions where practitioners provide alternate accounts for patient assessments that are institutionally acceptable. Stuart affiliates with this response by repeating the assessment in line 19, changing the solicitor's 'other things' to 'a lot'. He strengthens the justification that he has not read the information because hasn't just got 'other things' to think about, but 'lots of things'. Stuart also draws attention to the time element of capacity (knowingly or not), by adding 'at the moment'. Stuart manages to shift his position from a person who 'potentially shows signs of lacking capacity', evident through the solicitor's oblique referral to capacity following his statement, to a person who has capacity and understandably has other priorities at this time.

The sequence closes with the solicitor offering a quick agreement to his assessment. The interrogative that follows, though it is a question lexically, does not invite a non-affiliative, lengthy response, which is evident using: 'anything'. There is a lack of rising intonation in any of the words and the question is also somewhat ambiguously addressed to 'you'. Without gaze direction information we cannot know if this is addressed to a single person or the couple. After a long pause, Alana answers with the affiliate response of: 'no'. In this last interrogative, the solicitor manages to further increase her position of expertise with her formulation. The solicitor encourages a negative response, and thus an agreement that she has provided all the information they need. She also uses the term ‘feel’ for the clients, a weaker formulation than the active ‘I haven’t covered’. In other words, it is possible for the clients to feel she has not provided all the information, but it does not mean she has or has not done this sufficiently.

This extract shows how capacity statements are used by the solicitor to explicitly call attention to her expert status in this setting, and her ‘right to assess’ the clients. Capacity statements are not used to interrogate a client’s capacity but rather to draw attention to the solicitor’s legal duty to assess and state a client's capacity. There is an absence in all meetings of explicit capacity checking. Capacity checking is implicit when present; there is a nuance adopted to assess capacity, but also missed opportunities to enable and ensure capacity.

Discussion and conclusion

This chapter identifies two main themes from the observational data, which I have explored using CA. The analysis highlights several key points which I will now discuss. First, is how clients attempt to demonstrate their experiential expertise, and the solicitor interrogates this knowledge (which is not in her epistemic domain). This first point highlights a stark contrast to other institutional settings, specifically counselling and medical interactions. What is missing from these data is the solicitor asking the client to reformulate the information in her epistemic domain (the legal actions/ramifications/restrictions). Rather than doing a form of checking understanding by asking clients to reformulate information in her domain, she interrogates knowledge which belongs to the client’s domain, experiential knowledge (either the physical presentation of documents which are problematic or ignored or asking for information which is already known).

Research into person-centred counselling interaction shows that asking clients to reformulate a suggestion/therapeutic plan stated by the counsellor is a normative practice. This works interactionally to check that both parties are on the same epistemic field and have equal access to and understanding of the information which is being shared (Fitzgerald, 2013; Peräkylä, 1993, 2011; Peräkylä & Vehvilƒinen, 2003). This is a missed opportunity for the solicitor to assess the clients’ understanding of legal information and is completely missing from this dataset. This may be a simple, quick way for solicitors to identify their clients’ level of understanding of the legal decision that they wish to make. Reformulation of information is not absent in these data, so its use could be easily transferred to allow for a clear assessment of a client’s understanding.

Through interrogating the clients' knowledge, the solicitor manages to identify potential gaps in the presented information (especially where this information is physical, outdated wills). This is necessary for the solicitor to complete the client’s request (to make a new will). This type of action shares similarities with group therapy interaction, where knowledge displayed by the facilitator can highlight potential indecencies in what a client has said; however, this encourages further explanation from the client (Pino, 2016). The differing institutional contexts may explain some differences between counselling and solicitor interactions. However, both work to achieve a shared plan, and require clients to share personal information and understand specialised information. Recommendations for improved solicitor-client interaction could be achieved using commonplace counselling techniques, as identified through CA.

The second point raised in these data is the central importance of epistemics to all interactions in this setting. There is inevitably an interactional asymmetry between client and solicitor if we focus only on the social setting (a solicitor’s office) (Ehrlich & Freed, 2010). However, by paying attention to the epistemics of the interaction we can identify how both client and solicitor have epistemic primacy (either through experience, or expertise) (Heritage, 2013b; Raymond, 2014). This creates a problematic epistemic field for both parties to navigate to successfully achieve the task at hand (drawing up a will). Capacity is centrally about knowledge, understanding and ability. Epistemics, and understanding the epistemics of the conversation in which capacity is being assessed, is essential. The solicitor-client relationship for LPAs and wills is often unique in that they do not need to meet more than once. The solicitor in these data has spoken to all clients (or one person in the couple) on the phone prior to the meeting to establish what legal decision the client wants to make.

All information pertinent to the legal decision is taken at the meeting, and therefore, it is imperative the solicitor is given access to the client’s experiential knowledge.

Equally, to meet legal requirements and ensure understanding, the solicitor must impart their expert knowledge. As seen in these data, there are difficulties when both parties claim to have expertise on a subject (which will be further explored in chapter 8).Recommendations for resolving this issue could be identified by turning to medical interactions; specifically, how doctors can use empathy statements to bridge a gap of knowledge where patient and doctor plans differ (Ford, Hepburn, & Parry, 2019). In this study, the researchers investigated four different medical settings where treatment plans were being discussed and identified and how a doctor uses empathetic statements to build a rapport with the patient, resulting in a more affiliative stance. However, we must be cautious in directly transferring this finding to solicitor meetings, and further research observing solicitor practices is essential to understand and improve this interaction.

Also evident is the heteronormativity of the solicitor/client interaction. The solicitor accepts that male-female partners in a marriage (though they are understood to be individual clients) can stay in the same room for the meeting and capacity assessment. At no point is either party asked to leave to ensure there is no undue influence from the other party. The solicitor does highlight on occasion that ‘both must talk’ or ‘you don’t have to do the same’, but what is clear in this analysis is the difference between the treatment of Clara and the other clients observed. Clara’s daughter-in-law is not a client of the solicitors, however, Clara as a single woman is then disadvantaged by not having the support available of her deceased spouse (or her nominated supporter; her daughter-in-law). The solicitor allows married couples to enable one another’s capacity to understand the information (as is seen through one person generally presenting all paperwork/information) but does not allow single persons the presence of another supporter. This is not entirely to place blame on the solicitor, as this is a wider societal issue. However, it is important to note its presence here and highlight this issue for future legal decision making law reforms. This recognition means equality inclusion practices need to become commonplace for solicitors.

This chapter gives new insight into how capacity is enacted, avoided and referenced in solicitor-client meetings. By referring to other institutional settings, I have made some recommendations for improved practice; further research is absolutely necessary to understand this unique institutional setting. Solicitors must engage with observational research.

Chapter 8: Conclusion

Throughout this thesis I have argued and provided conclusions on the individual topics of discussion, here I bring these together. I demonstrate how I have answered my research questions, state the limitations of my research, and propose future topics for research which have emerged from my findings. First and foremost, this research reflects the lived experience of people with dementia and their carers. Their needs and wishes are central and therefore require action from researchers, which I hope I have shown in this project.

Restatement of the research

In this thesis I have investigated how laws governing wills and LPAs affect people with dementia and their carers by speaking to people with dementia and their carers. The central focus of this thesis is the voices of, and stories from, people with dementia and their carers. This thesis contributes to knowledge about how people who have supportive relationships access and use legal decisions, and conceptualise their experiences of dementia. I observed law as an everyday social activity conducted by individuals in the home or in the solicitor's office. This thesis contributes to socio-legal research on law in everyday lives, giving novel insight into the relationship between solicitor and client in this unique legal space. I have shown that people with dementia are negatively affected by legal definitions of mental capacity. I theorise and have provided evidence on the impact of neuroculture on UK law, and the problematic assumption that people with dementia are somehow 'less than' people without dementia. Using my empirical data I have been able to evidence these issues and argue for several changes to current capacity law.

I sought to answer the following research questions with this thesis:

1. How do people living with dementia and their informal carers access and interpret legal advice?
    a) What is the content of this legal advice, and how does the rhetoric form the construct of 'capacity law'?
    b) What impact does this have on their understanding of their legal rights and their mental capacity?
2. How do legal actors assess capacity, and how does this impact the legally relevant decisions made in the lives of people with dementia.
3. What is the contribution of observational methods, such as Conversation Analysis, to understanding legal decision making in action?

As my thesis is data-driven, the questions I initially set out were deliberately broad. Using a constructionist approach, I have been able to explore the data beyond my initial questions, and further comment on the interconnectedness between society, capacity law, and dementia. I will now explain how I have answered my research questions one-by-one. I will do this by drawing on findings from across the thesis, demonstrating how I expanded upon the initial inquiry and made a unique contribution to this socio-legal field of knowledge.

How theory contributes to my thesis

By examining the history of legal discourse regarding capacity, I have shown how the concept of capacity has progressed from one of purely medical competency to cognitive models of capacity and working memory being incorporated. . As stated in chapters 1 and 2, capacity knowledge is restricted by the cognitive and psychiatric descriptions used in legal settings. I argue that this may, in part, be due to the neurocultural and hypercognitive society in which we find ourselves. Definitions of personhood are integral to our definition of capacity. To meet the requirements of Article 12 in the UN CRPD we must resist the constrictive rhetoric of cognitive psychology and psychiatry, which invariably encourage the individualistic model of law. Instead, we must seek to adopt a relational model of personhood and law, therefore influencing legal practices. Through a neuro-centric lens, society does not enable or place value on those with mental disabilities. I have also shown how the definition of disability and definition of dementia differ. For the UN CRPD to be properly understood by people with dementia and those working to protect their rights, this misalignment should be understood and rectified. We must work to unify the rhetoric of disability and dementia, as shown by the protections offered by disability law, the work of Shakespeare et al (2019), and dementia organisations in recent years.[106] I have shown the disparity between law in action and law as doctrine through my empirical research. Therefore, I can make recommendations regarding how law is conducted in practice and how we might shape this by making changes to codes of practice and guiding policies.[107] Capacity law still does not accurately reflect peoples' lived experiences. In this thesis, I have highlighted how there are multiple barriers and disparities between how capacity is enacted, how it is interpreted, and how it is used by legal actors and legal professionals. I will now outline how I have answered my research questions and draw together findings from across the empirical chapters evidencing my arguments.

Research question 1

To understand how people with dementia and their carers approach and are affected by legal decision making, I first analyse several theories of culture, society, and personhood.

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[106] Such as Deep (2016), and the recognition of dementia as a disability by the APPG in 2019, see https://www.alzheimers.org.uk/about-us/policy-and-influencing/2019-appg-report

[107] See chapter 4-7

Using these theories, I was able to posit how, at a societal level, restrictions or limited expectations may be placed on people with dementia in terms of decision making. I discuss this in chapters 1 and 2 and this analysis influenced how I approached answering this question, and informed my conceptual framework. Additionally, by examining existing research conducted within healthcare settings, I was able to understand how capacity may be understood in different contexts (Williamson 2012, Williams, Boyle et al. 2014, Wilson 2017, Scott, Weatherhead et al. 2020). This informed my conclusion that dementia and capacity are not clearly defined concepts within professional settings, and highlighted the need to understand them from perspectives of people under scrutiny, as this had yet to be investigated. Essentially, I sought to understand how people with dementia and their carers construct legal decision making, what components make up this construction, and whether legal advice and the content of this legal advice is central to the decision. As I began my interviews, it became apparent that though many interviewees had made, or were in the process of making, a legal decision, it did not mean they had instructed a legal professional. This is because LPAs and wills can be made without professional input. I will now outline how I deconstructed the various components that make up a legal decision affected by capacity law. I do this from the perspective of my interviewees, highlighting why it is important that the law pays heed to these constructs, and incorporates them into everyday practice.

The components of legal decisions, facilitators and barriers

In chapter 4 I outline how capacity and dementia are conceptualised by interviewees. Dementia itself is markedly not constructed as part of the personal capacities of an individual. It is acknowledged that there may be an impact on 'official' capacity however and that such deficits are overcome by the shared knowledge and trust within the spousal or family relationship. I delve into this further in chapter 3, where I argue that this relational aspect of living with dementia can and does enable people to continue to make decisions in a supported way within trusted and valued relationships.

The constructs of capacity and dementia are two keys parts of legal decision making. Capacity is heavily misinterpreted as akin to cognitive psychology, as I evidence in chapter 2. The three-stage test (evolved from the prior two-stage test), does rely on medicalised diagnostic information to some degree (particularly in courts). Additionally, prior research within healthcare settings was predominantly focused on best interest decision making. The assumption of capacity was somewhat lacking from descriptions of arriving at a best interest decision, and where a capacity assessment was investigated, researchers found that practitioners were not confident in their knowledge or ability to carry out an assessment of capacity. My thesis contributes to this discussion by highlighting how people with dementia and their carers (people likely relied upon to contribute to best interests decisions) define capacity and what is perceived as important. Capacity, as defined by people with dementia and their carers, can be divided into two distinct categories: 1. Everyday capacity to participate in daily life, maintain historical hobbies and relationships, and; 2. 'Official' capacity, in which other people might lack the ability to make an official decision, or where a financial decision might be too difficult to take on individually. Importantly, people with dementia and their carers emphasised their everyday capacity. The ‘official’ incapacity was distinctly othered. It was an issue to be faced by people who lacked a meaningful relationship which might enable their cognitive skills. Most interviewees had made a legal decision. They had interacted, on some level, with capacity law, and yet their constructs differed because they placed value on the relational nature of life rather than the unrealistic individualistic autonomy proposed by law.

As my focus is on how people with dementia are affected by capacity law, I interrogated how dementia is perceived and analysed its impact on daily life. In doing so I demonstrate how, akin with other illness constructs, dementia is othered.[108] I argue that this serves to protect the personhood of the individual with dementia and can be beneficial, as it enables the person to continue their daily life. People with dementia and their carers experience dementia as a relational event. The 'we-ness' of dementia is prevalent, as I demonstrate in chapters 4 and 7. Dementia is experienced as an unwanted third party affecting both parties in the couple. Dementia needs to be reframed and understood as a relational life event, as it has a presence within the couple's lives, not just the individual's brain function and cognitive skill. Couples show an awareness of the value of a 'healthy' brain; the influence of neuroculture works to protect and separate the person from the negative consequences of dementia. It's important to note that people with dementia and their carers do not relate personal capacities with dementia. Capacity assessments in legal practice, which are not prescriptive, could be adapted to acknowledge a person's historical skills and context. As a start, I would suggest amending the MCA code of practice. as well as the Law Commission making a conscious effort to incorporate adaptive capacity assessments into any practice guidelines produced because of the delayed wills review.

As I discuss in chapter 6, the very space of a solicitor's office can act as a barrier to people making legal decisions, given the heteronormativity of the space, and the value of biological kinship I evidence. Further research is needed with a more diverse population (both

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[108] See chapter 4 for my discussion of the construction of illness.

solicitors and clients) to evaluate if this occurs in other solicitor's offices, but it is significant here. If relational legal practice isn't implemented, then biological kinship and heteronormativity will continue to dominate the legal space. Currently, different types of relationships are not properly accounted for or accepted as reasonable levels of support. In this data, spousal relationships expect support for one another, whereas the non-spousal relationship is treated as suspect and a potential case of undue influence. I discuss this phenomenon further below, in reference to research question 2.

Knowledge of law, making or not making a legal decision

Most people with dementia and their carers, even where there has been legal engagement, do not fully understand their legal rights. This finding is expected, given the wealth of literature examining legal engagement and layperson understandings (e.g. Solan 2018), and legal consciousness research (e.g. Cowan 2004). What my study does offer, is the novel finding that people with dementia do show an awareness of legalities regarding medically assisted dying and assisted suicide. As I discuss in chapter 5, people with dementia express a desire to control the end of their life, and idealistically select medically assisted dying or assisted suicide to achieve this control. People are aware that this choice is not legal within the UK, but still express a desire to have this option. Additionally, people with dementia and their carers use hypothetical and real examples of what ‘not having capacity’ may look like, to show how and when a person might be restricted. Throughout my thesis, I have found that, although people cannot verbalise or state their rights or offer a clear construction of what they may be, they are able to identify when law may restrict a person’s actions, particularly where end-of-life is concerned. Even where some legal engagement had occurred, the rights being protected or associated with LPAs and wills were absent from discussion. LPAs and wills, as they are currently understood and used, do little to inform people with dementia and their carers of their rights. Public awareness campaigns are evidently needed to ensure people understand what human rights are, and what documents are relevant to protect them.

Many participants, even where a legal decision had already been made, could not articulate their own legal rights. When asked: 'what do you know about legal rights?' (or a similar formulation of this question), most participants said they did not know what they were. When prompted with a hint like 'so as a person in this country you have a right to…' people spoke about a right to professional care, or knowledge that the right to die was not respected in the UK. This finding brings to the fore the issue of legal literacy and awareness. Though many participants had made wills and LPAs, which legally work to protect an individual without capacity and grant them equal access to legal rights, this was not discussed. Interviewees did not construct law as relevant and belonging to their personal everyday domain, yet the decisions and rights protected in LPAs are everyday decisions and rights that exist in everyone's lives. For mental capacity law to be useful, even in its current state, without amendments to practice guidelines, it must be made relevant to the everyday lives of individuals who make documents such as LPAs and wills. It is a potential source of underuse if people are not aware of how LPAs or ADRTs might enable their human rights. If people do not know what these rights are, they may not know or understand how to action them. As with the meaning of capacity, which must be specific to law but also incorporating multiple fields of knowledge rights must be made relevant to reflect everyday life and increase awareness, use and understanding. Again, what I evidence is a need for the further exploration of how to enact supported decision making as first investigated by Harding and Tascioglu (2018).

Given the absence of discussion about legal rights, I use my lens of neuroculture and relationality to understand why end-of-life decisions were constructed in this way. As I demonstrate in chapter 5, due to hypercognitive ideals and society's negative death culture, people with dementia and their carers are hesitant and feel unable to plan their end-of-life care. The health and welfare LPA should be publicised as a useful care-planning tool available for all; this may address some of the social and cultural issues. Additionally, I argue in chapter 5 that for people with dementia and their carers to be able to make future plans, we must address the negative death culture of the UK and the taboo surrounding death and dying. This is further complicated by a neurocentric society. People with dementia and their carers construct the end of life as dependent on ideals of bodily integrity and agency. Capacity law also values individual agency through adopted individualistic personhood, as I show in chapters 1 and 2. Rather than enabling persons to plan for the end-of-life, law perpetuates the negative image of dying with dementia influenced by neuroculture and death culture. People with dementia and their carers do not feel able to plan sufficiently for the future. This is, in part, because capacity law exacerbates the ideals of cognitive and bodily integrity which is not realistic for persons with dementia at the end of their lives.

The discord between how people with dementia and their partners view capacity and how law constructs capacity adds to the issue of knowledge of law amongst laypeople..[109] As I highlight in this research, relationality is present in decision making and everyday life, regardless of how legal practice occurs. Where law restricts a person, it does so based not on their everyday lived realities, but on unrealistic, hypercognitive, individualistic ideals of decision making.

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[109] Outlined previously in this chapter and in chapter 4.

Research Question 2

In answer to my second research question, the legal actor I observed did not explicitly assess capacity, but instead referred to it when explaining their practices. Where implicit capacity assessment occurs, the solicitor, influenced by the golden rule for testamentary capacity, equated age with potential lack of capacity. Rather than assessing capacity, the solicitor referred to it to highlight institutional roles and legal duty. Where implicit capacity checking occurs, solicitors ask for information which is expected to be known to the client. Capacity is used as a specialist term by the solicitor when asserting epistemic primacy. They use metaphors and other descriptors to speak of capacity in less formal ways and achieve understanding with clients. There is a disparity between how this solicitor speaks of capacity as an authority and how she seeks to achieve understanding. The term is given an epistemic weight which belongs only in the solicitor's domain. To achieve understanding, the solicitor must explain what capacity is, which I observe through her use of metaphor. What is missing is the following interrogation of a client's understanding of capacity. Do they understand that the metaphor used relates to the capacity needed to make such a legal decision and that the solicitor has a duty to check that they possess certain cognitive skills The vague interrogatives, like asking both parties to speak, potentially demonstrates that some kinds of capacity assessment are insufficient. The solicitor is not equipped to assess capacity in the solicitor's office. References to capacity in solicitor-client meetings are used to demonstrate legal duty and authority, rather than assess a client's ability to carry out an action. As seen in my data, with the case study of Clara, testators who are visibly upset and/or older and physically disabled, are judged on this basis by the solicitor, rather than through knowledge and understanding checks. This is where solicitors might benefit from engaging in counselling and clinical conversational practices, such as asking the client to repeat back what has been said in their own words. I suggest that these practices, and the research evidencing how they work, is included in solicitor training programmes.

As I show with reference to wider case law and critical kinship studies, solicitors act in this way due to an awareness of a bias in society (and in courts) where a will may be contested. Solicitors and legal reformers must be mindful of the societal biases toward marital and biological kinship if testamentary freedom is to become a reality. This thesis contributes new knowledge to how capacity is understood, used, and is absent in this legal space.

The role of epistemics

By analysing the epistemics at play in this interaction, I show how clients work hard to validate their own knowledge in this institutional space. By analysing the interaction through the epistemic field, and the different 'expert' roles being fulfilled in the interaction, I have shown how the solicitor may interrogate one aspect of capacity: 'know and understand'.[110] However, as I demonstrate in chapter 7, this approach is somewhat difficult. To interrogate someone's knowledge, which belongs in their own epistemic domain, is an odd activity in the interaction. It makes the interaction more adversarial, with both parties seeking to claim epistemic primacy over information. This highlights how the lack of step-by-step guidance for this interactional assessment of capacity can result in poor conversational practices. As such, I recommend that solicitors draw from knowledge gained in research into other institutional interactions. Further investigation is needed into the solicitor-client

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[110] As stipulated in the MCA

interaction, to establish if solicitors might benefit from conversation training, such as the Conversation Analytic roleplay method (Stokoe, 2014).

Research question 3

My methodology allowed me to contribute to the theory of law as language, particularly supporting Endicott (2002) and Bittar (2020). Using my social-constructionist approach to my research questions I was able to evidence how law is enacted by language. My use of CA and TDA evidence how language is an active, meaning-making process, not a passive experience. My methodology shows how language can be used to create understanding of difficult information, infer power dynamics, and give insight into the individual meaning of legal texts or medical definitions. The methodology I use has not previously been applied to this institutional setting. Using Conversation Analysis for the observations of solicitor-client meetings means I can offer unique insight into how capacity is assessed in and through conversation. Capacity assessments occur through conversation, so the application of this analysis means I have been able to dissect and identify what capacity is in this setting. Capacity assessments are not a prescribed exercise and so we can only properly understand the concept of capacity in this setting through this micro-level analysis. I have been able to identify the epistemic tensions between client and solicitor and show how solicitors neglect to interrogate capacity.

The importance of both datasets

Given the difficulty recruiting solicitors for observational research, my interview data and subsequent TDA provided a wealth of insights. This provided me with insight into how people with dementia approach legal decision making, as none of the solicitor’s clients disclosed a dementia diagnosis. Additionally, due to the relational and often historical basis of legal decision making, the interview data proved vital for giving a broader overview of the processes of making an LPA or will. These valuable findings would not have been possible without this data. I recognise the importance of using both TDA and CA with observation and interview data. The purist CA approaches proposed at the inception of CA would not have been suited to answering my research questions, and indeed, this observational data would have missed the relational nuances I was able to observe in interviews. TDA allowed me to apply the constructionist lens to my interview data and ensure that persons with dementia and their carer's voices were at the centre of my findings. Taking a constructionist approach benefits this socio-legal analysis. The traditional doctrinal hierarchy, which is not reflective of everyday practice, is subterfuge. As I have shown in this thesis, the application of thematic Discourse Analysis allows for a deeper understanding of how law exists, integrates, and acts upon, a person's life.

Accessing solicitors

As I have shown through my analysis in chapter 6, the findings to be gained from even a small data set are rich and enlightening. Further conversation analytic research is needed into this unique interaction to make specific recommendations to solicitors, which are more ingrained in the solicitor-client practice. A larger catalogue of solicitor-client interactions is required to ensure the continued improvement and understanding of these exchanges. One way to achieve this may be through incorporating research participation in solicitor training. Encouraging solicitor involvement at the outset of education could help change the culture of research for solicitors. This thesis shows how inaccessible this unique setting can be, and why it is important it for future research attention.

Reflections and the limitations

This research is limited in that the laws I discuss are relevant only to England and Wales. Therefore, the application for reform is somewhat limited. However, the wider themes of neuroculture, biological kinship, and negative consequences in law, can be applied to broader western cultural contexts.[111]

Additionally, as discussed in the methods chapter, the observational data collected was limited. The solicitor's practice was a small-medium firm in a small town and just one solicitor at this firm agreed to participate in the research. Without further research, including a broad range of firms and practices, I am hesitant to make strong assertions about the representativeness of this data.

The homogeneity of my participant sample means I cannot comment on further marginalised groups in society (such as the LGBTQIA+ community, people of colour, gypsy and traveller communities, immigrants and asylum seekers). These groups are difficult to reach, but I acknowledge that this research contributes to these issues of diversifying research populations. As previously stated, it would also be useful to evaluate if this research could be carried out with different kinds of relationships. Diverse types of relationships should certainly be explored. Additionally, future research might engage people with dementia at the start of the research process, working with this group to incorporate their needs and insights into the design of the project, using methods such as those listed by Williams et al (2020).

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[111] See chapter 2 and chapter 7.

Questions for future research

This work has highlighted a deficit in ethnographic/observational research. Legal spaces outside of the courtroom must be investigated further. Conversation Analysis (and Discourse Analysis) have yet to enter this unique legal space (outside of this thesis). I would suggest that further research would gain insight from including a range of solicitors and solicitor firms. It would be helpful to gain insight into firms in large urban areas, as well as more rural settings. Additionally, the making of LPAs and wills also occurs outside of legal settings, and so it is pertinent that professional will writers are open to research participation. Furthermore, several interviewees had made wills through an online service. Given the general trend of enabling online legal spaces, it is important to research what this means for practice moving forward.[112] Socio-legal research needs to be conducted in all legal spaces, and I suggest Conversation and Discourse Analysis are apt tools for investigating socio-legal phenomena.

Further research is also needed into how dementia and its effects on individual's futures interact with the law's static idea of futures. This is important when considering why people with dementia express suicidal ideation in place of end-of-life care planning. If people with dementia are expressing a wish to end their life, it is our responsibility as researchers to understand why, and potentially how this might be achievable. We cannot neglect this question just because it might feel too inoperable or controversial. As I state in the outset of this thesis, the number of people with dementia is rising, and we must seek to understand how to enable them to live and die how they choose.

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[112] The introduction of virtual (online) courts for example were introduced in 2016 by the Civil Courts Structure Review, https://www.judiciary.uk/publications/civil-courts-structure-review-final-report/

As I suggest in my recommendations, it would be helpful if solicitor training incorporated how to assess capacity and how to interact with people with dementia and their carers when they want to make legal decisions. I also propose that this invites a new research area: investigating the attitudes and assumptions that solicitors have regarding people with dementia and their carers, as well as people with chosen families, or those people who exist outside of the heteronormative. I acknowledge that solicitors are bound by law, but as I have shown in my thesis, attitudes and assumptions, whether individual (the solicitor, see chapter 6), or social and cultural (influences I propose in chapters 1 and 2), have an impact.

Final thoughts

To conclude, I offer a quote from Lina giving her thoughts on law and lawyers:

> 'They don't talk in layman's talk. It's like somebody who, say for argument's sake, Hank is cooking and what have you, if I said to him, go and cook a roast dinner, he wouldn't have a clue what to do. They know what they're on about. But as layman, you don't know.'

People with dementia and their carers are told to make legal decisions but are not always equipped to make full use of them. Meanwhile, the law is not equipped to enable those persons in practice. In this thesis my aim was to evidence and make a compelling argument for support, to help people with dementia and their informal carers better plan for and manage their lives (and deaths).

Mental capacity law is unavoidable for the rising population of people with dementia, and their families, friends, and carers. Mental capacity law purports to ensure and protect a person's right to make a legal decision. But, as I have shown through this research, it is not used, interpreted, or understood as a tool for this by the majority of people subjected to its restrictions in practice. Law as doctrine, and constructions of law by legal actors, do not match. Therefore, there is discord between law in action and law as written. Essentially, it is imperative that people with dementia are respected by lawmakers and practitioners; their needs and interpretations of selfhood are central to any legal practice which is likely to target them. Documents like the UN CRPD can help argue this, but if a person doesn't even know what their rights are, or how making legal decisions enacts or protects these rights, not enough has been done. Lawmakers and practitioners must work to improve rhetoric around capacity and personhood, incorporate different types of knowledge, and reflect people's actual relational lived experiences. If this is not done, capacity law practice will continue to penalise people with dementia unfairly. A narrow, cognitive, neurocultured understanding of capacity helps no one. A relational, contextual understanding of capacity not only helps all but is reflective of how people use and experience capacity in their everyday lives, in other words, what current capacity law claims to protect. As I state at the start of this chapter, we must not ignore the voices of people with dementia. I have begun to engage with solicitors and third sector organisations to present the findings of my research and find out how we can move forward with this knowledge.[113] Researchers, lawmakers, and practitioners must engage with the people they claim they want to enable and protect. People with dementia deserve a capacity law practice which reflects their daily lives in all their complexity.

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[113] See Appendix S for the project report and lay summary

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Appendices

Appendix A

Research Data Management Plan (draft v4)

1. Overview
a. Researcher's Name: Chloe Waterman
Title of Research Project: Legal Decision-Making and Dementia: A conversation and discourse analytic study **b.**
c. Length of Project **Start Date: 01/10/17** **End Date:01/10/20**
d. A brief statement of the aim(s) of the project The aim of this thesis is to explore how decisions about wills and power of attorney are made in the everyday lives of individuals with dementia and their families/carers. This project also aims to add to the theoretical development of the concept of relationality through empirical investigation using conversation analysis of observed legal decision making. I aim to investigate how legal decision making may become a more supported process through adherence to the UN CRPD, as well as the use of relational theory, and the development of 'person-centred' law. I aim to contribute to legal discussions about future supported decision making, and supported wills (under review) and LPA's.

2. About the Project Data	Help, Guidance and *Example Answers*
a. Briefly describe the data that you will collect for the project I will audio record interview with participants using a digital recorder, then transcribe these verbatim into text. I will also observe and audio record meetings between solicitors and their clients using a digital recorded (with full consent), these will be transcribed verbatim, and small sections will be transcribed using the Jefferson technique.	*I record interviews with subjects using a digital audio recorder, then transcribe them into text.* *I test my catalyst under a number of conditions, then submit samples of the products to analysis facilities.* *I generate data using model code that I've written, then process it various ways to produce visualisations.* *I combine existing data from a number of sources*

	[e.g.…] and reanalyse them to derive new conclusions.
b. Frequency of new data (how often will you get new data and over what time period?) I aim to collect all of my data within a year, at the earliest I will start data collection over summer (July 2018), at the latest I will complete data collection by August 2019. However, given my reliance on voluntary participation, I am reliant on their availability, and my data collection period will need to be flexible and contingent on their availability.	*All of my data will come from a single 3-month field trip in my second year.* *I expect to run two or three experiments each week through my second year and much of my third year – about 100 in total.*
c. Quantity of data (Terabytes, other forms of storage) 115.2 mb of Observation data (approximately) 432mb of Interview data (approximately) 1 lockable box folder of paper forms 2mb of transcription data and notes	*Each experiment produces about 50MB of data, so over the course of my PhD I expect this to add up to about 5GB.* *2 drawers of a standard filing cabinet*
d. What format is the data in? Audio recordings in MP3 data files Word documents of transcripts	*Binary data* *The format used by a particular instrument* *paper notebook.*
e. Could the data be considered high value and/or vulnerable? E.g. is your data likely to attract "hactivists"? How could this be mitigated? My data is not considered high value, it is not vulnerable to hacking. I have previously attended data protection and security training at Keele University.	*My data is of high value and may be subject to threats from overseas governments, I will check for advice in the Information Security Awareness training Canvas course* https://birmingham.instructure.com/courses/5162

3. Data Collection and Storage	Help, Guidance and *Example Answers*
a. What different versions of the data do you create? E.g. versions of data files I will convert my data files from MP3 format to WAV. During analysis I may have both MP3 and WAV formats of the files, all will be securely stored. I will also create extracts of the longer audio recordings, these will be separate files, stored securely.	*As I survey new cohorts, data is appended to the dataset and saved as a new file.* *There is only ever one version of each data file — new experiments create new data, which is stored in a new set of files.* *Each time I run a new version of my model, intermediate files are written over, but the final results are saved as a new file*
b. What additional information is necessary to understand the data? E.g. abbreviations, supplementary notes. I will keep field notes from both data sets, these will be taken with pen and paper, which will be transferred to a word document and kept with the audio recording. The notebook will be kept with the consent forms and other paperwork in a locked filing cabinet or folder.	*I keep additional notes about interviews and participants in a Word document with the audio recordings and transcripts.* *Abbreviations used for column headings are kept in a separate text document.*

I will keep an excel spreadsheet to keep track of all necessary paperwork and the recording it pertains to, to ensure anonymity and confidentiality, whilst being able to identify any participants who may wish to withdraw their data, or match any field notes to recordings and transcripts.	*The content of digital photographs are recorded in the file name.*
c. Where will the data be stored? (For electronic data there should be 3 places, including one off campus.) I will store the data on my personal laptop, which is password protected, and have two encrypted hard-drives, one of which I will keep secure at home, one of which I will keep securely at university in a locked filing cabinet.	*My primary copy is on the university X: drive, and I copy files to my laptop to work on while away from the office.*
d. Describe the system to name and structure any electronic files. Each file name will start with the date on which the recording was taken, followed by the code stated on the consent forms.	*I use the structure <thesis chapter>/<date>-<experiment number>.* *A folder for each project phase, and within those a folder for each interview.* *Each filename starts with the date on which the data was collected.*
e. Describe the regime for backing up the data. I will transfer all audio files to my laptop on the day they have been taken. Once a week I will back up all data on the external drives, and delete all recordings from the audio recording device.	*Working data is backed up on the UoB Research Data Store. I make sure I copy the latest versions of my working files there each day.* *I regularly scan my paper-notebook and store digital copies on the X:drive*
f. Describe the procedure to be used to ensure files can be restored from the backups. When I conduct my weekly back up, I will check the data files are not corrupted.	*Weekly check that files on the X: drive are still usable.*

4. Data Availability to Others	Help, Guidance and *Example Answers*
a. Who owns the data?	For clarification on who owns the data, consult the University's Code of Practice for Research, and/or

	discuss with your Principal Investigator. Also check your agreements or contracts with any sponsors or collaborators.
b. Are there restrictions on who can use the data, and if so, what are they? Any data which contains identifying information must be anonymised before sharing.	*All my data is covered by a confidentiality agreement and cannot be shared.* *Some of my data identifies individual patients and must be anonymised before sharing.*
c. If the data can be made openly available, at what point can this happen?	

5. Archiving (preserving the data for future use)	Help, Guidance and *Example Answers*
a. What data should be kept beyond the end of the project? All anonymised data will be kept beyond the end of the project (transcripts and recordings)	*All data, both raw and processed.* *Only simulation code and input parameters.* *Transcripts of all interviews, but not recordings.*
b. How long should it be kept? For 10 years after the end of my project is complete.	*Until the end of my PhD* *For 10 years after the end of the project*
c. Where will the data be archived? On the UoB research data archive	*In the UK Data Archive* *On the UoB Research Data Archive.*
d. Who will create and maintain the archive of data? My supervisor will deal with this.	*I am responsible for archiving data, and the archive service will maintain it.* *My supervisor will deal with this.*
e. Are there restrictions on who can access the archived data? Full data will never be public as it contains sensitive personal information, but anonymised data will be made available on request.	*Data will be embargoed for 12 months to enable patent protection.* *Full data will never be public as it contains sensitive personal information, but anonymised data will be made available on request.*
f. What are the likely (estimated) costs of preserving the data? I do not foresee any charges applying	Consider the likely amount of storage you will need, and how long this will need to be archived for. The ITS Research Data Archive provides 1Tb of free storage per project. For quantities in excess of 1TB, charges will apply. For more information see https://intranet.birmingham.ac.uk/it/teams/infrastructure/research/midplus/LTSA/index.aspx

6. Implementing this Plan	Help, Guidance and *Example Answers*
a. Name of person responsible for implementing this plan. I will take responsibility for carrying out the actions required by this plan and report them to my supervisor as appropriate.	***I will take responsibility for carrying out the actions required by this plan and report them to my supervisor as appropriate.***
b. Frequency of review and/or updates of this plan. My supervisor and I will review it every 6 months and update if necessary	***My supervisor and I will review it every 6 months and update if necessary***
c. Actions required in order to implement this plan. Ask my supervisor to request research storage space for my project set up a backup system. Test I can restore from my backup. Purchase encrypted storage devices.	***Ask my supervisor to request research storage space for my project*** ***Set up a backup system.*** ***Test I can restore from my backup.*** ***Learn how to anonymise data for archival.***
d. List any further information needed to carry out the actions above. I will research (online) what the best encrypted devices are for my purpose and budget.	**Where can you find this information?** **Who might you be able to ask?**

UNIVERSITY OF BIRMINGHAM
APPLICATION FOR ETHICAL REVIEW

Who should use this form:

This form is to be completed by PIs or supervisors (for PGR student research) who have completed the University of Birmingham's Ethical Review of Research Self Assessment Form (SAF) and have decided that further ethical review and approval is required before the commencement of a given Research Project.

Please be aware that all new research projects undertaken by postgraduate research (PGR) students first registered as from 1st September 2008 will be subject to the University's Ethical Review Process. PGR students first registered before 1st September 2008 should refer to their Department/School/College for further advice.

Researchers in the following categories are to use this form:

1. The project is to be conducted by:
    - staff of the University of Birmingham; or
    - postgraduate research (PGR) students enrolled at the University of Birmingham (to be completed by the student's supervisor);
2. The project is to be conducted at the University of Birmingham by visiting researchers.

Students undertaking undergraduate projects and taught postgraduate (PGT) students should refer to their Department/School for advice.

NOTES:

- An electronic version of the completed form should be submitted to the Research Ethics Officer, at the following email address: aer-ethics@contacts.bham.ac.uk. Please **do not** submit paper copies.
- If, in any section, you find that you have insufficient space, or you wish to supply additional material not specifically requested by the form, please it in a separate file, clearly marked and attached to the submission email.
- If you have any queries about the form, please address them to the Research Ethics Team.

☒ **Before submitting, please tick this box to confirm that you have consulted and understood the following information and guidance and that you have taken it into account when completing your application:**

- **The information and guidance provided on the University's ethics webpages (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-of-Research.aspx)**
- **The University's Code of Practice for Research (http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf)**

UNIVERSITY OF BIRMINGHAM **APPLICATION FOR ETHICAL REVIEW**	*OFFICE USE ONLY:* Application No: Date Received:

1. TITLE OF PROJECT

Legal Decision-Making in Dementia: A conversation analytic study

3. THIS PROJECT IS:

University of Birmingham Staff Research project ☐
University of Birmingham Postgraduate Research (PGR) Student project ☒
Other ☐ (Please specify):

4. INVESTIGATORS

a) PLEASE GIVE DETAILS OF THE PRINCIPAL INVESTIGATORS OR SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	Professor Rosie Harding
Highest qualification & position held:	Professor of Law and Society, PhD
School/Department	College of Arts and Law, Law
Telephone:	[redacted]
Email address:	[redacted]

Name: Title / first name / family name	Professor Elizabeth Peel
Highest qualification & position held:	Professor of Communication and Social Interaction, PhD
School/Department	Loughborough University, Social Sciences
Telephone:	[redacted]
Email address:	[redacted]

b) PLEASE GIVE DETAILS OF ANY CO-INVESTIGATORS OR CO-SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	
Highest qualification & position held:	
School/Department	
Telephone:	
Email address:	

c) In the case of PGR student projects, please give details of the student

Name of student:	Chloe Waterman	Student	[redacted]
Course of study:	Law PhD FT	Email	[redacted]
Principal supervisor:	Professor Rosie Harding		

Name of student:		Student No:	
Course of study:		Email address:	
Principal supervisor:			

5. ESTIMATED START OF PROJECT	Date:	01/10/17 – Empirical research: 01/19 (approximately)
ESTIMATED END OF PROJECT	Date:	01/10/20 - Empirical research: 09/19 (approximately)

6. FUNDING

List the funding sources (including internal sources) and give the status of each source.

Funding Body	*Approved/Pending /To be submitted*
ESRC DTP Midlands Graduate School	Approved

If you are requesting a quick turnaround on your application, please explain the reasons below (including funding-related deadlines). You should be aware that whilst effort will be made in cases of genuine urgency, it will not always be possible for the Ethics Committees to meet such requests.

7. SUMMARY OF PROJECT

Describe the purpose, background rationale for the proposed project, as well as the hypotheses/research questions to be examined and expected outcomes. This description should be in everyday language that is free from jargon. Please explain any technical terms or discipline-specific phrases.

Purpose

The purpose of this project is to identify how decisions about wills and Lasting Powers of Attorney (LPA) are made in everyday lives of individuals with dementia and their families/carers. I will use my empirical investigation to observe how everyday practice occurs, and to investigate how legal discourse is constructed and understood by clients.

Supporting people with cognitive impairments to make their own decisions is a pressing contemporary socio-legal issue, mandated by the United Nations Convention on the Rights of Persons (UN CRPD) with Disabilities. This qualitative empirical socio-legal project will explore how legal professionals and family members support people with dementia to make decisions about wills and Lasting Power of Attorney (LPA). In the case of a dementia diagnosis, functional mental capacity may be in question, particularly if the client has difficulties with processing information or communicating their decisions. The Mental Capacity Act 2005 requires that legal actors and family members assess the capacity of people with dementia to make decisions and provide support where necessary to help them to do so.

Rationale

There is little empirical research regarding how capacity assessments take place in legal settings. Capacity assessments form the basis for the right to make a will and to register an Lasting Power of Attorney. These assessments are informed by the *Banks v Goodfellow* case test, the Mental Capacity Act, and the UN Convention of Rights for Persons with Disabilities. Legally these should inform and dictate how capacity assessments are carried out in order to ensure full legal rights and freedoms are enjoyed. However, capacity is a concept which is also informed by psychology, and psychology actors also carry out capacity assessments.

What needs to be identified is the way in which these four areas:1) legal practice,2) legal theory, and 3) psychological practice and 4) psychological theory intersect and identify exactly what capacity is and how it is used in a legal context to determine a person's ability to be an active participant in their legal rights and affairs.

This study will focus on clients with (or close to) a diagnosis of dementia. Dementia diagnoses are consistently rising and people with dementia are vulnerable to losing their capacity (mental and legal). Little is known about how capacity is determined in legal settings in practice.

This project will aid in identifying how capacity is defined in law in action, as well as by the people with dementia and family members.

Research Questions

Using observations of client/solicitor interactions and subsequent conversation analysis I will explore:

1. How do legal actors assess capacity, and how does this impact the legally relevant decisions made in the lives of people with dementia

Using interviews with individuals with (or suspected) dementia and their family members/carers and subsequent discourse analysis I will explore:

2. How do people living with dementia and their informal carers access and interpret legal advice?

I will then use my empirical work to explore:

3. What is the contribution of observational methods, such as Conversation analysis, to understanding legal decision-making in action?
    i) Can these observations inform legal methods and frameworks?

Outcomes

The empirical work used in this project will provide new findings about how solicitors assess capacity, and how clients understand their legal rights, and what information is accessed and understood.

I aim to use this knowledge to help inform the current debates regarding capacity in the law and improve how capacity is understood and assessed for individuals with dementia.

8. CONDUCT OF PROJECT

Please give a description of the research methodology that will be used

This research will use 1) conversation analysis of solicitor-client interactions, and 2) discourse analysis of interviews of individuals with dementia and their informal carers.

Observational

The research will use a qualitative design. Naturalistic observational audio recordings of solicitor appointments will be analysed using conversation analysis.

I will be present for all observations unless it is requested by any of the participants that I leave. I will be present to explain or answer any questions before the audio recording begins. I will audio record the meeting between the solicitor and client(s) using a digital audio recorder. This will only occur once I have explained my project, and both client(s) and solicitor have read the information sheet and signed the consent forms. Client(s) will also be asked to complete a demographic questionnaire, but this is not compulsory if the client declines (but still consents to recording).

During the meeting, and immediately afterwards I will take field notes.

At the end of the meeting I will stop the recording, and both client and solicitor are required to confirm they wish to submit the recording, evidenced through the tick boxes on the consent forms.

Participants are able to withdraw their data up to 3 months after their recording is made.

Audio recording has been chosen because it allows for better anonymisation than video and is less intrusive. Furthermore, the verbal interaction will provide the data required for the research questions, and field notes can be used for supplementary information.

Interview

The interviews will answer the second question posed by this research. I will audio record the interviews using a digital audio recorder. I will have contacted the participants regarding the research and have explained the project prior to arranging an interview. I will conduct the interviews at either the participants' home, or if requested, an office space.

I will conduct semi-structured interviews with the participants, which will last approximately 60 minutes. I have created an interview schedule which is flexible so will be adaptable to the client's knowledge levels and is not dependent on whether they have already sought information or legal advice.

I will conduct the interviews with both the individual with a diagnosis of (or suspected) dementia, and their family member/carer together. This project uses varied data and multiple data collection sources. It would be unethical to gain a surplus of interview data that would not be feasible to analyse within the scope and time scale of this project hence I aim to conduct interviews with both person with dementia and their family member together. I do not predict that this will negatively affect the quality of the interviews. There are also advantages to conducting the interviews with both carer and person with dementia present, such as creating a more supportive environment for a potentially emotionally distressing topic. Questions in the interview will be directed to both parties, but also included will be questions directed at either carer or individual with dementia to ensure both parties are given opportunity to talk and express personal views. Theoretically conducting the interviews with both participants is advantageous as it gives the potential for a relational framework of decision making to be more explicitly observed and understood, if present. Relationality asserts (in a reductive and simplistic sense) that individuals are not autonomous beings and that all decisions are affected by those with whom we hold close relationships. I will mainly be interrogating this in the observational data, but through including both parties in the interviews I may also in the interview data. Interviews will only take place when all parties have read and understood the information sheet and signed the consent form. A demographics questionnaire is also included but is not compulsory.

I will produce easy-read versions of all consent forms and information sheets for the solicitor clients, and individuals with dementia.

All data will be transcribed verbatim and subsequently analysed. The observational data will be analysed following the conversation analysis method. The interview data will be analysed using the discourse analytic method.

9. DOES THE PROJECT INVOLVE PARTICIPATION OF PEOPLE OTHER THAN THE RESEARCHERS AND SUPERVISORS?

Yes ☒ No ☐

Note: 'Participation' includes both active participation (such as when participants take part in an interview) and cases where participants take part in the study without their knowledge and consent at the time (for example, in crowd behaviour research).

If you have answered NO please go to Section 18. If you have answered YES to this question please complete all the following sections.

10. PARTICIPANTS AS THE SUBJECTS OF THE RESEARCH

Describe the number of participants and important characteristics (such as age, gender, location, affiliation, level of fitness, intellectual ability etc.). Specify any inclusion/exclusion criteria to be used.

Observational data
Participants will be recruited via opportunity sampling and participation is entirely voluntary.
Solicitor firms will be recruited (4-5 initially), individual clients (15-20) will then be offered the opportunity to take part when making an appointment (see email attached).
I will not explicitly ask the clients what their diagnosis is, but they may indicate on the participant demographic questionnaire if they have a diagnosis. Participants making an LPA are likely to have a diagnosis of dementia, or suspected diagnosis.

Interview data
The participants will be individuals with mild dementia, or a diagnosis of suspected mild dementia, and their family members/supporters, this is made explicit in the advert for the project, and in the information, sheets provided. I will not explicitly ask the interviewees what their diagnosis is, but they may indicate on the demographics questionnaire if they have a diagnosis of a dementia (or other degenerative mental disability). Participants accessed through dementia groups are presumed to have a diagnosis of dementia, or a suspected diagnosis.

It is not essential that participants have made an LPA or will. The participants may be affiliated with a dementia network, but this is not essential. Participants will be located within the UK and reasonable travelling distance from either Birmingham, Loughborough, Dorset or London.
Ideally 30 individuals and their families will take part in the interviews. These individuals can be the same participants from the observational data set, if they have consented to take part in both parts of the study.

Exclusion criteria
Participants will be excluded if they do not have the capacity to consent to take part in the research.

11. RECRUITMENT

Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student).

Note: Attach a copy of any poster(s), advertisement(s) or letter(s) to be used for recruitment.

Observational data participation

Paperwork provided for recruitment:

- Information sheet for Lawyers
- Information sheet for Clients
- Consent form for Lawyers
- Consent form for Clients
- EasyRead Information sheet
- Easyread consent form
- Demographics form
- Contact information form
- Support Information sheet
- Website page for legal settings (attached as an email link).
- Template email for lawyers to send to clients

I will request to be introduced to several potential law firms by the Society of Trust and Estate Practitioners (STEP) and Centre for Professional Legal Education and Research (CEPLER). I will then discuss my research project with the firm and give them copies of my information and consent forms. Through discussing the potential to take part I will establish any concerns the solicitors have regarding communication and organization and address these, I will not change the approach of my research dependent, only the logistical aspects working with the administration to organise participation (if the firm has agreed). I will be available to attend any face-face or virtual meetings with the firm and their solicitors. If the firm agrees to participate then I will provide them with solicitor specific information sheets and consent forms which must be signed prior to any client contact.

With each firm I will set up notification system with them dependent on how they would like to proceed, so that I am made aware when clients discussing wills or LPA's have appointments. (e.g. email or telephone contact at regular time to check potential observations, e-calendar invite)

I will give the firm the option of using an email template to notify clients of the project before any scheduled meetings.

I will also give the firm the option of using a poster (or alternative format) with information about the project and their involvement.

Clients will be approached before the meeting is taking place via email about the research. If clients wish to participate they will be asked to arrive 15minutes before their appointment so that I can explain my research and clients can read and sign all consent forms. I will emphasise there is no pressure to take part. The clients will be given an easy read information sheet and consent form. Once reading the information sheet they will be asked if they have any questions, and if they wish to take part to read and sign the consent form.

Interview participation

Paperwork Provided for recruitment:

- Information sheet
- EasyRead information sheet
- EasyRead consent form
- Consent form
- Demographics form
- Poster for gate holder organisations (which may be edited into preferred format, i.e. leaflet, email attachment, website link)
- Support Information sheet

Several organisations which offer support and information to people with dementia and their families/carers will be contacted regarding the research (such as Alzheimer's Society, Young Dementia UK and DEEP). They will be invited to advertise the project through their support networks, in whatever format they deem suitable (online, posters at locations, researcher presentation, leaflets). Dependant on the response I will provide the relevant materials for the advertisement of the project, or attend a group meeting and present my research and be available to discuss the research in person.

In the advertisement I will provide my contact information so that individuals who would like to participate can volunteer themselves, and contact me with any questions, to discuss the project, and subsequently if desired set up an interview.

It will be made clear on the advertising material that I am interested in individuals with dementia or suspected dementia and their family members/carers. I will also make clear that the person with dementia must have capacity to consent to research, therefore will be in the early stage of the disease.

I will also use the Join Dementia Research website to advertise the project (https://www.joindementiaresearch.nihr.ac.uk). This website advertises research looking for participants with dementia, this website is operated by the National Institute for Health Research. As stated on the application 'the system enables researchers to identify and contact potential volunteers. To use the system you will need to be issued with a user account, undergo a one-hour training programme and your institution will need to approve your use through a Data Processing Agreement. This will be managed as part of your application, which can take 6-8 weeks'.

If there is little response to this avenue of recruitment I will request that an email is sent through the university internal email system to students and/or staff about taking part in the study to access this potential participant group. I will attach in this email the information sheet and consent forms. I will transform the poster advertisement into email format.

Clients who take part in the observational research will be given the opportunity on the optional contact information form to indicate if they would be interested in taking part in an interview for the project, and to provide their contact information if they wish to. If a client provides contact information I will contact them after the meeting and discuss the proposed interview, and if they have an email address send them the information sheet and consent forms. If they do not have an email adress I will post hard copies.

12. CONSENT

a) Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why**.** If the participants are minors or for other reasons are not competent to consent, describe the proposed alternate source of consent, including any permission / information letter to be provided to the person(s) providing the consent.

Fully informed consent will be obtained for this project. Easy-read information sheets and consent forms will be used for the clients and interviewees.
Solicitors will be required to read and sign a separate information sheet and consent form prior to any recordings taking place. They will also be required to sign and consent to each individual meeting recording.

All participants will give informed consent to take part. Dual consent forms will be used, whereby one is kept by the participant for their records, and one will be kept by the researcher. Clients will be required to read the information sheet in full prior to consenting to take part. Before the consent forms are signed, I will ask if there any questions arising from the information sheet. After the recording is made the client, solicitor, and any supporter(s) present are required to re-affirm that they allow the recording to be submitted for use, by using the tick boxes on the second part of the consent form. If this is not ticked, it must be assumed that the participants have not given full consent, and the data cannot be used (unless contacted and submission is confirmed).

Interviewees will be sent information sheets and consent forms prior to organising an interview either by email or if that is not possible, by post. Before the interview begin and the recording starts interviewees are required to read the information sheet and will have the opportunity to ask any questions. Interviewees are then required to sign the consent form if they wish to participate.

In both settings I will emphasise that there is no pressure to take part in the research, and that they can withdraw at any time during the recording, and that they may withdraw their data up to 3 months after the date it took place.

Note: Attach a copy of the Participant Information Sheet (if applicable), the Consent Form (if applicable), the content of any telephone script (if applicable) and any other material that will be used in the consent process.

b) Will the participants be deceived in any way about the purpose of the study? **Yes** ☐ **No** ☒

If yes, please describe the nature and extent of the deception involved. Include how and when the deception will be revealed, and who will administer this feedback.

13. PARTICIPANT FEEDBACK

Explain what feedback/ information will be provided to the participants after participation in the research. (For example, a more complete description of the purpose of the research, or access to the results of the research).

All participants will be offered access to the final thesis through the university of Birmingham thesis repository. A brief lay summary will be created for ease of consumption, but they will have access to the full thesis if desired.

14. PARTICIPANT WITHDRAWAL

a) Describe how the participants will be informed of their right to withdraw from the project.

The right to withdraw will be expressed on the information sheet. Furthermore clients and solicitors will have the opportunity to remove consent at the end of each recording, if they are no longer happy to submit the recording. This will be evident by the second page of the consent form. Offering the two-stage consent ensures that each recording submitted is fully consented to, and the right to withdraw is very evident to the participants.

For the interviews that take place clients will be contacted the day before the interview is due to take place to check that they still wish to conduct the interview. Before the interview takes place the client will be given the information sheet which will explicitly state the right to withdraw at any time during the interview, before and/or after. At the end of the interview I will verbally ask the interviewee if they are happy for me to use the recording, as they consented to at the start of the session.

All participants will have been given my contact information, as well as my supervisors contact information so that they can withdraw their data if they wish to do so up to 3 months after the interview or observation took place.

b) Explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant's data if they withdraw.

For the participant there will be no consequences of withdrawing their data, they are free to do so. If a participant withdraws their data, all data will be deleted from any and all devices it stored on. All consent forms will be securely disposed of (along with any transcripts created).

15. COMPENSATION

Will participants receive compensation for participation?

i) Financial **Yes** ☐ **No** ☒

ii) Non-financial **Yes** ☐ **No** ☒

If **Yes** to **either** i) or ii) above, please provide details.

If participants choose to withdraw, how will you deal with compensation?

16. CONFIDENTIALITY

a) Will all participants be anonymous? **Yes** ☐ **No** ☒

b) Will all data be treated as confidential? **Yes** ☒ **No** ☐

Note: Participants' identity/data will be confidential if an assigned ID code or number is used, but it will not be anonymous. Anonymous data cannot be traced back to an individual participant.

Describe the procedures to be used to ensure anonymity of participants and/or confidentiality of data both during the conduct of the research and in the release of its findings.

Participants will not be anonymous in the raw data collected, as I will be present to explain the study, and for the recording (unless requested to leave). This is unavoidable given the naturalistic observational data. However, during transcription of all data the participants will be made anonymous, through giving pseudonyms and replacing any identifying information with fake information. A list of pseudonyms will be kept with the real names in a spreadsheet on a password protected computer so that if a participant wishes to withdraw their data then the researcher can do so and also remove their consent forms from the collection. Any audio data to be presented publicly (outside of the researcher and supervisors) will be anonymised using pitch shifting so voices will not be recognisable.

All data will be kept confidential, no data will be discussed outside of the research team. It will be kept on a password protected computer, and an encrypted flash-drive and the University of Birmingham secure drive. I will transfer all recordings to the password protected laptop, encrypted flash-drive and university of Birmingham secure drive on the same day that the recording takes place, and then deleted the recording from the digital recording device. I will store the data in three places as per the university of Birmingham data management plan guideline.

Though I will keep all data confidential, if extenuating circumstances were to occur such as any instances where a client gives cause for concern about safety of themselves or others, or discloses any illegal acts, I will adhere to those guidelines in place by the BPS and the University of Birmingham and will disclose this information to the relevant organisations and notify the clients that I have to do this. I will also work within any additional stipulations put forth by the solicitors to protect confidentiality.

If participant anonymity or confidentiality is not appropriate to this research project, explain, providing details of how all participants will be advised of the fact that data will not be anonymous or confidential.

17. STORAGE, ACCESS AND DISPOSAL OF DATA

Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

Only myself and my supervisors, will have access to the recordings and contact information forms (or any other form with identifying information). All data will be kept confidential, no data will be discussed outside of the research team. In the event of using a confidential transcription service, the transcriber will also have access to the recordings prior to anonymisation.

Audio recordings of interviews and observations

- Audio recordings will be stored during the research on a password protected laptop, an encrypted flash-drive, and the University of Birmingham research data server. The audio recordings will be transferred from the recording device on the day they are made, no recordings will be stored on the recording device for longer than 24hours.
- This raw data will have to be destroyed after the PhD thesis is submitted, as it will not be anonymised.

Anonymised transcripts of interviews and observations

- All names, places and other identifying information will be replaced with fake information (pseudonyms etc…) in transcripts and reports.
- All transcripts will be anonymised when being written up
- They will be stored on a password protected laptop, an encrypted flash drive, and the University of Birmingham data server. Any printed copies will be stored in a locked filing cabinet.
- The data will be transferred to the university of Birmingham research data archive when the PhD thesis is submitted and be stored here for the duration of 10years and available for future research.

Pitch modified audio clips (anonymised audio)

- Anonymity measures such as pitch shifting voices will be used for any data clips used in presentations and played outside the primary research team. Only short segments of the interactions will be reproduced in reports and presentations, so it is unlikely that a reader/audience member would recognise the speaker from their personal circumstances. However, particularly distinctive events or descriptions will not be quoted or played beyond the research team.
- Any names or places in these audio recordings will be muted.
- Audio recordings will be stored during the research on a password protected laptop, an encrypted flash-drive, and the University of Birmingham research data server.
- The data will be transferred to the university of Birmingham research data archive when the PhD thesis is submitted and be stored here for the duration of 10years and available for future research.
- Anyone who has access to this data must do so following the same precautions put in place.

All paper forms (consent forms, demographics information, field notes)

- All forms will be stored during the research in a locked filing cabinet, the demographics form and contact information forms will be kept in a different locked drawer in the filing cabinet to the other forms (consent etc…). Field notes will also be kept in this draw. This is to avoid the identifiable information being kept in the same place as the coded information and increase confidentiality and security of anonymity.
- When the PhD thesis is submitted all forms with contact information, or any other identifying information will be destroyed. All consent forms will be digitised and uploaded to the university of Birmingham research data server and stored for 10 years.

18. OTHER APPROVALS REQUIRED? e.g. Criminal Records Bureau (CRB) checks or NHS R&D approvals.

☐ YES ☒ NO ☐ NOT APPLICABLE

If yes, please specify.

19. SIGNIFICANCE/BENEFITS

Outline the potential significance and/or benefits of the research

This research is unique as it will observe naturally occurring conversations about capacity in a legal setting, and use conversation analysis to establish how participants are constructing capacity through their talk, how capacity is oriented to in this setting, and how it is navigated by both client and solicitor. This has not been done before and is imperative to understanding how the Mental Capacity Act, Banks v Goodfellow test, and the UN CRPD inform everyday practice.

Legal firms benefit from taking part in this research by contributing to research which aims to improve legal practice, and provide feedback to legal actors of good practice with clients.
Clients benefit from taking part because as a result of the research I hope to be able to contribute to how legal practice concerning capacity occur, and what this means for law and policy (particularly on wills and LPAs)

The interviews for this research will provide insight into how law is understood by those persons it is in place to protect, what information is accessed and understood, and how it is interpreted. This will contribute to the knowledge about how to enable individuals to access their legal rights, and provide new insight into how legal capacity is constructed by the people which it is most likely to become affected.

20. RISKS

a) Outline any potential risks to **INDIVIDUALS**, including research staff, research participants, other individuals not involved in the research and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap

The observational research poses no potential risks any greater than that experienced in everyday life, because the research is using naturally occurring data in a safe and secure environment. The only infringement is the presence of the recording device and the researcher (unless requested to leave), and all the data will be stored safely and securely.

The interviews pose risk to the interviewer (only I will carry out the interviews). I will employ a lone worker protocol to ensure my safety. The interview take place at their place of residence or an office space if requested. If an office is requested I will be familiar with the space and know safety protocols and make the interviewee's aware of these. I will follow a lone protocol to avoid any unnecessary risk. When arriving to conduct an interview I will notify an individual via text, and when leaving I will notify them via text. If they do not hear from me after 3 hours (unless I have notified them otherwise) this will indicate that I need to be contacted.

The subject matter, particularly in the interviews is emotive and therefore may cause some upset in the participants. I am providing support and advice information sheets to all participants, detailing websites specific to will making and lasting powers of attorney for information (e.g. Willaid.org.uk, www.gov.uk/make-will, www.gov.uk/power-of-attorney). Also included is information about dementia and Alzheimer's support services (The Alzheimer's society), and general emotional and wellbeing support contacts (www.samaritans.org, www.nhs.uk/conditions/counselling/). Participants are also explicitly notified on the information sheets and consent forms that they can stop the interview at any time and do not have to answer every question asked. Observation participants are given the opportunity to re-confirm their consent at the end of the meeting, and it is explicit on the information sheet that they can stop the recording at any time and ask the researcher to leave at any time.

b) Outline any potential risks to **THE ENVIRONMENT and/or SOCIETY** and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap.

There are no foreseen risks to the environment or society.

21. ARE THERE ANY OTHER ETHICAL ISSUES RAISED BY THE RESEARCH?

Yes ☐ **No** ☒

If yes, please specify

I will only be recruiting participants who have the capacity to consent. I will use the Mental Capacity Act (2005) section 3 capacity assessment. This assessment stipulates that a person has capacity to consent if they understand the information, can retain it, weigh the information, and communicate this decision. It also states that the participant must be given all information to aid them to make the decision.
I will abide by what the Mental Capacity Act states and provide all information and ensure every participant before consenting to take part has understood and evaluated the information.

22. EXPERT REVIEWER/OPINION

You may be asked to nominate an expert reviewer for certain types of project, including those of an interventional nature or those involving significant risks. If you anticipate that this may apply to your work and you would like to nominate an expert reviewer at this stage, please provide details below.

Name
Contact details (including email address)
Brief explanation of reasons for nominating and/or nominee's suitability

23. CHECKLIST

Please mark if the study involves any of the following:

- Vulnerable groups, such as children and young people aged under 18 years, those with learning disability, or cognitive impairments ☒
- Research that induces or results in or causes anxiety, stress, pain or physical discomfort, or poses a risk of harm to participants (which is more than is expected from everyday life) ☐
- Risk to the personal safety of the researcher ☒
- Deception or research that is conducted without full and informed consent of the participants at time study is carried out ☐
- Administration of a chemical agent or vaccines or other substances (including vitamins or food substances) to human participants. ☐
- Production and/or use of genetically modified plants or microbes ☐
- Results that may have an adverse impact on the environment or food safety ☐
- Results that may be used to develop chemical or biological weapons ☐

Please check that the following documents are attached to your application.

	ATTACHED	NOT APPLICABLE
Recruitment advertisement	☒	☐
Participant information sheet	☒	☐
Consent form	☒	☐
Questionnaire	☒	☐
Interview Schedule	☒	☐

24. DECLARATION BY APPLICANTS

I submit this application on the basis that the information it contains is confidential and will be used by the University of Birmingham for the purposes of ethical review and monitoring of the research project described herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any other purpose without my prior consent.

I declare that:

- The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it.
- I undertake to abide by University Code of Practice for Research (http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines.
- I will report any changes affecting the ethical aspects of the project to the University of Birmingham Research Ethics Officer.
- I will report any adverse or unforeseen events which occur to the relevant Ethics Committee via the University of Birmingham Research Ethics Officer.

Name of principal investigator/project supervisor:	
Date:	

Please now save your completed form, print a copy for your records, and then email a copy to the Research Ethics Officer, at aer-ethics@contacts.bham.ac.uk. As noted above, please do not submit a paper copy.

Appendix B

Literature search criteria

I used the Web of Science database for two searches and FindIt@Bham for a final search. The first web of science search criteria can be seen in the table 2.1:

Table B.1 Web of Science search

Topic	Categories Included	Type
Capacity OR Competency AND assessment AND review - Within results: Decision	Psychology Within Psychology; - Multidisciplinary, clinical, applied, biological, social, behavioral sciences, gerontology, clinical, clinical neurology, or geriatrics gerontology.	Article

This search yielded 47 results, 26 were relevant. Those that were not relevant were either, not in English or on another topic (namely, Schizophrenia patients, suicide and fisheries).

I conducted a second web of science search, as the initial search was focused on reviews, and searched for articles specifically about the MMSE, which is cited as the most used test in the U.K.

The second web of science search criteria can be seen in the table 2.2:

Table B.2: Web of Science Search 2

Topic	Categories Included	Type
MMSE OR Mini-Mental State Exam AND Assessment AND Capacity - Within results: Decision - Within Results: Decision-making	Psychology Within Psychology; - developmental, geriatrics, gerontology, clinical, neurology, psychiatry, behavioural science,	Article

	experimental, social sciences, interdisciplinary, multidisciplinary OR health care sciences.	

This yielded 52 results, 17 were relevant. Those that were not relevant were either not in English, or on another topic.

Finally, after encountering access issues in the web of science searches I conducted a 'findit' search through the University of Birmingham library service. This yielded 58 results, 6 were relevant. Those that were excluded were primarily book or article reviews, or not available in English. The search criteria can be seen in the table 2.3:

Table B.3:Diversity of Birmingham FindIt library search

Title	Journal topics excluded	Type
Capacity AND Decision AND Assessment	Schizophrenia Research Stroke Rehabilitation	Article

These three literature searches provide a comprehensive basis of capacity assessments used in psychology. I made a list of all assessments used, including those used outside of the U.K. In Table 2.4 I detail the comprehensive list produced from this search and categorised these tests to give an indication of their use, and what each test consists of. I decided to include non-UK tests to explore the field of psychology and its capacity definitions fully.

Appendix C

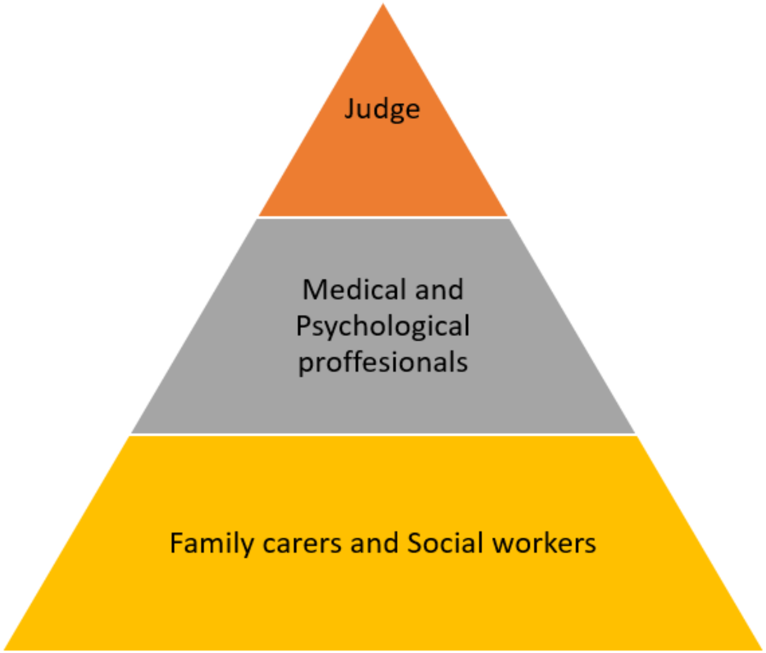
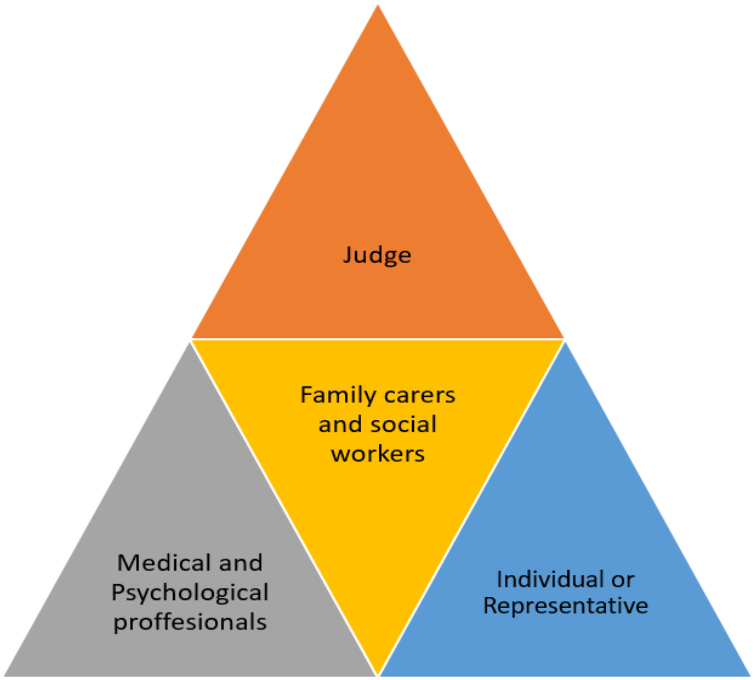
List of cases included in content analysis

Name of case
A County Council v E [2012] EWCOP 4161
A Local Authority v A [2010] EWHC 978 (Fam)
A Local Authority v AK [2012] EWCOP B29
A Local Authority v E [2012] EWHC 1639 (COP)
A Local Authority v F G, A G, H G 2011 EWHC 3932 (COP)
A Local Authority v H [2012] EWHC 49 (COP)
A Local Authority v K [2013] EWCOP 242
A Local Authority v SY [2013] EWCOP 3485
A Local Authority v TZ [2013] EWCOP 2322
A Local Authority v TZ [2014] EWCOP 973
A London Local Authority v JH [2011] EWCOP 2420
A NHS Trust v DE [2013] EWHC 2562 (Fam)
A NHS Trust v Dr A A NHS Trust v Dr A [2013] EWHC 2442 (Fam) [2014] Fam. 161
A Primary Care Trust v LDV [2013] EWHC 272 (Fam)
A v X [2012] EWHC 2400 (COP)
Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67
AJ v A Local Authority [2015] EWCOP 5
Banks v Goodfellow (1869-70) LR 5 QB 549
D Borough Council v AB (Rev 1) [2011] EWCOP 101
D County Council v LS (2010) EWHC 1544 (Fam)
D v R (The Deputy of S) & Anor [2010] EWHC 2405 (COP)
Derbyshire County Council v AC [2014] EWCOP 38
Dunhill v Burgin (2012) EWCA Civ 397
G v E [2010] EWCOP 621
GW v A Local Authority [2014] EWCOP 20
Heart of England NHS Foundation Trust v JB [2014] EWCOP 342
HL v United Kingdom (2004) 17 BHRC 418
IM v LM and others [2014] EWCA Civ 37 [2015] Fam. 61
In Re A (Capacity Refusal of Contraception) [2010] EWHC 1549 (Fam) [2011] Fam 61
KC v City of Westminster [2008] EWCA Civ 198
Key v Key [2010] EWHC 408 (Ch) [2010] 1 WLR 2020
Kicks v Leigh [2014] EWHC 3926 (Ch)
KK v STCC [2012] EWCOP 2136
LBL v RYJ [2010] EWCOP 2665
LBX v K & Ors [2013] EWHC 3230 (Fam)
LBX v TT [2014] EWCOP 24
London Borough of Ealing v KS [2008] EWHC 636 (Fam)
London Borough of Hillingdon v Neary [2011] EWHC 1377 (COP)
London Borough of Islington v QR [2014] EWCOP 26
London Borough of Redbridge v G [2014] EWCOP 485
Loughlin v Singh & Ors [2013] EWHC 1641 (QB)
Masterman Lister v Jewell [2002] EWCA Civ 1889 [2003] WLR 1511
Mental Health Trust v DD [2014] EWCOP 8
Mental Health Trust v DD [2014] EWCOP 11
Mental Health Trust v DD [2014] EWCOP 13

Mental Health Trust v DD [2015] EWCOP 4
NCC v PB and TB [2014] EWCOP 14
NHS Foundation Trust v X [2014] EWCOP 35
NHS Trust v FG [2014] EWCOP 30
Nottinghamshire Healthcare NHS Trust v RC [2014] EWCOP 1317
P v Cheshire West and Chester Council; P and v Surrey County Council [2014] UKSC 19
Parker v Felgate and Tilley (1883) 8 PD 171
PC and NC v City of York Council [2013] EWCA Civ 478
Pearce v Beverley [2013] EW Misc 10 (CC)
PH v A Local Authority [2011] EWHC 1704 (Fam)
R v Bournewood [1999] 1 A.C. 458 [1998] 3 W.L.R. 107
R v C [2009] UKHL 42 [2009] 1 W.L.R. 1786
Re A (Male Sterilization) [2000]
Re Beaney [1978] 1 WLR 770
Re CA (A Baby) (2012) EWHC 2190 (Fam)
Re F [2009] EWCOP B30
Re P Capacity to tithe inheritance [2014] EWHC B14 (COP)
Re RGS [2012] EWCOP 4162
Re S and S (protected persons) [2008] EWHC B16 (Fam)
Re SB (A Patient; Capacity To Consent To Termination) [2013] EWCOP 1417
Re UF [2013] EWCOP 4289
Rochdale BC v KW [2014] EWCOP 45
Royal Free NHS Foundation Trust v AB [2014] EWCOP 50
RT v LT [2010] EWCOP 1910
Sandwell Metropolitan Borough Council v RG [2013] EWCOP 2373
Sheffield City Council v E & Anor [2004] EWHC 2808 (Fam)
SMBC v WMP [2011] EWCOP B13
Surrey And Sussex Healthcare NHS Trust v Ms AB [2015] EWCOP 50
The Local Authority v HP [2013] EWCOP B40
The Public Guardian v CT [2014] EWCOP 51
Tower Hamlets v TB & Anor [2014] EWCOP 53
Turner v Phythian [2013] EWHC 499 (Ch)
W v M [2011] EWCOP 2443
Wandsworth CCG v IA [2014] EWCOP 990
Westminster v Sykes [2014] EWHC B9 (COP)
X v A Local Authority [2014] EWCOP 29
X v MM [2007] EWHC 2003 (Fam)
XCC v AA [2012] EWCOP 2183
Y County Council v ZZ [2012] EWCOP B34
YLA v PM & Anor [2013] EWHC 4020 (COP)
Greenwich RBC v CDM
Y v A Healthcare NHS Trust
Ashman v Thomas
Dudley MBC v S
HH, Re
James v James
JMA, Re
JMK, Re
Malik (Deceased) v Shiekh

NHS Trust v Y
Nutt v Nutt
Purvis v Purvis
PW v Chelsea and Westminster Hospital NHS Foundation Trust
UKT_2018_01_43644531
Wheeler v Scottish Ministers
A Hospital NHS Trust v CD
A Local Authority v D
Abertawe Bro Morgannwg University Local Health Board v RY and Another
ADS v DSM and others [2017]
Brent LBC v SL [2017]
Cheshire and Wirral Partnership NHS Foundation Trust v Z
N v ACCG and others [2017]
Newcastle Upon Tyne City Council v P
NHS Acute Trust v C
PB v RB and another
Poole and another v Everall and another
R (on the application of Liverpool city council) v secretary of state for health [2017]
Re G
Re IH (Observance of muslim practice [2017]
Re N (Deprivation of Liberty Challenge)
Re R (Serious Medical Treatment)
Re RD
Re SW_EWCOP [2017]
Rochdale Metropolitan Borough Council v KW (No 2)
Southwark LBC v KA
Staffordshire County Council v k
Staffordshire County Council v SRK and others
University Hospital NHS Trust v CA
Watt v ABC

Cases selected for thematic analysis

	Neuro-Centric Model of MC Law	**Person-Centred Model of MC Law**
Model		
Cases	D v R (The deputy of S) & Anor (2010) Loughlin v Singh & Ors [2013] E Wandsworth CCG v IA [2014] E A Local Authority v SY [2013] GW v A local authority [2014] E Key v Key [2010] ewch 408 NHS Foundation Trust v X [2014]	Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67 Cheshire West and Chester Council v P [2014] UKSC 19 Ilott v The Blue Cross [2017] UKSC 17 Masterman Lister v Jewell [2002] A Local Authority v TZ [2013] A London Local Authority v JH [2011]

Theory	Neuro culture Hypercognitive ideals Brainhood Kantian individualistic autonomy	Person centred theory from care ‘best interests’ definition Personhood and person-centred’ness Slight relational autonomy, but not fully.

Appendix D

Literature review criteria and reasoning

I conducted three structured literature searches, and then used the 'berry picking' method to find original citations and include frequently cited works (Bates, 1989). I searched public health websites such as the NHS, and Alzheimers.org.

Categorisation of assessments

I categorised assessments based on use and theoretical underpinnings. Theoretical underpinnings included cognitive psychology, neurocognition, everyday function, person-centred care. There were similarities between cognitive psychology and everyday function, hence these were categorised under functional/cognitive assessments. There were also tests explicitly created for use in legal settings

Table D1
These capacity assessments assess cognitive, financial, functional and general capacity. They have been categorised here as person-centred, forensic (for use in legal settings or adhering to legal definitions) or functional tests focusing on neurocognitive function. Some tests appear in multiple categories as they include multiple elements spanning across categories.

Forensic assessments (used in/for legal settings) Person-Centred/Integrated assessments	
Assessment Name	**Theoretical understanding**
Assessment Name	**Theoretical understanding**
Independent living scales (Bucks, Ashworth, Wilcock, & Siegfried,	For carer reports, identify activities of daily living, self-care, orientation, and mobility
MacArthur Competence Assessment Tool for Treatment (Grisso & 1996; Cullum et al., 2001; Debettignies, Mahurin, & Pirozzolo, 1990; Appelbaum, 1998) Graf, 2013)	Person-centred values and cognitive psychology knowledge as factors for everyday capacity. Functional capacity approach
Hopemont capacity assessment interview (Edelstein, 1999)	Person-centred values and cognitive psychology knowledge and case law examples
Hopkins Competency Assessment Test (Janofsky, Mccarthy, & Foistein, 1992)	Psychiatric competency assessing understanding
Capacity to Consent to Treatment Instrument (Marson, Ingram, Cody,	values) Cognitive
Assessment of Consent Capacity for Treatment (Appelbaum, 2007) & Harrell, 1995)	Person-centred care
Hopemont Capacity Assessment Interview (Edelstein, 1999)	Person-centred values and cognitive psychology knowledge and case law examples
The Lichtenberg Financial Decision Screening Scale (Lichtenberg, Financial Capacity Instrument (Marson et al., 2000) Stoltman, Ficker, Iris, & Mast, 2015)	Person-centred values and cognitive psychology knowledge Cognitive and functional ability (i.e. check book management)
Assessment of Competence for Everyday Decision-Making (Lai & Karlawish, 2007)	Person-centred values and cognitive psychology knowledge, case law examples, and clinical medical information.
The Lichtenberg Financial Decision Screening Scale (Lichtenberg et al., 2015)	Person-centred values and cognitive psychology knowledge

Functional/ cognitive assessments	
Assessment Name	**Theoretical Understanding**
Instrumental Activities of Daily Living Scales (Lawton & Brody, 1969)	Functional ability performance
Abbreviated mental test (Hodkinson, 1972)	Cognitive
Mini-Mental State Examination (MMSE) (Folstein, Folstein, & Mchugh, 1975)	Cognitive
Cognitive Competency Test (Wang & Ennis, 1986)	Cognitive
Battery for Neuropsychological Assessment (Morris et al., 1989)	Neurocognitive
Ontario Competency Questionnaire (Draper & Dawson, 1990)	Cognitive
Direct Assessment of Decision-Making Capacity (Fitten, Lusky, & Hamann, 1990)	Cognitive
Kohlman Evaluation of Living Skills (Thomson, 1992)	Functional ability performance
Capacity to Consent to Treatment Instrument (Marson et al., 1995)	Cognitive
A.D. assessment scale (Galasko et al., 1997)	Neurocognitive
Clinical Dementia Rating Scale (Morris, 1997)	Cognitive
Disability Assessment for Dementia (Gélinas, Gauthier, Mcintyre, & Gauthier, 1999)	Functional ability performance (e.g. Self-care, daily living)
Addenbrookes cognitive examination (Mathuranath, Nestor, Berrios, Rakowicz, & Hodges, 2000)	Cognitive, neurocognitive
Test of Everyday Functional Abilities (Cullum et al., 2001)	Functional ability performance

Capacity Assessment Tool (Carney, Neugroschl, Morrison, Marin, & Siu, 2001)	Cognitive
Mini-Cog (Borson, Scanlan, Chen, & Ganguli, 2003)	Cognitive
Vignette method (Vellinga, Smit, Van Leeuwen, Van Tilburg, & Jonker, 2004)	Cognitive
Montreal Cognitive Assessment (MoCA) (Nasreddine et al, 2005)	Cognitive
Assessment of Competence for Everyday Decision-Making (Lai & Karlawish, 2007)	Person-centred values and cognitive psychology knowledge, case law examples, and clinical medical information.
Semi-Structured Clinical Interview for Financial Capacity (Marson, 2009)	Cognitive

Appendix E

Useful Information (Page 1 of 2)

Please find below my contact information, if you have any questions after you have taken part please do not hesitate to contact me.

Name: Chloe Waterman

Email: [redacted]

Telephone: [redacted]

Please find below contact details of several organisations which may be of interest for you and/or which offer support and assistance.

Information/Advice on Making a Will or Lasting Power of Attorney:

- Government information websites on wills and Lasting Powers of Attorney:
  www.gov.uk/make-will
  www.gov.uk/power-of-attorney
- There are several will writing charities:
  www.willaid.org.uk
  freewillsmonth.org.uk/
- *AgeUk* are a charity which offer help and support to all older people and they have practical information on will making and lasting powers of attorney
  www.ageuk.org.uk/information-advice/money-legal/
  AgeUk Advice Line: 0800 055 6112
- *Young Dementia UK* have information tailored to individuals who would like to make a will who have a dementia diagnosis:
  www.youngdementiauk.org/making-will
- *The Alzheimer's society* have legal information available on their website, as well as the Dementia support phoneline:
  www.alzheimers.org.uk
  Dementia Support phoneline: 0300 222 11 22

- Office of the Public Guardian is a government body. It supplies legal information and helps protect people who lack mental capacity.
  www.gov.uk/government/organisations/office-of-the-publicguardian
  0300 456 0300
- Citizens Advice gives free information and advice in person, by phone or online.
  www.citizensadvice.org.uk
  03444 111 444

Support Services

If you feel you need more support or feel you need to talk to someone, these are some services which may be of use to you.

- Sometimes we need to talk to a professional, someone who is trained to listen and the NHS offers information about counselling and how to find a counsellor:
  www.nhs.uk/conditions/counselling/
- The NHS have a website detailing potential support routes for people with dementia as well as information about charities and support forums:
  www.nhs.uk/conditions/dementia/help-and-support/
- *AgeUk* are a charity which offer help and support to all older people and they have offer advice and information about health and wellbeing, as well as local services
  www.ageuk.org.uk/information-advice/health-wellbeing/mind-body/mental-wellbeing
  AgeUk Advice Line: 0800 055 6112
- The Samaritans also offer a confidential listening service 24hours a day 365 days a year and you can speak to them by phone, email or letter:
  www.samaritans.org/
  Phone: 116 123
  Email: jo@samaritans.org
  Post: Freepost RSRB-KKBY-CYJK, PO Box 9090, STIRLING, FK8 2SA

Appendix F

Solicitor Information Sheet (Page 1 of 2)

Researcher: Chloe Waterman, [redacted]
Supervision: Professor Rosie Harding, [redacted] Professor Elizabeth Peel,
[redacted]

This research has been approved by the University of Birmingham Humanities and Social Sciences ethics committee.

Aims

The aim of this research is to explore:

> *How legal actors assess capacity, and how this impacts the legally relevant decisions made in the lives of people with dementia*

This research will form the basis of ESRC funded PhD research being undertaken at the University of Birmingham and Loughborough University. The data gathered will be analysed to identify practices used in conversations about wills and powers of attorney and how these inform these legal acts (the making of a will or Lasting Power of Attorney).

Invitation

You are invited to take part in this research because you are a solicitor at Silks and are likely to interact with clients making wills or lasting powers of attorney.

Do I have to take part?

No, participation is completely voluntary. Even if you do agree to participate, you are free to withdraw up to 3 months after your recording took place. You do not have to state why you want to withdraw.

If you agree to take part in this study then you will be asked to sign two consent forms, one for you to keep and one for my records.

What will happen if I take part?

If you agree to take part, you will be asked to contact clients with appointments regarding lasting powers of attorneys or wills (a template email will be provided) about the potential for an audio recording to take place as part of research. Additionally, you will adhere to the research organisation process as agreed with your firm so that I am notified when a recording can take place.

If the clients have agreed, I will audio record the meeting using a small recording device. I will also (most likely) remain in the room for the duration of the meeting and take notes. You do not need to do anything when taking part, the study is observational and I am interested in natural conversations. At the end of the meeting I will ask all participants to confirm they are still happy for the recording to be submitted for my research.
If you want me to leave, or for the recording to stop at any time, say so and this will happen.
Once the recording has taken place it will be transcribed and then analysed using conversation analysis. This analysis will then form part of my thesis.

If your firm has requested, I will create tailored executive summaries of the final thesis. If you would like access to the final thesis contact me and I will provide a link to this on the University of Birmingham thesis repository.

Are there any risks of taking part?

No. There are no foreseen risks if you agree to participate. You can stop the recording at any time.

You will be helping me to research communication practices regarding Lasting Powers of Attorney and wills and I hope to be able to improve/highlight good practice through my findings and provide relevant feedback of good practice use.

How will my information and data be used, and who will have access?

Who will have access?

Only the research team will have access to the original data.

How will you protect my confidentiality and anonymity?

The recordings will be stored on a password protected laptop and encrypted flash-drive.

All signed consent forms and participant information sheets will be kept in a locked folder.

All identifying information (names, dates, places etc) will be changed on transcripts used in presentations. I will obscure any voices in any audio recordings used in presentations and any identifying information will be deleted.

In accordance with university guidelines, the data can be stored securely and kept for 10 years after the research has concluded for use in the future. All confidentiality and anonymity rules will continue to apply to the data.

The only reason I would break confidentiality is if concerns are raised about your or another's safety, or if any illegal activity was disclosed. I would tell you if I had to break confidentiality and explain why.

How can I Withdraw?

If you would like to withdraw your data from the study you may do so up to 3 months after the recording has been made. If you wish for your data to be removed from the study and not used for the research you can email me at: [redacted] or via telephone on: [redacted] You do not need to state why you wish to withdraw and I will send you confirmation by email that I have destroyed all of your data (deleting all electronic copies and shredding any paper forms).

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to the me and I will do my best to answer your questions. Please contact me by Email: [redacted]. If you are unable to contact me by email then you may call me on [redacted]. Alternatively, if you do not wish to contact me you may contact Professor Rosie Harding using the email: [redacted] or telephone: [redacted], or contact via post at:
Birmingham Law School, University of Birmingham. Edgbaston, Birmingham, B15 2TT.

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please contact the research governance officer, Head of Research Governance and Ethics, via post at Research Governance and Ethics Manager, University of Birmingham, Edgbaston, Birmingham, B15 2TT.
If you have any further questions, please contact me at: [redacted]

Proposed Observation Process

1. Recruited solicitors: read and sign all consent forms before any clients approached
2. Solicitors admin send out email to clients making appointments about wills or LPAs, with website link, which will detail contact info and all information that is on the information sheet.
3. I email/phone admin to find out any opt out and appointment times (every week?)
4. I arrive 20mins before every scheduled appointment with all forms – info, consents, demographic, support, contact info.
5. In reception area/room I go through forms with clients, answer any questions 15mins before their appointment
6. When clients called to app I go in with them and start recording
7. At end of meeting before they leave I check I can keep the recording with everyone, just ask 'is everyone happy for me to keep this recording', and I tick the box on the consent forms from the clients.

Solicitor Consent form

Title of Project: Legal Decision-Making in Dementia, a conversation analytic study.

Principal Investigator: Chloe Waterman, [redacted]

Date:

Please tick box if you agree with the statement

You must agree to these statements to take part

1. I have read and understood the information sheet ☐
2. I have had the opportunity to ask questions ☐
3. I understand that my participation is voluntary ☐
4. I understand I am free to withdraw up to 3 months after the recording ☐
5. I agree to take part in this study ☐
6. I understand that all data will be treated confidentially ☐
7. I understand all data will be anonymised before it is used in reports and publ ☐ ons
8. I agree to written transcripts of data being stored for 10 years after the resea ☐ s complete.

The following statements are optional. You do not have to agree to them in order to participate in the research:

9. I agree audio recordings of data being stored for 10 years after the research is complete ☐
10. I agree to transcribed extracts of my data appearing in reports and publications ☐
11. I agree to allow the data to be used for future research projects ☐
12. I agree to audio clips from the data being used in reports and presentations ☐

Name of Solicitor	Date	Signature

Appendix G

Template Email

Dear **[insert client name]**

I am writing to you on behalf of Chloe Waterman, a PhD researcher at the University of Birmingham. **[Insert Firm Name]** has agreed to take part in her. She is researching how legal professionals and their clients talk about making a will, or a lasting power of attorney.

To take part in the research you will need to **arrive to your appointment 15 minutes before** it is scheduled. Chloe will go through all the information and consent forms with you before our appointment begins. During the appointment Chloe will use a small audio recording device to record the meeting

If you **do** want to take part in this research, **please reply to this email** and I will notify Chloe and she will be available before your appointment to go through the research. If you decide on the day not to take part in the research this is absolutely fine and it will in no way affect your appointment. You are under no obligations to take part in the research.

For your information please see below a link to a webpage about the research.

https://blog.bham.ac.uk/legaldecisionmaking/

Sincerely,

Appendix H

Client Information Sheet (page 1 of 3)

Researcher: Chloe Waterman, [redacted]
Supervisors: Professor Rosie Harding, [redacted] Professor Elizabeth Peel,
[redacted]

This research has been approved by the University of Birmingham Humanities and Social sciences ethics committee.

Aims

The aim of this research is to explore:

> *How legal actors assess capacity, and how this impacts the legally relevant decisions made in the lives of people with dementia*

This research will form the basis of ESRC funded PhD research being undertaken at the University of Birmingham and Loughborough University. The data gathered will be analysed to identify practices used in conversations about wills and powers of attorney and how these inform these legal acts (the making of a will or Lasting Power of Attorney).

Invitation

You are invited to take part in this research because you are attending an appointment with a legal professional to discuss making a Lasting Power of Attorney or will. I am especially interested in conversations where someone has early stage dementia (or other mental disorder), but this is not a requirement to take part in the research.

Do I have to take part?

No, participation is completely voluntary. Even if you do agree to participate, you are free to withdraw up to 3 months after your recording took place. You do not have to state why you want to withdraw.

If you agree to take part in this study then you will be asked to sign two consent forms, one for you to keep and one for my records.

What will happen if I take part?

I will audio record the meeting using a small recording device. I will also (most likely) remain in the room for the duration of the meeting and may take some notes. You do not need to do anything when taking part, the study is observational and I am interested in natural conversations.
If you want me to leave, or for the recording to stop at any time, say so and this will happen. There is no pressure to take part.
Once the recording has taken place it will be transcribed and then analysed using conversation analysis. This analysis will then form part of my thesis. If you wish to know the outcomes of my analysis I am happy to share these with you, please simply provide contact information.

Are there any risks of taking part?

No. There are no foreseen risks if you agree to participate. You can stop the recording at any time. I will provide contact details for several information and advice services if you feel you would like more information or support.

You will be helping me to research communication practices regarding Lasting Powers of Attorney and wills, and I hope to be able to improve/highlight good practice through my findings.

How will my information and data be used, and who will have access?

Who will have access?

Only the research team will have access to the original data.

How will you protect my confidentiality and anonymity?

The recordings will be stored on a password protected laptop and encrypted flash-drive.

All signed consent forms and participant information sheets will be kept in a locked folder.

The typed-up audio recordings (transcripts) will not contain any information that could be used to identify you. I will obscure any voices in any audio recordings used in presentations and any identifying information will be deleted.

In accordance with university guidelines, the data will be stored securely and kept for 10 years after the research has concluded for use in the future. All confidentiality and anonymity rules will continue to apply to the data.

The only reason I would break confidentiality is if concerns are raised about yours or another's safety, or if any illegal activity was disclosed. I would tell you if I had to break confidentiality and explain why.

How can I Withdraw?

If you would like to withdraw your data from the study you may do so up to 3 months after the recording has been made. If you wish for your data to be removed from the study and not used for the research you can email me at: [redacted] You do not need to state why you wish to withdraw and I will send you confirmation by email that I have destroyed all of your data (deleting all electronic copies and shredding any paper forms). If you do not have access to email you may contact me via telephone on: [redacted]

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to the me and I will do my best to answer your questions. Please contact me by Email: [redacted] If you are unable to contact me by email then you may call me on [redacted] Alternatively, if you do not wish to contact me you may contact Professor Rosie Harding using the email: [redacted] or telephone: [redacted], or contact via post at:
Birmingham Law School, University of Birmingham. Edgbaston, Birmingham, B15 2TT.

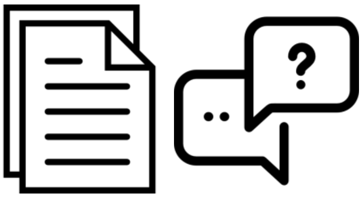
If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please contact the research governance officer, Head of Research Governance and Ethics, via post at Research Governance and Ethics Manager, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

Consent form: Observations EasyRead (Page 1 of 3)

Title of project: Legal Decision-Making in Dementia, a conversation analytic study.

Name of researcher: Chloe Waterman, [redacted]

If you tick 'No' on number 1-8 you cannot take part. If you tick 'No' on 9-12 you can still take part.

1		I have read the information sheet and have been able to ask questions.	Yes ☐	No ☐
2		I know I can choose if I want to take part or not.	Yes ☐	No ☐
3		I agree to take part.	Yes ☐	No ☐
4		I know I can stop at any time.	Yes ☐	No ☐
5		I know I can change my mind about taking part for 3 months after the interview.	Yes ☐	No ☐

6		I agree to the meeting being audio recorded.	Yes ☐	No ☐
7		I understand that nobody will be able to tell I took part because my name will be changed.	Yes ☐	No ☐
8		I agree that the **written record** may be stored for 10 years	Yes ☐	No ☐
9		*I agree that the researchers can use quotes from my recording in presentations and publications.*	Yes ☐	No ☐
10		*I agree that **audio recordings** may be stored for 10 years.*	Yes ☐	No ☐
11		*I agree to audio clips being used for presentations.*	Yes ☐	No ☐
12		*I agree to my recording being used for future research*	Yes ☐	No ☐

Name of participant(s)	Date	Signature
Name of participant(s)	Date	Signature
Name of participant(s)	Date	Signature
Researcher	Date	Signature

1 for Participant, 1 for Researcher

Do all people present confirm their consent to submitting this recording:

Yes ☐

No ☐

Observation Information Sheet (Page 1 of 3)

My name is Chloe Waterman, I am a PhD student at the University of Birmingham.

I am researching how legal decisions are made in the everyday lives of people with dementia or memory problems and their families/carers.

Please read this information sheet and decide if you would like your meeting to be audio recorded.

The University of Birmingham Social Sciences ethics committee approves this research.

You are invited to take part because you have booked an appointment with a solicitor and want to discuss wills or a Lasting Power of Attorney. If you have dementia or memory problems I am very interested in these meetings.

Do I have to be recorded?

✗ **No, it is your choice. It will not affect your meeting with the solicitor.**

You can also change your mind up to 3 months after the interview. Chloe will delete your recording, no questions asked.

If you decide to allow the meeting to be recorded, Chloe will ask you to fill in a consent form before we begin.

What would happen?

Arrive to your appointment 15 minutes before it starts, and Chloe will go through the information sheet and consent form with you.

Chloe will audio record your meeting with your solicitor, she can leave at any time, just ask.

Chloe is interested in normal natural conversation, you do not need to do anything differently in your meeting.

Chloe will type up the audio recordings, and look at the conversation skills.

What about my information?

The recording is in your control, if you want to stop you can. Chloe will also give you information for support/advice services.

Only the research team will listen to the orginal recordings. Chloe will replace all names and personal information when typing up the observations, no-one will be able to tell it is you.

The recordings collected must be kept for 10 years securely. Chloe will make sure you no-one will be able to tell it is you. They will always be kept locked up or password protected.

Problems? If you have any problems or questions about the interviews, contact Chloe. If you want to withdraw, contact Chloe up to 3 months after the recording.

Contact information:

Chloe Waterman

Email: [redacted]

Or call: [redacted]

Problems? Here is the supervisor information if you do not want to contact Chloe directly:

Rosie Harding:

Email: [redacted]

Telephone: [redacted]

Post: Birmingham Law School, University of Birmingham. Edgbaston, Birmingham, B15 2TT.

Complaints? Please contact:

Head of Research Governance and Ethics,

Post: Research Governance and Ethics Manager, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

Consent form (Page 1 of 2)

Title of Project: Legal Decision-Making in Dementia, a conversation analytic study.

Principal Investigator: Chloe Waterman, [redacted]

Recording date:

Please tick box if you agree with the statement

You must agree in order to take part

1. I have read and understood the information sheet ☐
2. I have had the opportunity to ask questions. ☐
3. I understand that my participation is voluntary ☐
4. I understand I am free to withdraw up to 3 months after the recording. ☐
5. I agree to take part in this study. ☐
6. I understand that all data will be treated confidentially ☐
7. I understand all data will be anonymised before it is used in reports and publ☐ons.
8. I agree to written transcripts of data being stored for 10 years after the resea☐s complete.

The following statements are optional. You do not have to agree to them in order to participate in the research:

9. I agree audio recordings of data being stored for 10 years after the research ☐ complete
10. I agree to transcribed extracts of my data appearing in reports and publicati☐
11. I agree to allow the data to be used for future research projects. ☐
12. I agree to audio clips from the data being used in reports and presentations. ☐

Consent form (Page 2 of 2)

Name of Client(s) Date Signature

Do

all

Name of Client(s) Date Signature

Name of Client(s) Date Signature

people present confirm their consent to submitting this recording (*Ticked AFTER recording***):**

Yes ☐

No ☐

Appendix I

Participant Demographic Form (Page 1 of 2)

This form is **not** compulsory. You **do not** have to complete this form to take part.

Session Date:

Session Number (see consent form for code):

Please state whether you have a diagnosis of dementia or other memory problems:

If diagnosis stated, when did you receive this diagnosis?

General Information:

1. **Gender (please tick)**

Male	
Female	
Other (non-binary)	
Prefer not to say	

2. **Age (please state)**

3. **Marital Status (please tick)**

Single	
Married	
Civil-partnership	
Divorced	
Separated	
Widowed	

4. **Do you have any children/dependents? (please tick)**

0 (None)	
1	
2	
3+	

5. **What is your average yearly income? (please tick)**

Less than £15,000	
£15,000 - £19,999	
£20,000 - £29,999	
£30,000 - £39,999	
£40,000 - £49,999	
£50,000 - £59,999	
£60,000 - £69,999	
£70,000+	

6. **Does your household own or rent your accommodation? (Please circle)**

Own outright	
Own with a mortgage or loan	
Part owns/part rents (Shared ownership)	
Rents (with or without housing benefit)	
Lives here rent free	
Residential supported living	

White	British English Welsh Northern Irish Scottish	
	Irish	
	Traveller of Irish Heritage	
	Gypsy / Roma	
	Any other White background	
Mixed	White and Black Caribbean	
	White and Black African	
	White and Asian	
	Any other Mixed background	
Asian or Asian British	Indian	
	Pakistani	
	Bangladeshi	
	Chinese	
	Any other Asian background	
Black or Black British	Black – Caribbean	
	Black – African	
	Any other Black background	
Other ethnic group	Arab	
	Chinese	
	Refused/Prefer Not to Say	
	Any other ethnic group	

7. Ethnicity (please tick)

8. Religion or belief (please tick)
Sexual orientation (please tick)

No religion/belief	
Christian	
Jewish	
Hindu	
Muslim	
Sikh	
Other	

9.

Heterosexual	
Homosexual man	
Homosexual woman	
Other	
Prefer not to say	

10. Do you consider yourself to have a disability (please tick)

Yes	
No	

11. What do you consider your social class to be? (please tick)

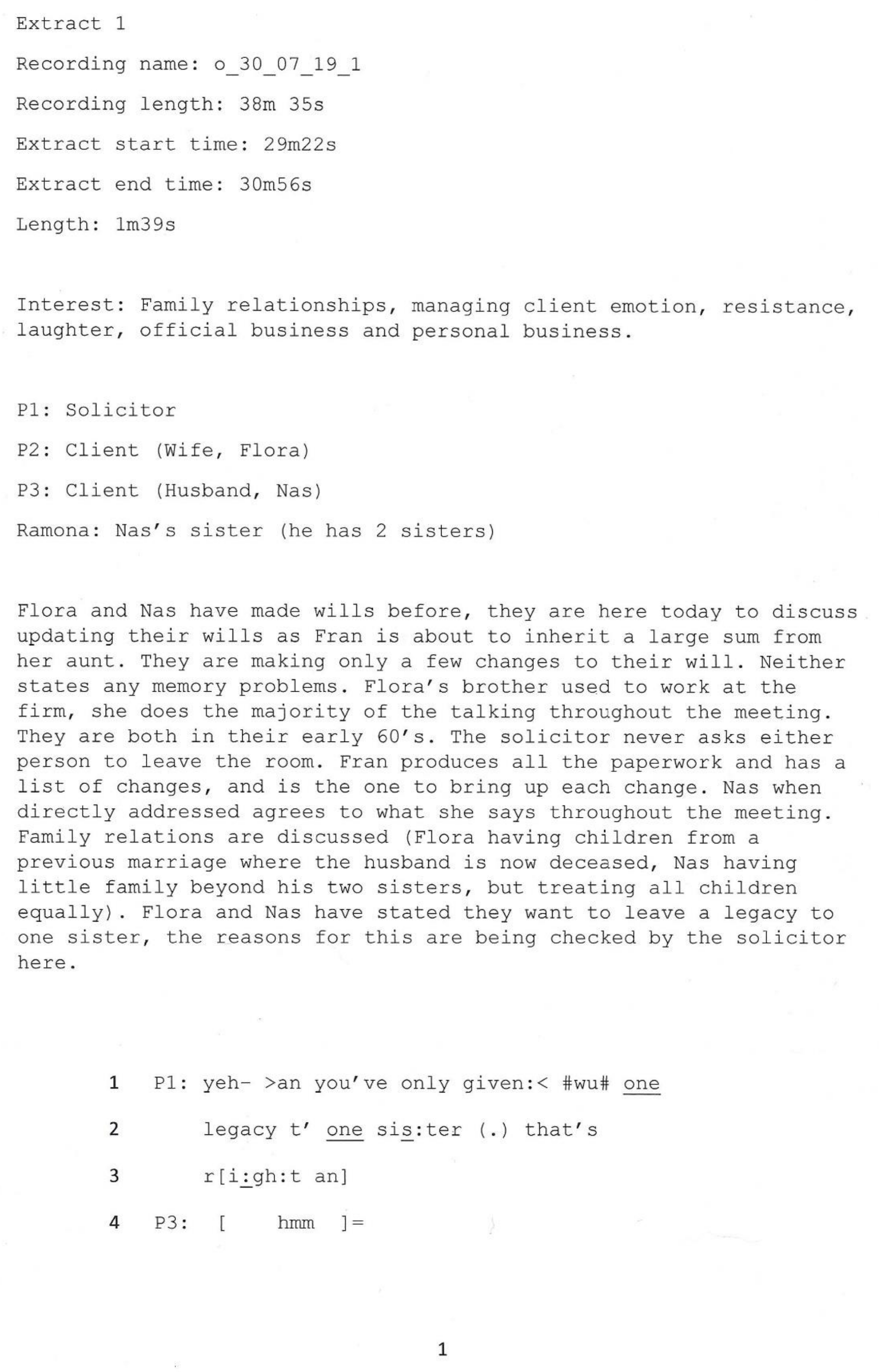
Working Class	
Middle Class	
Upper Class	

12. What is your highest qualification? (please tick)

Secondary School Education (GCSE'S/O-Levels)	
A-Levels/College	
University degree(s)	
Doctorate	

Professional qualifications (e.g teaching, nursing, accountancy	
Other vocational /work-related qualifications	
Foreign qualifications	
No formal qualifications	

Appendix J



Extract 1

Recording name: o_30_07_19_1

Recording length: 38m 35s

Extract start time: 29m22s

Extract end time: 30m56s

Length: 1m39s

Interest: Family relationships, managing client emotion, resistance, laughter, official business and personal business.

P1: Solicitor

P2: Client (Wife, Flora)

P3: Client (Husband, Nas)

Ramona: Nas’s sister (he has 2 sisters)

Flora and Nas have made wills before, they are here today to discuss updating their wills as Fran is about to inherit a large sum from her aunt. They are making only a few changes to their will. Neither states any memory problems. Flora’s brother used to work at the firm, she does the majority of the talking throughout the meeting. They are both in their early 60’s. The solicitor never asks either person to leave the room. Fran produces all the paperwork and has a list of changes, and is the one to bring up each change. Nas when directly addressed agrees to what she says throughout the meeting. Family relations are discussed (Flora having children from a previous marriage where the husband is now deceased, Nas having little family beyond his two sisters, but treating all children equally). Flora and Nas have stated they want to leave a legacy to one sister, the reasons for this are being checked by the solicitor here.

```
1  P1: yeh- >an you’ve only given:< #wu# one
2      legacy t’ one sis:ter (.) that’s
3      r[i:gh:t an]
4  P3:  [   hmm   ]=
```

← Apology by way of reference to

5 P1: =not to your brother-

6 (0.4)sorry not to your bro:ther: (0.5)

Doesn't set an account, matter of continuity

7 P3: °°mhm°°

8 (0.4)

9 P1: an sis:ter: (0.3) >.hh< an not to (.)

10 >you've got two: sisters?< ← Displaying knowledge

← legitimizing mistakes

11 P3: two sisters no. now be:caus::e (0.5) muy

12 PArents died my s:- (.) my other sis[ter]

13 P1: [mmm]

14 (0.3)

15

16

Different framing.

17 P3: got the hous[:e]

18 P1: [.hh]right [ok]

19 P3: so [sh]e'::s (.) .hhh

– Delay in TCU

20 [>sortuf<]

21 P1: [she's pr]ovi:ded [f]or ← so no moral obligation getting i

morally neutral, evade moral area.

22 P3: [yeh] yeah

23 P2: every:thing £.hp(h)hhhh£ ← 'making fun'

24 P3: O:Kay ← progression.

25 P2: i(h)t's .hvery weir:h (.)

26 h(h)u [h(h)] [h] [.h(h)]

27 P3: [ye]ah okay [l]et'[s::] °leave

28 that°.

29 P1: Yes .hh >but-< (.) uhm (0.2) i- (.)

30 she'::s >properly pro<vi:ded

31 fo[r: an Ramo:na:] upgraded

32 P3: [she's she's (good)]

Solicitors no comment, not her epistemic authority to say whats ridi

only to assess financial gains and losses so she sticks w the somewhat institutional lin of 'provide for'

Robin woofit.

weird, similar to interesting?

→ Judgement commenting, negative. complaint. → stop that issues → normally raise moral

So assumed agreed brother Positioning of siblings

So nothing too.

clipped.

← net family catagorization

P1: is: is: >somedy you would like tu<
P3: yeh.
P1: her:: to have [a]
P3: [°yeh°]=
P1: = >legacy< that's
fi:ne .hhh and (0.1) you say she hasn' got
any chil:dren.
P3: nho.
P1: no so (0.4) °yeah that's fine° .hhh
o:ka[y]
P2: [n]o an I I've got f- fou:r >brothrs
and sistrs all togeth-< well (.) plus a
foster siste but >no i [>>don't want to<<]
P1: [so: y-]
you're: happy t jus: (.) cut that side a
the [fam]ily ou:t=
P2: [ye]
P1: =and it just to go
straight down
P2: [yeh]
P1: [ok]ay
P1: yeah okay that's fine.

confirmed.

re-inserting herself to the conversati by aligning to project @ hand about brothers. sisters, also attempt to justify only leaving to 1 sister, she's leaving to none - so re-affir their right to d this and take the action.

3

Appendix K

Symbol	Definition and use
[yeah] [okay]	Overlapping talk
=	End of one TCU and beginning of next begin with no gap/pause in between (sometimes a slight overlap if there is speaker change). Can also be used when TCU continues on new line in transcript
(.)	Brief interval, usually between 0.08 and 0.2 seconds
(1.4)	Time (in absolute seconds) between end of a word and beginning of next. Alternative method: “none-one-thousand-two-one-thousand…”: 0.2, 0.5, 0.7, 1.0 seconds, etc.
Word Wo:rd	Underlining indicates emphasis Placement indicates which syllable(s) are emphasised Placement within word may also indicate timing/direction of pitch movement (later underlining may indicate location of pitch movement)
wo::rd	Colon indicates prolonged vowel or consonant One or two colons common, three or more colons only in extreme cases.
↑word ↓word	Marked shift in pitch, up (↑) or down (↓). Double arrows can be used with extreme pitch shifts.
.,_¿?	Markers of final pitch direction at TCU boundary: Final falling intonation (.) Slight rising intonation (,) Level/flat intonation (_) Medium (falling-)rising intonation (¿) (a dip and a rise) Sharp rising intonation (?)
WORD	Upper case indicates syllables or words louder than surrounding speech by the same speaker
°word°	Degree sign indicate syllables or words distinctly quieter than surrounding speech by the same speaker
<word	Pre-positioned left carat indicates a hurried start of a word, typically at TCU beginning
word-	A dash indicates a cut-off. In phonetic terms this is typically a glottal stop
>word<	Right/left carats indicate increased speaking rate (speeding up)
<word>	Left/right carats indicate decreased speaking rate (slowing down)
.hhh	Inbreath. Three letters indicate ‘normal’ duration. Longer or shorter inbreaths indicated with fewer or more letters.
hhh whhord	Outbreath. Three letters indicate ‘normal’ duration. Longer or shorter inbreaths indicated with fewer or more letters. Can also indicate aspiration/breathiness if within a word (not laughter)
w(h)ord	Indicates abrupt spurts of breathiness, as in laughing while talking
£word£	Pound sign indicates smiley voice, or suppressed laughter
#word#	Hash sign indicates creaky voice
~word~	Tilde sign indicates shaky voice (as in crying)
(word)	Parentheses indicate uncertain word; no plausible candidate if empty
(( ))	Double parentheses contain analyst comments or descriptions

Appendix L

Interview Questions

'How do people living with dementia and their informal carers access and interpret legal advice, and what impact does this have on their psychosocial wellbeing and understanding of their human rights?'

Topics: Diagnosis, Daily Life, Legal Actions, Information Sources, Legal Position

Diagnosis

1. Have you been to a doctor with concerns?
   Follow up: what prompted you **both**?

2. What do you **both** understand about having memory problems?

3. Do you think you have enough information, or given a good explanation from the doctor?

4. Have you told many people about the diagnosis (only ask if diagnosis is stated)
   Follow up: what is your reasoning?

Daily Life

1. In your day to day life, how does your dementia(/problems) affect both your lives?
   Prompt: your morning routine, or making meals.
   Prompt: as a person with dementia, and as a carer of someone with dementia?

2. How do you think you will all continue to manage your dementia…
   Prompt: do you have any ideas or plans, or are you taking it as it comes at the moment?

Legal Actions

1. Have you thought about getting your affairs in order since the diagnosis?
   Alternatives: if not, What do you think the process of getting help put in place will be like?

2. Who do you think will/who has made the first step in getting your affairs in order?
   Follow up: Why is that?

3. How do you think, if at all, your ability to get your affairs in order may be affected since the diagnosis? (Only ask if a diagnosis is stated)

Information Sources

1. Who do you think will find/who has found the information about getting your affairs in order?
   Prompt: the person with dementia, the primary carer, or another family/friend?
   Follow up: what resources will you use?

2. Is the legal system easy to understand, do you feel like you know your rights and how to access/keep them?

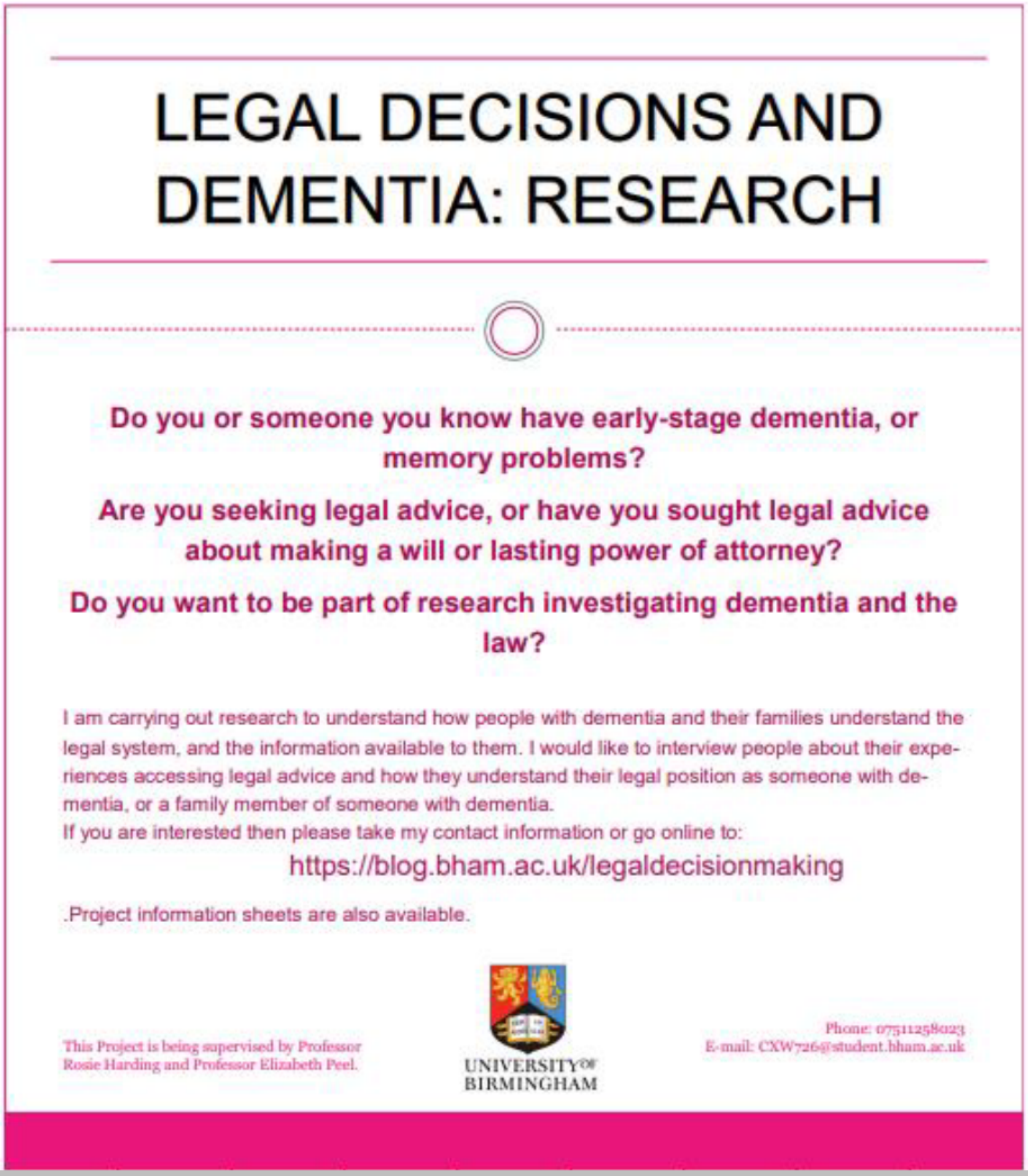
Legal Position

1. Have you heard of any of the laws which might apply to you now that you have a diagnosis of dementia, and what do you think of them?
   Prompt: (the mental capacity act)
   Alternative: What do you think they would/should say?

2. How do you think the law should help people with dementia?
   Alternative: Do you think it can?

Do you have something else you think I should know about your experience of dementia so far, or how you think the law should work for people with dementia?

Appendix M



LEGAL DECISIONS AND DEMENTIA: RESEARCH

Do you or someone you know have early-stage dementia, or memory problems?

Are you seeking legal advice, or have you sought legal advice about making a will or lasting power of attorney?

Do you want to be part of research investigating dementia and the law?

I am carrying out research to understand how people with dementia and their families understand the legal system, and the information available to them. I would like to interview people about their experiences accessing legal advice and how they understand their legal position as someone with dementia, or a family member of someone with dementia.
If you are interested then please take my contact information or go online to:

https://blog.bham.ac.uk/legaldecisionmaking

.Project information sheets are also available.

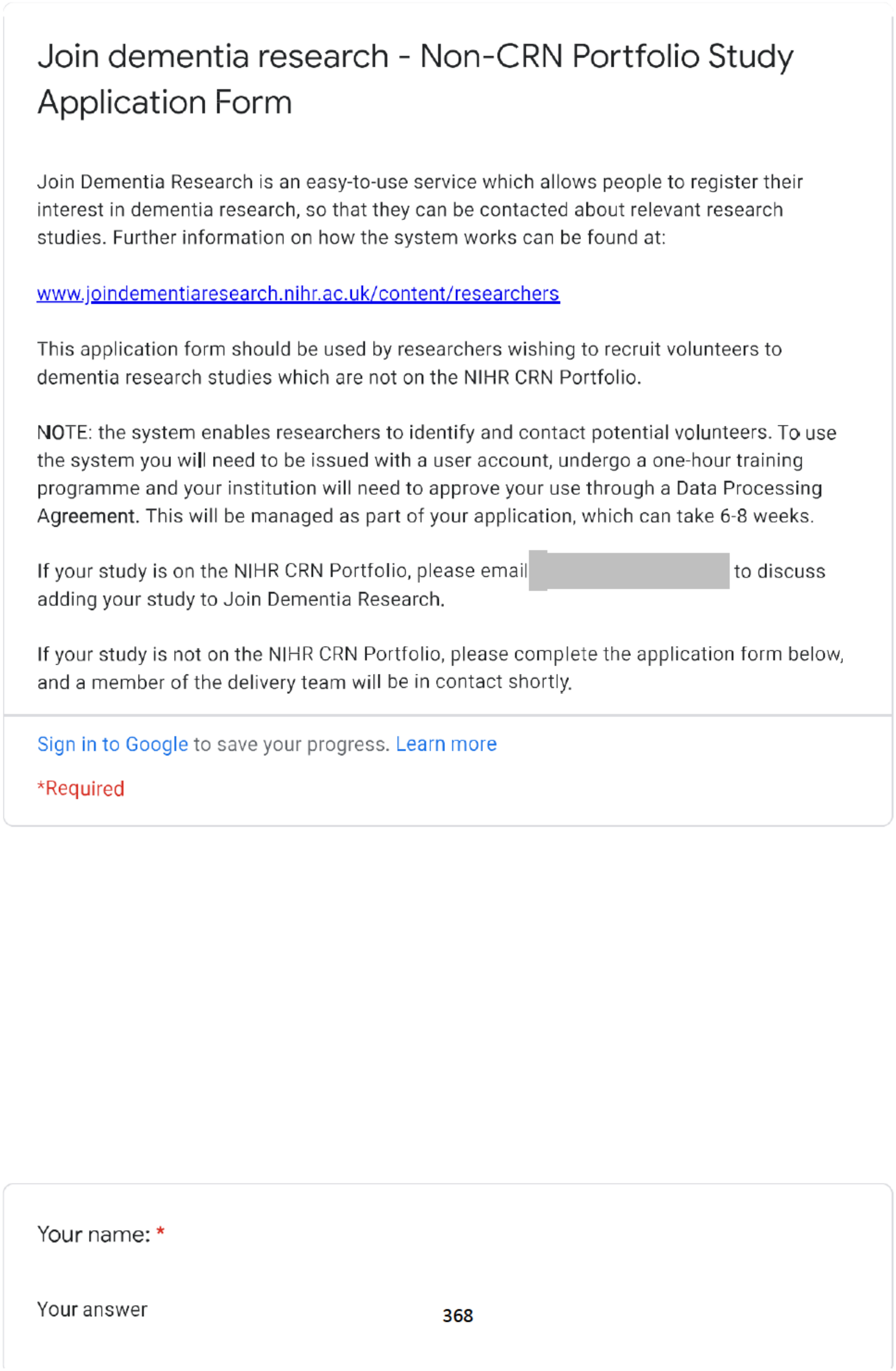
This Project is being supervised by Professor Rosie Harding and Professor Elizabeth Peel.

UNIVERSITY OF
BIRMINGHAM

Phone: 07511258023
E-mail: CXW726@student.bham.ac.uk

[redacted]

Appendix N



Join dementia research - Non-CRN Portfolio Study Application Form

Join Dementia Research is an easy-to-use service which allows people to register their interest in dementia research, so that they can be contacted about relevant research studies. Further information on how the system works can be found at:

www.joindementiaresearch.nihr.ac.uk/content/researchers

This application form should be used by researchers wishing to recruit volunteers to dementia research studies which are not on the NIHR CRN Portfolio.

NOTE: the system enables researchers to identify and contact potential volunteers. To use the system you will need to be issued with a user account, undergo a one-hour training programme and your institution will need to approve your use through a Data Processing Agreement. This will be managed as part of your application, which can take 6-8 weeks.

If your study is on the NIHR CRN Portfolio, please email [redacted] to discuss adding your study to Join Dementia Research.

If your study is not on the NIHR CRN Portfolio, please complete the application form below, and a member of the delivery team will be in contact shortly.

Sign in to Google to save your progress. Learn more

*Required

Your name: *

Your answer

Organisation name: *

Your answer

Address: *

Your answer

Telephone number: *

Your answer

Email: *

Your answer

Website:

Your answer

Do you have an NHS employment contract? *

○ Yes

○ No

If yes, who is your NHS contract with?

Your answer

Do you already have a Join Dementia Research account? *

○ Yes
○ No

Your study name:

Your answer

REC / Ethics number for your study:

Your answer

Who gave ethics approval? *

○ NHS
○ University
○ Social Care

Research funder: *

Number of volunteers required from Join Dementia Research: *

Your answer

Is your research study part of a PhD or Masters degree?

○ PhD

○ Masters

○ Other

○ not applicable

Geographical scope: *

(Give description and example e.g. by region and / or distance from site)

Your answer

Planned opening date on Join Dementia Research:

Date

dd/mm/yyyy

Planned closing date on Join Dementia Research:

Date

dd/mm/yyyy

Background to the research (In Layperson terms)

● Why is this research being done? Give 1 or 2 sentences as a background to why your research is important in the field. Aim(s) of the research ● 2 to 4 sentences maximum. What are you aiming to find out? Sets the scene ● Briefly mention here if there has been any Patient Public Involvement in the design of the study.

Your answer

What does the study involve? (In Layperson terms)

● What taking part in the study will involve for the volunteer. For example, what tests will be done? how is the study drug administered? what is the intervention? is it a one to one interview? ● Where will the study visit take place .i.e. in a hospital or home ● How many visits there are ● How long will the study run for/how long will the volunteer be involved in the study?

Your answer

Can you or are you willing to recruit people who live in care homes as part of your research study? *

○ Yes

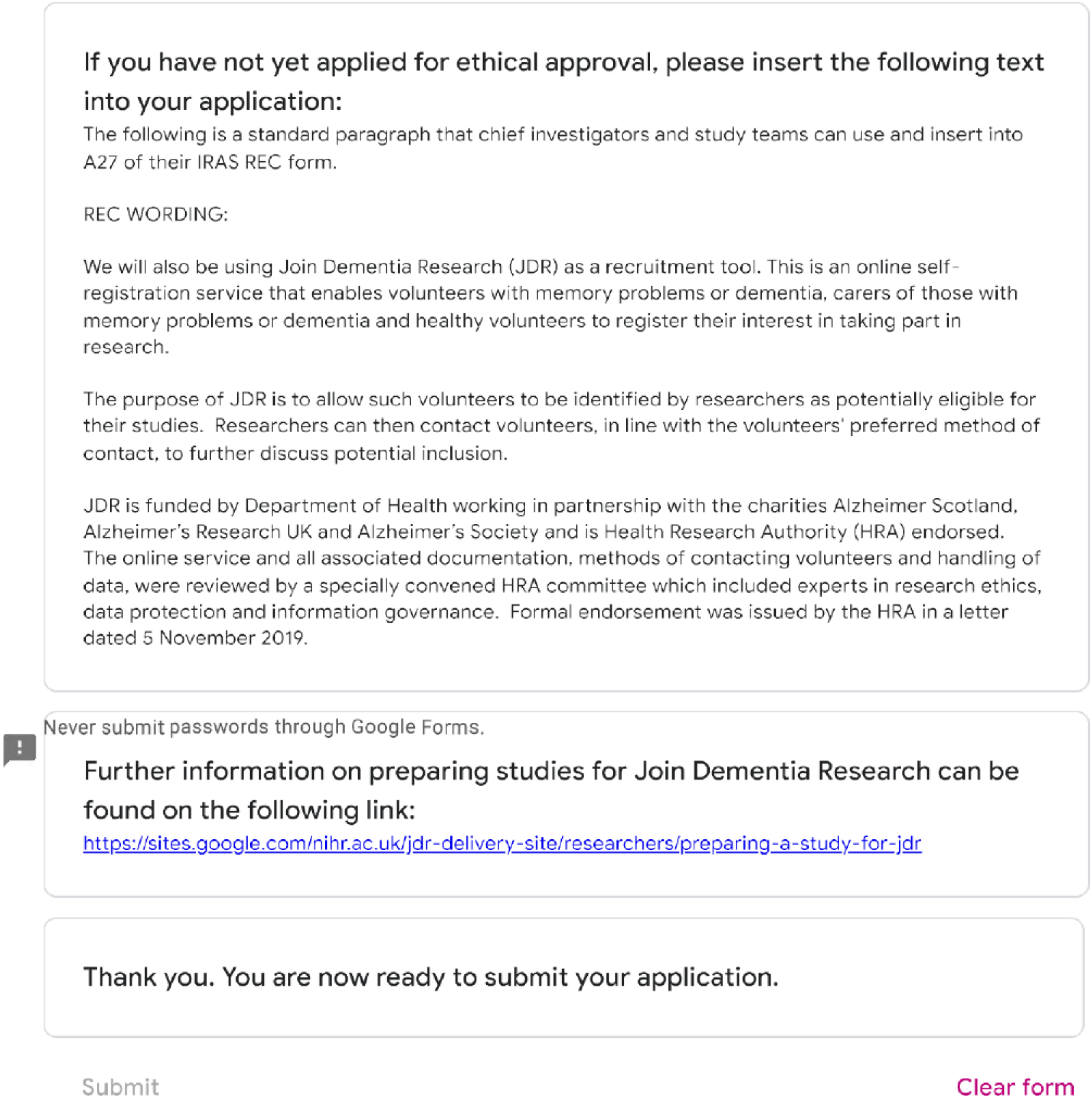
○ No

Would you like us to connect you with the ENabling Research In Care Homes (ENRICH) Network? (To find out more about ENRICH visit the website: https://enrich.nihr.ac.uk/) *

○ Yes

○ No

All studies using Join Dementia Research need to have appropriate ethical approval. If your study already has ethical approval but you did not previously mention Join Dementia Research in your application, you will need to make a minor amendment. Please download the template to complete and attach to your master file:
https://drive.google.com/file/d/0B0SQhhpDz20Zc3g4UFMxTDNOZ3M/view



If you have not yet applied for ethical approval, please insert the following text into your application:

The following is a standard paragraph that chief investigators and study teams can use and insert into A27 of their IRAS REC form.

REC WORDING:

We will also be using Join Dementia Research (JDR) as a recruitment tool. This is an online self-registration service that enables volunteers with memory problems or dementia, carers of those with memory problems or dementia and healthy volunteers to register their interest in taking part in research.

The purpose of JDR is to allow such volunteers to be identified by researchers as potentially eligible for their studies. Researchers can then contact volunteers, in line with the volunteers' preferred method of contact, to further discuss potential inclusion.

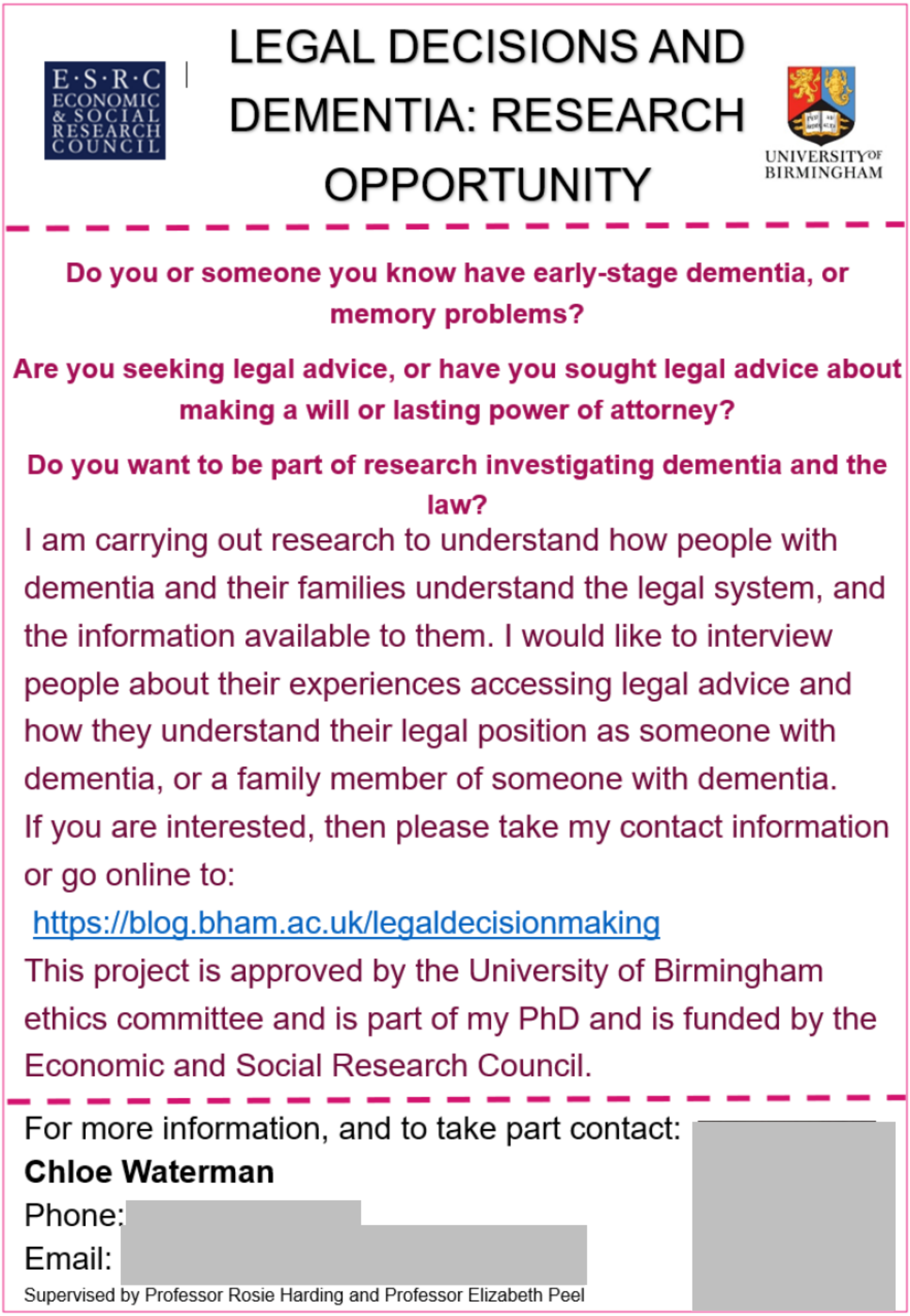
JDR is funded by Department of Health working in partnership with the charities Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society and is Health Research Authority (HRA) endorsed. The online service and all associated documentation, methods of contacting volunteers and handling of data, were reviewed by a specially convened HRA committee which included experts in research ethics, data protection and information governance. Formal endorsement was issued by the HRA in a letter dated 5 November 2019.

Never submit passwords through Google Forms.

Further information on preparing studies for Join Dementia Research can be found on the following link:
https://sites.google.com/nihr.ac.uk/jdr-delivery-site/researchers/preparing-a-study-for-jdr

Thank you. You are now ready to submit your application.

Appendix O



LEGAL DECISIONS AND DEMENTIA: RESEARCH OPPORTUNITY

Do you or someone you know have early-stage dementia, or memory problems?

Are you seeking legal advice, or have you sought legal advice about making a will or lasting power of attorney?

Do you want to be part of research investigating dementia and the law?

I am carrying out research to understand how people with dementia and their families understand the legal system, and the information available to them. I would like to interview people about their experiences accessing legal advice and how they understand their legal position as someone with dementia, or a family member of someone with dementia.

If you are interested, then please take my contact information or go online to:

https://blog.bham.ac.uk/legaldecisionmaking

This project is approved by the University of Birmingham ethics committee and is part of my PhD and is funded by the Economic and Social Research Council.

For more information, and to take part contact: [redacted]

Chloe Waterman

Phone: [redacted]

Email: [redacted]

Supervised by Professor Rosie Harding and Professor Elizabeth Peel

Appendix P

Consent form (Page 1 of 2)

Title of Project: Legal Decision-Making in Dementia, a discourse analytic study
Principal Investigator: Chloe Waterman, [redacted]
Interview date:

Please tick box if you agree with the statement

You must agree to these statements to take part

1. I have read and understood the information sheet ☐
2. I have had the opportunity to ask questions. ☐
3. I understand that my participation is voluntary ☐
4. I understand I am free to withdraw up to 3 months after the interview. ☐
5. I agree to take part in this study. ☐
6. I understand that all data will be treated confidentially ☐
7. I understand all data will be anonymised before it is used in reports and publications. ☐
8. I agree to written transcripts of data being stored for 10 years after the research is complete. ☐

The following statements are optional. You do not have to agree to take part:

9. I agree audio recordings of data being stored for 10 years after the research is complete ☐
10. I agree to transcribed extracts of my data appearing in reports and publications. ☐
11. I agree to allow the data to be used for future research projects. ☐
12. I agree to audio clips from the data being used in reports and presentations. ☐

____________________ Name of interviewee

_______________ Date

____________________ Signature

Name of interviewee	Date	Signature
Name of Interviewer	Date	Signature

Consent form: Interviews EasyRead (Page 1 of 3)

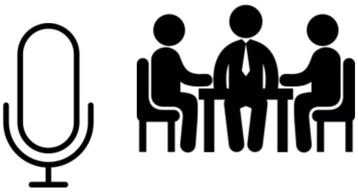
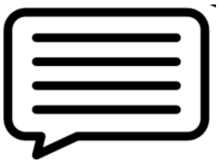
Title of project: Legal Decision-Making in Dementia, a discourse analytic study.

Name of researcher: Chloe Waterman,

[redacted]

If you tick 'No' on number 1-9 you cannot take part. If you tick 'No' on 10-13 you can still take part.

1		I have read the information sheet and have been able to ask questions.	Yes ☐	No ☐
2		I know I can choose if I want to take part or not.	Yes ☐	No ☐
3		I agree to take part.	Yes ☐	No ☐
4		I know I can say no to any question.	Yes ☐	No ☐

5		I know I can stop at any time.	Yes ☐	No ☐
6		I know I can change my mind about taking part for 3 months after the interview.	Yes ☐	No ☐
7		I agree to the interview being audio recorded.	Yes ☐	No ☐
8		I understand that nobody will be able to tell I took part because my name will be changed.	Yes ☐	No ☐
9		I agree that the **written record** may be stored for 10 years	Yes ☐	No ☐
10		*I agree that the researchers can use quotes from my interview in presentations and publications.*	Yes ☐	No ☐

11	📅	*I agree that **audio recordings** may be stored for 10 years.*	Yes ☐	No ☐
12	🔊	*I agree to audio clips being used for presentations*	Yes ☐	No ☐
13	📅	*I agree to my interview being used for future research*	Yes ☐	No ☐

Name of participant(s) Date Signature

Name of participant(s) Date Signature

Name of participant(s) Date Signature

Researcher Date Signature

1 for Participant, 1 for Researcher

Interview Information Sheet (Page 1 of 3)

My name is Chloe Waterman, I am a PhD student at the University of Birmingham.

I would like to talk to you about your personal experience of dementia and getting legal information (e.g. will making or Lasting Powers of Attorney).

The University of Birmingham Social Sciences ethics committee approves this research.

You are invited to take part in an interview because you have early stage dementia (or memory problems). You may also be a family member or carer of someone with early stage dementia.

Do I have to talk to you?

No, it is your choice.

You can also change your mind up to 3 months after the interview. I will delete your recording, no questions asked.

If you decide to be interviewed, Chloe will ask you to fill in a consent form before we begin.

What would happen?

If you want to be interviewed, contact Chloe and she will set up a time and place for the interview. She will also send you some information.

Chloe will ask you questions about any legal information you have seen and what you think about how the law works for people with memory problems.

If you want to stop at any time, just tell Chloe and she will stop.

Chloe will audio record the interview, this can be with your family carer.

What about my information?

The interview is in your control, if you want to stop you can. Chloe will also give you information for support/advice services.

Only the research team will listen to the orginal recordings. Chloe will replace all names and personal information when typing up the interviews, no-one will be able to tell it is you.

The recordings collected must be kept for 10 years securely. Chloe will make sure you no-one will be able to tell it is you. They will always be kept locked up or password protected.

Problems? If you have any problems or questions about the interviews, contact Chloe. If you want to withdraw, contact Chloe up to 3 months after the interview.

Want to take part? Contact Chloe using this information:

Chloe Waterman

Email: [redacted]

Or call: [redacted]

Problems? Here is the supervisor information if you do not want to contact Chloe directly:

Rosie Harding:

Email: [redacted]

Telephone: [redacted]

Post: Birmingham Law School, University of Birmingham. Edgbaston, Birmingham, B15 2TT.

Complaints? Please contact:

Head of Research Governance and Ethics,

Post: Research Governance and Ethics Manager, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

Interview Information Sheet (Page 1 of 2)

Researcher: Chloe Waterman, [redacted]
Supervisors: Professor Rosie Harding, [redacted] Professor Elizabeth Peel,
[redacted]

This research has been approved by the University of Birmingham Humanities and Social Sciences ethics committee.

Aims

The aim of this research is to explore:

> *How people living with dementia and their informal carers access and interpret legal advice*

This research will form the basis of ESRC funded PhD research being undertaken at the University of Birmingham and Loughborough University.
The interviews will inform my research on how law, with a focus on lasting powers of attorney and wills, is operating on a day-day basis for people with dementia and their carers. Additionally, I aim to understand what these findings mean for the legislation we have in place and proposals for the future.

Invitation

You are invited to take part in this research because you are a person with a diagnosis of dementia (or memory problems) and are in the early stages of the disease. You may also be a family member or carer of someone with early stage dementia. You do not need to have sought legal advice to take part in the project.

Do I have to take part?

No, participation is completely voluntary. Even if you do agree to participate, you are free to withdraw at any time 3 months after the interview. You do not have to state why you want to withdraw.

If you agree to take part in this study then you will be asked to sign two consent forms, one for your records and one for my records.

What will happen if I take part?

If you want to take part in the research, you can contact me at the details given and we can set up an interview time and place. I can conduct the interview at a mutually convenient location. I will send you information before the interview.
I will ask you questions about any legal information you have accessed and what you understand about your legal position.
I will audio record the interview and may take some notes. I will interview you (individual with dementia diagnosis) and any family members/carers together, unless you request otherwise. The interviews will last roughly 1 hour.

Are there any risks of taking part?

There are no foreseen risks if you agree to participate. You can stop the recording at any time and you are free not to answer any question. I understand the subject of the interview is emotive and you can pause the interview at any time. I will also provide you with an information sheet of several information and support services that you may wish to contact if you feel you need more support or information regarding the topics we have discussed.

You will be helping my research which aims to improve how legal information is understood and how the law operates for people with a dementia diagnosis and their family members and carers.

How will my information and data be used, and who will have access?

Who will have access?

Only the research team will have access to the original data.

How will you protect my confidentiality and anonymity?

The recordings will be stored on a password protected laptop and encrypted flash-drive.

All signed consent forms and participant information sheets will be kept in a locked folder.

The typed-up audio-recording (transcript) will not contain any information that could be used to identify you. I will obscure any voices in any audio recordings used in presentations and any identifying information will be deleted.

In accordance with university guidelines, the data will be stored securely and kept for 10 years after the research has concluded for use in the future. All confidentiality and anonymity rules will continue to apply to the data.

The only reason I would break confidentiality is if concerns are raised about yours, or another's safety, or if any illegal activity was disclosed. I would tell you if I had to break confidentiality and explain why.

How can I Withdraw?

If you would like to withdraw your data from the study you may do so up to 3 months after the recording has been made. If you wish for your data to be removed from the study and not used for the research you can email me at: [redacted] You do not need to state why you wish to withdraw and I will send you confirmation by email that I have destroyed all of your data (deleting all electronic copies and shredding any paper forms). If you do not have access to email you may contact me via telephone on: [redacted].

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to the me and I will do my best to answer your questions. Please contact me by Email: [redacted] If you are unable to contact me by email then you may call me on 07511258023. Alternatively, if you do not wish to contact me you may contact Professor Rosie Harding using the email: [redacted] or telephone: [redacted] or contact via post at:
Birmingham Law School, University of Birmingham. Edgbaston, Birmingham, B15 2TT.

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please contact the research governance officer, Head of Research Governance and Ethics by post: Research Governance and Ethics Manager, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

Researcher Contact Details:

If you wish to take part in an interview, please contact me on:

Email:

[redacted]

Telephone:

[redacted]

Appendix Q

Interviews basic transcripts codebook

Nodes

Name	Description	Files	References
family extracts		17	48
Ideas and experience of law		20	186
law		18	80
legal experience		20	84
Rights		11	22
Legal and Medical information		19	112
'Legal' consequences		20	105
Driving		16	29
Finances		20	76
Legal documents		20	88
LPA		19	53
wills		17	35
Life trajectories		20	110
Death		13	29
future living		18	63
homecare		12	18
Relationships		20	222
family		20	103

Name	Description	Files	References
R dynamics		20	119
Representations of dementia affects in life		20	136
capacity		15	35
activity		20	82
behaviour		16	48
Memory		15	39
Dementia is...		20	101
brain		12	27

Nodes

Name	Description	Files	References
brain		3	5
brain cells		1	1
healthy brain		1	1
normal brain		1	1
sharp brain		1	1
small brain deterioration		1	1
different things		1	2
different things		1	2
early onset		1	2
early onset		1	2
little plaque		1	1
little plaque		1	1

Name	Description	Files	References
people		3	3
different people		1	1
remembering people		1	1
stories — people		1	1
something		2	2
certainly something		1	1
reading something		1	1
test		1	2
complicated tests		1	1
standard test		1	1
things		4	8
damn thing		1	1
different things		1	2
great thing		1	1
main thing		1	1
obvious things		1	1
strange things		1	1
wretched thing		1	1
thought		2	2
natural thought process		1	1
thought train		1	1
time		2	2
dark time		1	1
traumatic time		1	1

Appendix R

Number	Name of guidance document
1	3 Key Points about the Golden Rule - Will Claim Solicitors
2	A Guide to Mental Capacity Assessment - YouTube
3	About Us, Mental Capacity Experts ~ TSF Consultants
4	An introduction to testamentary capacity - The MDU
5	Assessing Mental Capacity - Guidance ~ Anderson Rowntree ~ Solicitors in West Sussex ~ Lawyers ~ Legal Practice
6	Assessing mental capacity ~ Community Care
7	Banks v Goodfellows TEST PURPLE private BASIC WILLS
8	Brain-Injury-News-Issue-6-Autumn2015
9	Capacity-Assessments-Guide-August-2016
10	Client Capacity - Lawyers Defence Group
11	COP3 Form - Mental Capacity Assess
12	Court of Protection Lawyers ~ Simpson Millar Solicitors
13	Court of Protection Solicitors - Thornton Jones Solicitors in Wakefield, Garforth, Ossett
14	Coventry~ Understanding Mental Capacity - Assessing Mental Capacity
15	Decisions, Decisions, Decisions~ How to assess the mental capacity of people with dementia ~ British Geriatrics Society
16	Developments in the legal test for mental capacity
17	Do You Know What You're Signing~ - Testamentary Capacity - Foskett Marr Gadsby & Head
18	Everything you need to know about testamentary capacity ~ The Gazette
19	Factsheet~ What is Mental Capacity~ ~ martin searle solicitors
20	Five key steps to assessing capacity ~ Community Care
21	How Do I Know if My Parent has Testamentary Capacity to Update their Will~ - Arbon Legal Group
22	How do I know if my relative has the mental capacity to make a will~
23	How do you assess testamentary capacity~ - Levi Solicitors LLP
24	How is testamentary capacity determined~ - YouTube
25	How Lawyers Should Approach Issues of Mental Capacity ~ HuffPost Canada
26	How to assess capacity right - Mental Capacity Act ~ QCS Blog
27	How to Assess Mental Capacity
28	How to make sure your Will is valid - YouTube
29	Is the GP the best person to conduct Mental Capacity assessments~ - Lawskills
30	Lack of Testamentary Capacity in Will Contests ~ Learn About Law - YouTube
31	Making a Will and Mental Capacity
32	MCA - Mental Capacity Assessment - YouTube
33	MCA~ Assessing capacity ~ SCIE
34	Medico-legal~ Testamentary capacity ~ GPonline
35	Mental capacity - GMC
36	Mental Capacity - Importance and Assessment- Martin Tolhurst Solicitors
37	Mental Capacity - Importance and Assessment- Pickering & Butters Solicitors
38	Mental Capacity - Importance and Assessment- Solicitors - Uckfield, East Sussex - Dawson Hart
39	Mental Capacity - Importance and Assessment- Solicitors in Ash Vale, Fleet & Farnborough
40	Mental Capacity - Importance and Assessment- Solicitors in Bexleyheath, Dartford, Orpington, Kent
41	Mental Capacity - Importance and Assessment Solicitors in Loughborough, Leicestershire
42	Mental Capacity - Importance and Assessment- WMK Solicitors
43	Mental Capacity - Nash & Co Solicitors LLP, Plymouth, UK

44 Mental Capacity ~ Cartwright King Solicitors ~ Legal 500 Firm
45 Mental Capacity Act - Mental Capacity Assessment - Stephensons Solicitors LLP
46 Mental Capacity Act - NHS
47 Mental Capacity Act & Assessments - JMW Solicitors
48 Mental Capacity Act 2005 ~ Burt Brill & Cardens Solicitors
49 Mental Capacity Act 2005 ~ Switalskis Solicitors
50 Mental Capacity and Court of Protection ~ Duncan Lewis
51 Mental Capacity Assessment Legal Advice. Assessing Mental Capacity ~ martin searle solicitors
52 Mental Capacity Assessment - Roythornes Solicitors
53 Mental Capacity Assessments - Appoint Us Services
54 Mental Capacity Assessments ~ Clear Psychology
55 Mental Capacity Assessments and Best Interests Decisions For Solicitors ~ Gary Crisp
56 Mental Capacity Solicitors ~ Wilsons Solicitors LLP
57 Mental Capacity Test When Making A Will l Wills & Probate Blog l Nelsons
58 Mental Capacity To Make A Lasting Power Of Attorney
59 Mental Capacity - Minton Morrill Solicitors
60 Mental Capacity~ Dealing with Fluctuating Capacity - OFH
61 Mental health and capacity - Coodes Solicitors
62 New guidelines for lawyers on assessing mental capacity ~ News ~ Law Gazette
63 News - Hay & Kilner Law Firm - Solicitors in Newcastle upon Tyne
64 Power of Attorney Mental Capacity Assessment - Mental Capacity Assess
65 RACGP - Test for medical capacity~ What GPs need to know
66 Risk Assessment and the Mental Capacity Act (MCA) - Mental Capacity Act ~ QCS Blog
67 Test for capacity - setting the threshold of understanding ~ LawSkills
68 Testamentary capacity - Wikipedia
69 Testamentary capacity & undue influence ~ Preparing A Will Preston ~ Will Preparation Blackburn - Napthens
70 Testamentary capacity ~ Mills & Reeve
71 Testamentary capacity and ~the golden rule~ ~ Hugh James
72 Testamentary Capacity and the ‘Golden Rule’
73 Testamentary capacity and the Golden Rule - Will Claim Solicitors
74 Testamentary capacity and the not-so golden rule~ Burns v Burns [2016] EWCA Civ 37 – Park Square Barristers
75 Testamentary Capacity Assessment ~ TSF Consultants
76 Testamentary Capacity~ Law, Practice and Medicine ~ STEP
77 Testamentary Capacity~ Law, Practice and Medicine ~ STEP (2)
78 Testamentary Mental Capacity Assessments ~ Gary Crisp
79 testamentary_capacity_and_the_mental_capacity_act_-_article_-_2
80 The Challenges Of Assessing Testamentary Capacity In the Covid-19 Era ~ Today's Wills and Probate
81 The Complexities Of Assessing Mental Capacity l Blog l Nelsons
82 The Legal Test for Mental Capacity - Family and Matrimonial - UK
83 The Mental Capacity Assessment
84 The principle of assessing mental capacity for enduring power of attorney ~ HKMJ
85 Undue influence~ what is sufficient legal advice~ ~ Analysis ~ Communities - The Law Society
86 What is testamentary capacity~ ~ Ashfords Solicitors
87 What is Testamentary Capacity~ ~ UK Will Disputes London
88 What is the meaning of mental capacity~ ~ Crown Law Solicitors
89 Why Establishing Testamentary Capacity Is Not a Tick-Box Exercise ~ Today's Wills and Probate

[90] Working with clients who may lack mental capacity ~ The Law Society

Appendix S

Legal Decision Making and Dementia: Summary

I have been conducting this research as part of my PhD at the University of Birmingham. I am supervised by Professor Rosie Harding and Professor Elizabeth Peel (at Loughborough university).

I conducted 20 interviews with people with dementia (or similar cognitive disorder) in 2019 between February and August.

I also conducted 4 observations at a solicitor’s office in 2019 between July and September.

[redacted]

The analysis has been carried out between January 2020-March 2021. You will be able to access the full thesis when complete on the Birmingham thesis online repository website, alternately if requested, a PDF version can be emailed to you (the thesis should be completed by January 2022).

If you have any questions about this summary, or would like to know more, please get in contact with me, Chloe Waterman, via email: [redacted] or phone: [redacted]

Research purpose:

- Understand how people with dementia and their informal carers approach legal decision making (focusing on wills and power of attorneys).
- Ensure law reflects real life decision making and enables people with dementia and their carers.

It was important that people with dementia and their carers, and their experiences, informed this research project, and it is their insights and stories which give the results and inform the recommendations here.

I used thematic discourse analysis, and conversation analysis to analyse my interviews and observations. By paying attention to the way people talk about the law, dementia, and capacity, I can show how people with dementia and their carers are negatively affected by capacity law in England and Wales, and why.

I can make recommendations based on this research to improve capacity law in England and Wales. The key findings and recommendations are listed below.

Key findings

- People with dementia and their carers are subject to barriers accessing equal legal right, I surmise this is in part due to societies non-critical engagement with neuroscience and cognitive psychology. People with dementia are likely to face difficulties when living in a society which values the 'healthy brain'.
- Within solicitors' offices, married couples are given a privileged status. The presence of a spouse is not seen as a potential

undue influence claim. The presence of other family members for support and/or information may be seen as a source of undue influence.

- People with dementia and their carers express a desire to plan their futures, but do not currently know of, or have access to, the tools to do so (i.e. wills and LPAs are not used as or seen as sufficient).
- People with dementia and their carers do not know their legal rights, even where a legal decision has been made.
- People with dementia and their carers are supported and informed by their relationships when making legal decisions, regardless of laws definition of individual decision making.
- Solicitors are not equipped to assess capacity explicitly in their interactions, and due to rules in wills law, may equate age with loss of capacity.
- People with dementia and their carers deserve a legal system which accurately reflects their everyday decision-making processes and recognises the positive value of their relationships.

Key recommendations

- Awareness campaigns are needed to inform all people, particularly those with dementia and their carers, about *all* legal tools available, their usefulness, and how they can be useful for care planning as well as financial management.
- Further work is needed to de-stigmatise dementia, this may include further research into how societal values influence understandings of dementia, and the values placed on 'healthy brains'.
- Some people with dementia express a desire to control the point of the end of their life, work is needed to understand why

this is and if using end of life care planning can help give people the desired control. People with dementia should also be further included in debates around medically assisted dying and assisted suicide both in the UK and abroad (as it is still very difficult to access this in countries where medically assisted dying and assisted suicide are legal).

- Checking understanding through asking for repetition may be one simple way for solicitors to check capacity through their conversations with clients.
- Further research is needed in the unique space of solicitors' offices, for this to happen solicitors should be more open to the opportunities research presents, to improve and highlight best practice.
- For the values of the UN CRPD to be met, and for people with dementia and their informal carers to achieve equal legal rights, capacity law in England and Wales should adopt a more relational model of law.

Acknowledgements

I would like to sincerely thank all my participants for giving me their insight and stories. I want to thank my interviewees particularly for welcoming me into their homes, and for responding so positively to my research, for offering cups of tea, and giving me so much of their attention, time, and energy.

I would like to thank the solicitor and solicitor's assistant who took part in my research for granting me access. I sincerely appreciate the time and energy taken to accommodate my research and reach out to clients on my behalf.

I would also like to thank my supervisors for their guidance, support, and patience.

The aims of this project were to investigate how capacity law affects people with dementia and their family carers. It was important that people with dementia and their carers, and their experiences, informed this research project, and it is their insights and stories which give the results and inform the recommendations here.

For this research I interviewed people with dementia and their families to understand how they understand, experience, and interpret legal decision making. I also observed solicitor-client meetings to understand how legal decision making happens in practice, in this legal environment. I used thematic discourse analysis, and conversation analysis to analyse this data. By paying attention to the way people talk about the law, dementia, and capacity, I can show how people with dementia and their carers are negatively affected by capacity law in England and Wales, and why.

I can make recommendations on the basis of this research to improve capacity law in England and Wales. The key findings and recommendations are listed below.

Key findings

- People with dementia and their carers are subject to barriers accessing equal legal right, I surmise this is in part due to societies non-critical engagement with neuroscience and cognitive psychology. People with dementia are likely to face difficulties when living in a society which values the 'healthy brain'.
- Within solicitors' offices, married couples are given a privileged status. The presence of a spouse is not seen as a potential undue influence claim. The presence of other family members for support and/or information may be seen as a source of undue influence.
- People with dementia and their carers express a desire to plan their futures, but do not currently know of, or have access to, the tools to do so (i.e. wills and LPAs are not used as or seen as sufficient).
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- Solicitors are not equipped to assess capacity explicitly in their interactions, and due to rules in wills law, may equate age with loss of capacity.
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Key recommendations

- Awareness campaigns are needed to inform all people, particularly those with dementia and their carers, about *all* legal tools available, their usefulness, and how they can be useful for care planning as well as financial management.
- Further work is needed to de-stigmatise dementia, this may include further research into how societal values influence understandings of dementia, and the values placed on 'healthy brains'.
- Some people with dementia express a desire to control the point of the end of their life, work is needed to understand why this is and if using end of life care planning can help give people the desired control. People with dementia should also be further included in debates

around medically assisted dying and assisted suicide both in the UK and abroad (as it is still very difficult to access this in countries where medically assisted dying and assisted suicide are legal).
- Checking understanding through asking for repetition may be one simple way for solicitors to check capacity through their conversations with clients.
- Further research is needed in the unique space of solicitors' offices, for this to happen solicitors should be more open to the opportunities research presents, to improve and highlight best practice.
- For the values of the UN CRPD to be met, and for people with dementia and their informal carers to achieve equal legal rights, capacity law in England and Wales should adopt a more relational model of law.

Re-introduction to project

[redacted]

I have been conducting this research as part of my PhD at the University of Birmingham. I am supervised by Professor Rosie Harding and Professor Elizabeth Peel (at Loughborough university).

I conducted 20 interviews with people with dementia (or similar cognitive disorder) in 2019 between February and August.

I also conducted 4 observations at a solicitor's office in 2019 between July and September.

The analysis has been carried out between January 2020-March 2021. You will be able to access the full thesis when complete on the Birmingham thesis online repository website, alternately if requested, a PDF version can be emailed to you (the thesis should be completed by January 2022).

If you have any questions about this report, or would like to know more, please get in contact with me, Chloe Waterman, via email: [redacted] or phone: [redacted]

Research purpose:

- Understand how people with dementia and their informal carers approach legal decision making (focusing on wills and power of attorneys).
- Ensure law reflects real life decision making and enables people with dementia and their carers.

Background of project:

People with dementia and their informal carers, as a significant proportion of the population, need and deserve access to legal decision-making tools such as making a will or a power of attorney.

Currently, the Mental Capacity act and case law for wills, puts people at a disadvantage when making legal decisions. Due to the current mental capacity assessments used for both wills and power of attorney, people with dementia are not given equal access to legal rights.

People with dementia have more hurdles to pass than someone without dementia, to make a legal decision. Law aims to protect, but it is also restrictive.

The United Nations in their Convention on the Rights of Persons with Disabilities, state that people with disabilities (dementia being included in this category), should be enabled to have equal access to legal rights to that of any other person. Though the UK has signed this convention, the law does not yet reflect what the convention states (as legal capacity is restricted through mental capacity in English and Welsh law).

Scholars suggest that through paying attention to the importance of everyday decisions and the importance of relationships, we could achieve the goals set by the convention.

Method

Interviews:

- I interviewed and audio recorded 20 people with dementia and their informal carers (18 with their partner, 1 with a partner and child, and one with a close friend).
- 19/20 interviewees were contacted through the Join Dementia Research website.
- I asked questions about both persons experiences of diagnosis, daily life changes, and legal decision making.

Observations:

- I observed and audio recorded 4 meetings at a solicitor firm where clients were making a will with a solicitor.

Analysis:

I used analysis which focuses on the experience of the people I observed and spoke to. This meant I focused on the language that participants used to understand their perspective and experiences. The type of analysis (called discourse analysis) means that through paying special attention to the way language is spoken I can build a picture of that person's experience.

Findings from interviews

All interviewees have been anonymised in this report. Here I give a summary of the findings from my interviews. My interviews were very informative and covered a wide range of topics, I have focused on the following findings to help answer my research aims.

What are Dementia and capacity?

Dementia

Dementia was constructed as both and emotional and personal experience, and a 'thing' unwanted in the relationship. There were further subthemes which help understand how interviewees view and understand dementia.

Anonymous subject – Personified as another unwanted person, therefore becoming separate to the person with the disorder. This protects the person with dementia from being too closely associated with the negative impact of dementia. An example of this is 'it's a thief'. The person who is affected by dementia is being acted upon by the dementias action of theft. The two are separated. The person, and the dementia.

Emotional reactions and experiences - People use common phrases and saying to make a unique and personal experience understandable to all, for example '[when] the doctor there said Alzheimer's it hit us like a sledgehammer'. This is just one example of the way people with dementia and their carers work hard to make a unique experience understandable to a wider audience. It also has implications for the way dementia is spoken about in wider society, and if it is truly reflective of how people live with and react to dementia (such as the 'living well with dementia' campaigns).

Capacity

Capacity was seen as something which was unique to everyone. People talked about the difference between everyday life skills, and decision-making capacity. People with early-stage dementia and their informal carers use examples of what people without capacity may do, to demonstrate why they both do possess capacity.

Everyday capacity - People draw attention to the skills that the person with dementia does have. Everyday skills are a valued part of a person's capacity, but they are not fully appreciated in law.

Decision making capacity - People give examples of what people without decision making capacity might look like, to show how they are different and do have capacity. It needs to be made clear to all persons what capacity is and why it is relevant for them. Equally, law needs to better define capacity to reflect everyday life.

How do people with dementia plan for the future?

Wills and powers of attorney can be used to help people plan for their futures. However, interviewees did not often describe them in this way, and the future was something unknowable, and therefor difficult if not impossible to plan for. This is interesting as most interviewees had made either a will and/or and LPA. This research shows that wills and LPAs are not interpreted as a useful tool to plan for the future. The following topics were discussed in relation to current future planning, care plans and formal legal plans.

Current plans were vague, and the future was seen as uncertain. Dementia still carries some stigma, and work needs to be done to help people with dementia and their carers deal with the idea of a future with dementia. An example from the data is 'I don't particularly want to spend my time dwelling on what could be about to happen'.

Care planning was seen as something to discuss and happen 'at the right time'. It was a very personal activity and was not seen as being relevant for legal planning. Formal care planning tools widely used by doctors and care homes could be a useful tool for people considering their own care. Care planning is part of the health and welfare LPA, this needs to be made clearer for people making LPA's.

Formal legal plans were mainly seen as decisions relating to money, these plans are also made to protect the family. This highlights the potential difficulty people have making care plans, and why care plans are not seen as a 'legal' activity. Furthermore, family were often seen as a good resource of information and or involved in some aspect of the process. People with dementia and their carers do involve family in their decisions and this needs to be taken into account.

As well as current future plans people spoke about their ideal plans. These may be plans they had prior to the dementia diagnosis or plans they would still like to keep but anticipate the failure of this ideal plan. People want to be able to control their future, but dementia and law makes this difficult.

There are also certain types of futures which are not wanted. Currently people with dementia do not feel able to achieve their ideal futures. Legal tools that are available need to be publicised further, and legal tools which are not currently available need to be investigated. The following topics were discussed in relation to ideal future planning, managing death, legal rights.

Managing death means people want to be able to have control over the end of their life, and these decisions must be taken at the 'right time'. However this was seen as the moment of ending life rather than the period leading up this. End of life care planning is not used/or known of by people with dementia when thinking about their end of life. People with dementia and their carers need to be made aware of different types of end-of-life care planning available to them in the UK.

Legal rights were discussed in relation to how a person is able to control their life and death. Most people said they did not know or understand their legal rights. But those who spoke about medically assisted dying or assisted suicide knew that this was not legal in the UK. Care plans like those in LPA's are not seen as enough and/or used to give a person control over the way their life ends. More research needs to be done to address the concerns people with dementia have about dying and choosing when and how to die.

Importance of Relationships

Relationships are important to every part of a person with dementia's life, including legal decision making. When making a legal decision which defines people as individual and can remove the support of their relationship when taking a capacity assessment, it may make it more difficult for people to pass the assesment. For example one interviewee on asking what to do to help people make legal decisions 'The answer is to have a loving family around you'.

Findings from observations

Observations of solicitor client meetings have, to my knowledge, not been carried out for the purpose of research before. This data though small, is significant and provides interesting findings. Furthermore as the laws and guidance governing all solicitors assisting clients making legal decisions, I can assume that this data is representative of solicitor practices. Further research is needed to understand a broader range of client-solicitor meetings.

In this research I found that the way the solicitor interacted with an older physically disabled person, attending with their daughter in law, was very different to the interactions with older married couples. I also gained understanding of how clients contest the power dynamic in the solicitor meeting (the solicitor acting as legal authority, client acting as authority on their own affairs). The following two themes summarise the key findings from this data.

What is mental capacity in a solicitor's office?

- Clients work hard to show how they can bring their own knowledge and information to the meeting.
- People in couples can attend the meetings together, their capacity is not seen as being affected by being in the same room.
- Simple 'do you understand' statements are one of the only ways solicitors obviously checks capacity.

- Checking on understanding through asking people to repeat back what has been said could be an easy way to check a person's capacity.

How are relationships relevant in a solicitors office?

- The solicitor offers positive and negative comments on different relationships, making it easier or more difficult for those relationships to be involved in the legal decision.
- Married couples are privileged by being able to attend the meeting together, whereas other types of family may be asked to leave.
- The solicitor and the way the meeting is run means that social expectations are re-enforced.

Recommendations

1. Awareness campaigns are needed to ensure people with dementia and their carers know about *all* legal tools available to them, and how to *effectively* use these tools (particularly the health and welfare LPA).
2. People with dementia and their carers should be encouraged to discuss future planning, one way to achieve this may be through reframing dementia as a terminal illness.
3. Lawyers and law makers need to recognise that people with dementia are just the same as other people, their context and life history will shape what they do and do not understand about affairs relating to legal decision making (for instance household finances).
4. Lawyers and law makers must be mindful of equating aging with lack of capacity, and affording married status privilege in legal settings.
5. Solicitors should look to similar institutional settings where understanding is checked, namely medical settings. Asking for a client to repeat what has been explained to check understanding can be a simple way for the solicitor to meet current requirements of checking capacity.
6. People with dementia and their carers do not define capacity in the same way as law. Lawmakers must involve a more representative sample to re-define what capacity is, and how it is and is not relevant for the making of legal decisions, and do this with the understanding that people exist within a relational context.

Further reading and information

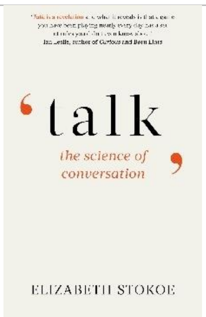
If you want to know more about the laws mentioned here:

- The full Mental Capacity act can be found here: https://www.legislation.gov.uk/ukpga/2005/9/contents
- A summary of the Mental capacity Act and its impact for people with dementia can be found here: https://www.alzheimers.org.uk/get-support/legal-financial/dementia-mental-capacity-act
- The Law commission have been conducting an enquiry into reforming wills law, the progress of which can be found here: https://www.lawcom.gov.uk/project/wills/
- The UN convention of rights of persons with disabilities can be found here, a summary is provided as well as the full text: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/the-convention-in-brief.html

If you need help making legal decisions, or finding out what kinds of decisions you can make:

- AgeUk are a charity which offer help and support to all older people and they have practical information on will making and lasting powers of attorney:
  www.ageuk.org.uk/information-advice/money-legal/
  AgeUk Advice Line: 0800 055 6112
- Citizens Advice gives free information and advice in person, by phone or online.
  www.citizensadvice.org.uk
  03444 111 444
- Office of the Public Guardian is a government body. It supplies legal information and helps protect people who lack mental capacity.
  www.gov.uk/government/organisations/office-of-the-publicguardian
  customerservices@publicguardian.gov.uk
  0300 456 0300
- For more information on living wills (or advanced decisions), information can be found here
  https://adassistance.org.uk/
  Or by calling: 01768 775566

If you want to know more about the method of analysis used:

Talk: The science of Conversation, by Elizabeth Stokoe. Available at most book retailers.	
TedX Talk: The science of analysing conversations, second by second. Elizabeth Stokoe. TEDxBermuda.	https://www.youtube.com/watch?v=MtOG5PK8xDA

Discourse analysis, a quick summary: https://www.infobloom.com/what-is-discourse-analysis.htm