Best interests decisions for people with advanced dementia: a qualitative study of nurses’ perspectives in England

Jayne St Claire Murphy

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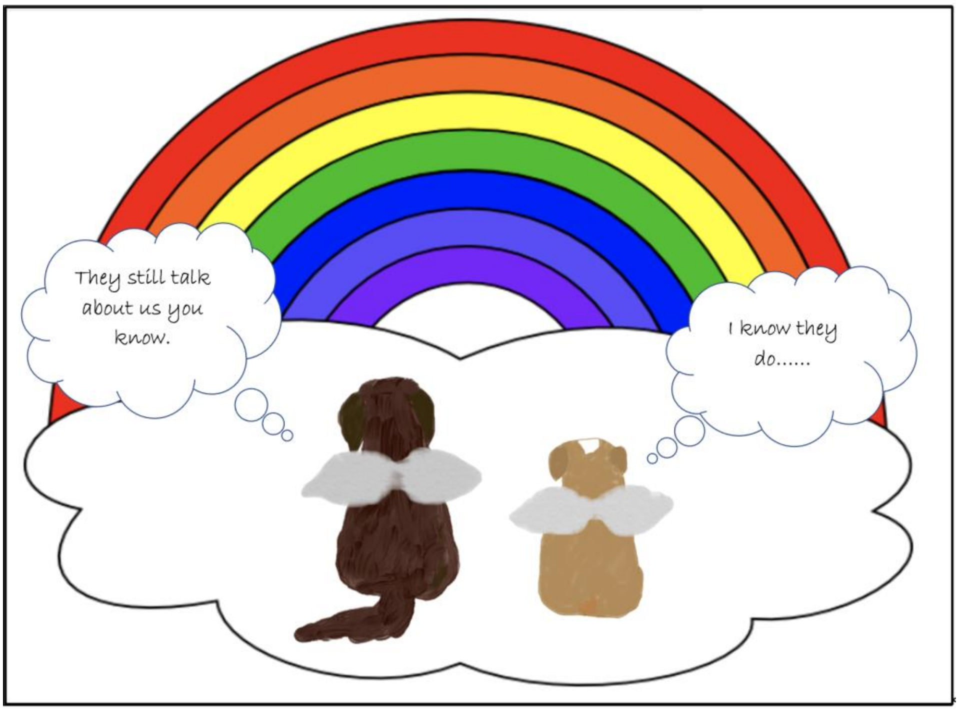

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Abstract

In the United Kingdom (UK), there are 907,900 people aged over 65 with dementia, 546,500 of whom would be classed as having severe dementia (Wittenberg *et al* 2019). Advanced dementia is now recognised as a leading cause of death in the UK and across the world (Sampson *et al* 2018). There is a gradual but insidious decline in a range of abilities and a subsequent reliance on family or formal caregivers to meet the needs of the individual and this reliance on others often leads to people with advanced dementia not being involved in decision-making (Miller, Whitlatch and Lyons 2016). The *Mental Capacity Act* (MCA) (2005) was implemented in 2007 and sought to provide a secure framework in which all parties concerned can make best interests decisions about care for people who may lack capacity (Ryan *et al* 2009; Graham and Cowley 2015). Unfortunately, widespread failure to adhere to the MCA is common (Wade and Kitzinger 2019).

A case study approach was utilised to provide in-depth analysis of Best Interests Standards as part of the MCA (2005) and best interests decision-making. In order to explore nurses' thoughts and feelings about best interests decision-making, two vignettes were utilised, depicting two situations where treatment decisions were required to explore the research question:

- What factors do nurses consider when determining best interests for patients with advanced dementia?

Thematic analysis of the results identified four key areas; that participants overall accepted the criticism presented about the MCA and best interests, that there was evidence of both explicit and tacit knowledge of the legislation through the discussion that participants initiated. Participants also referred to clinical experience to support their responses and fourthly, person-centredness influenced responses about what should happen to the

characters in the vignettes. Recommendations from the study are to promote advance care planning, to consider alternative approaches to education and to share experience in best interests meetings to improve outcomes and address the ongoing criticisms.

Glossary

ACP	Advance Care Plan is a method of recording preferences of care prior to any potential loss of capacity. It is utilised well in palliative care settings and awareness is developing for all life limiting conditions. It gives the individual the opportunity to record wishes and preferences and to make advance statements of what treatment or care they may or may not want. It proves useful in any best interests determinations
ADRT	Advance Decision to Refuse Treatment- a legally binding intention to stipulate treatment that they individual wishes to refuse in a specific set of circumstances. Should be in writing if the refusal may lead to their death. The right to complete the document is specified within the MCA (2005)
Advance statement	A statement of wishes made before capacity is lost that gives details of treatments and care that the individual may or may not wish to have. It is different to an ADRT in that it is not legally binding but may inform best interests decisions on behalf of the individual when they are unable to make the decision for themselves
Alzheimer's Disease (AD)	AD is the most common form of dementia, with 60% of people diagnosed with dementia having this sub type. It progresses relatively slowly (over years) and is due to abnormal amyloid proteins, and tau proteins disrupting the neurological functioning of the brain as well as a lack of acetylcholine, which is an important neurotransmitter
Best Interests	Best Interests is a statutory principle set out in section 4 of the Mental Capacity Act. It states that 'Any act done, or a decision made, under this Act or on behalf of a person who lacks capacity must be done, or made, in his best interests'
BIA	Best Interests Assessor is a registered professional with additional training who evaluates whether the decision (to be detained in hospital or live in a care home for example) was made considering the best interests of the person lacking capacity
BPSD	Behavioural and Psychological Symptoms of Dementia – symptoms that 90% of people living with dementia can experience because of internal or external factors that manifest in behaviour that may be challenging for others to understand and manage. An example is hallucinations or delusions
CANH	Clinically Assisted Nutrition and Hydration refers to all forms of tube feeding, via a percutaneous gastrostomy tube (PEG), naso gastric (NG) or parenteral nutrition. For this thesis it also includes 'supported oral feeding' as some of the studies cited referred to supported oral feeding and PEG, NG or parenteral nutrition.
COP	Code of Practice (2007) gives guidance for decisions made under the Mental Capacity Act 2005
Dementia	Dementia is an umbrella term used to describe a set of symptoms resulting from deterioration of the structure of the brain from a

	disease (such as Alzheimer's) or a condition (such as atherosclerotic plaques causing vascular narrowing). Dementia is the commonly used term, more technically/clinically known as neurodegeneration. All dementias have common aspects in that they are progressive, the symptoms are due to structural damage to the brain and there is no current cure. There are well over 100 causes of dementia symptoms
DSM-5	Diagnostic Statistical Manual version 5 is a diagnostic tool published by the American Psychiatric Association and serves as a tool for psychiatric diagnoses. It is utilised in the UK along with the ICD-10 for dementia diagnoses
DOLS	Deprivation of Liberty Safeguards were implemented in 2009 as part of the Mental Capacity Act (2005). The safeguards were intended to protect individuals who lacked capacity from being deprived of their liberty without reasonable cause and appropriate safeguards being in place. DOLS have been a significant reason for the criticisms from the House of Lords Select Committee.
Frontal-Temporal Dementia (FTD)	A relatively rare cause of dementia that has similarities/links to motor neurone disease. It is caused by structural damage to the frontal lobes and temporal lobes specifically that cause symptoms relating to behaviour, understanding language and factual knowledge
HOLSC	House of Lords Select Committees are small groups of members of the House of Lords appointed to investigate public policy, proposed laws and government activity. The Select Committee on the Mental Capacity Act (2005) was established in May 2013 to conduct post-legislative scrutiny of the Mental Capacity Act 2005. Their task was to answer the question of whether the Act is working as Parliament intended
ICD-10	International Classification of Diseases version 10 is the World Health Organisation diagnostic classification standard for all clinical and research purposes. Dementia diagnosis is conducted with reference to ICD-10
IMCA	Independent Mental Capacity Advocate is a person appointed to represent the person deemed to lack capacity who does not have anyone to represent them or advocate for them. They are appointed to represent the person in serious medical decisions or accommodation decisions. They are appointed through a charitable organisation, such as Voiceability (depends on local authority area)
Lewy Body Dementia (LBD)	Also known as DLB (Dementia with Lewy Bodies). The third most common dementia overall but the second most common <u>neurodegenerative</u> dementia after AD and is often misdiagnosed as Parkinson's Disease or AD. It has similar pathology to AD and Parkinson's Disease and its presenting symptoms are unpredictable and may fluctuate. It has similar protein deposits as AD, which cause damage to the structure of the brain

LPA	Lasting Power of Attorney – as part of the MCA, an individual can register an attorney to act on behalf of them for property and finance and for health and welfare at a time when they lack the capacity to make their own decisions
LPS	Liberty Protection Safeguards will replace DOLS in April 2022 and were devised to address the criticisms of DOLS as being too complex to apply. They focus on protecting liberty rather than safeguarding when liberty is deprived. Arrangements should be necessary and proportionate in line with the likelihood of the person experiencing harm from the situation
MCA (2005)	Mental Capacity Act (2005) is a piece of legislation that applies to everyone involved in the care, treatment and support of people aged 16 and over living in England and Wales who are unable to make all or some decisions for themselves
NG tube	Nasogastric – a tube that is inserted in the nose and enters the stomach through which nutritional supplements are infused when patients are unable to sustain their own oral nutrition and hydration
NMC	Nursing and Midwifery Council – the regulator for registered nurses and nursing associates in the United Kingdom
Parenteral nutrition	Intravenous method of nutrition when patients are unable to sustain their own oral nutrition and hydration
PEG Tube	Percutaneous Endoscopic Gastrostomy – a tube inserted through the abdomen into the stomach for the purposes of nutritional support when patients are unable to sustain their own oral nutrition and hydration
PLWD	People Living with Dementia/Person Living with Dementia
Service User	Pertains to a person who is a direct recipient of health or social care services, often used as the social care equivalent of ‘patient’ in a health care sense. Most often used for people who are receiving social care services or health services where traditional treatment interventions are not the focus of the care and where social care interventions are on an equal footing to health interventions. For example people with learning disabilities in in-patient units are referred to as service users rather than patients.
SDM	Surrogate Decision Making – a nominated individual decides on behalf of a person who lacks the capacity to decide. This decision should be based on the values, wishes and feelings of the individual if known. In some countries, it is the formal process of decision-making for an incapacitated person (for example Australia)
Vascular Dementia (VaD)	Vascular dementia is the second most common form of dementia, although it has a secondary cause rather than direct neurodegenerative damage. It is caused by impaired blood supply to the brain through cardiovascular disease (which could be stroke or hypertension, etc). It progresses in a step-wise presentation, with a sudden change in functioning

Chapter One
Introduction

Introduction

The purpose of this chapter is to present an overview of the study and the personal and professional reasons for choosing the topic. It will present the background of dementia and the reason that the *Mental Capacity Act* (MCA) (DCA 2005) is an important piece of legislation for people living with dementia and more specifically, an advanced stage of dementia. It will consider aspects of dementia that might impact on care, such as stigma, and will regard how decision-making is engaged by nurses and individuals with intact and impaired cognition. The development of the legislation will be presented, followed by a consideration of how policy is implemented in practice. A rationale for the study will also be clarified and knowledge defined. Chapter one will also clarify the structure of the thesis and the research questions that will be further defined in the methodology chapter.

1.1 Background

To clarify the topic of interest it is logical to review how the author's interest in dementia developed and how the ideas for research have evolved. The author's clinical role in community nursing did not originally involve dementia as a specialism. However, community nurses work with all areas of the adult population and patients with dementia are commonly cared for by a community nursing team (Harrison Dening and Hibberd 2016). At times, complex treatment decisions need to be made and when patients with dementia are unable to understand the reason for the treatment, nurses perceive delivering care as challenging (Yous *et al* 2019).

When the MCA was implemented in 2007, there was a significant amount of training delivered to inform all healthcare professionals of what the Act meant to individuals (Taylor 2015a) but the approach toward delivery of training was not sufficient to give staff the insight into a complex piece of legislation (Marshall and Sprung 2018). Before the Act was in place, there was little external guidance available and no scrutiny of those making decisions for people who lacked capacity to consent or refuse interventions (Stanley and Manthorpe 2009). A lot of clinical practice could have been challenged in respect of patients who lacked capacity to consent to such treatments (Taylor 2015b). For example, when a patient was incapable of giving valid consent, any treatment not permitted under the doctrine of necessity was considered an assault (Law Commission 1991). As the author had responsibility for education of community nurses, the MCA was one education topic that was in focus. Of particular interest was professionals' understanding and interpretation of the MCA as well as their application of it in practice. From experience, it was not clear that it was fully understood or implemented by many practitioners, not through lack of interest but because of the complexities of decision-making in some circumstances. The scarcity of ongoing education to strengthen awareness of the Act in everyday practice was also an issue that added to the apparent variable application in practice (Scott *et al* 2020).

1.2 Dementia

In 2020, it was estimated that over 50 million people worldwide live with dementia (World Health Organisation (WHO) 2020). There are a projected 907,900 people in the United Kingdom (UK) aged over 65 with dementia and of this number, 546,500 would be classed as having severe dementia (Wittenberg *et al* 2019 p. 3). There are an estimated 42,000 people living with dementia who are under the age of 65 (Alzheimer's Society 2014). The UK cost of dementia in 2019 was £34.7 billion, which includes health and social care and unpaid care provided by families (Wittenberg *et al* 2019). The global cost of dementia is suggested to be \$1 trillion (Alzheimer's Disease International 2019). If dementia were a country it would be the 18th largest economy, exceeding the market value of companies such as Apple and Google (Prince *et al* 2015). These are startling statistics but may not actually mean anything to the average person, unless they are currently affected by or have previously been affected by dementia.

The numbers of people living with dementia is increasing and looks set to continue to increase, which is a concerning prospect for most countries and economies (Global Burden of Disease Neurology Collaborators 2016). There is significant focus on raising awareness of the potential impact of dementia on individuals and society, for instance with the *Prime Minister's Challenge on Dementia* (Department of Health (DH) 2015). However, the scope of the impact is far-reaching and though explored, not entirely understood (DH 2013). In the National Health Service (NHS) policy for England, dementia provision is now incorporated into the *NHS Long Term Plan* (NHS 2019) having previously been addressed in the *National Dementia Strategy* (DH 2009) and the *Prime Minister's Challenge on Dementia 2020* (DH 2015) which focused on improving dementia care in England. *The National Dementia Strategy* (DH 2009) declared an intention to inform the public and professionals, and to reduce the fear and stigma associated with dementia, in turn encouraging high quality care. There were 17 strategic objectives covering a range of aspects around dementia from care settings to care delivery and research. *The Prime Minister's Challenge on Dementia* 2020 (DH 2015) set out to build on the initiatives in the previous document but emphasised an ambition for England to be the best country in the world for dementia care and support, alongside the best place in the world to undertake research into dementia. Research investment was set to double between 2015 and 2020 (NHS England 2019). However the Government has not yet provided this funding, nor set out a timetable for when it will be met (All Party Parliamentary Group on Dementia (APPG) 2021). *The NHS Long Term Plan* (NHS England 2019) acknowledged the public health crisis presented by the increasing number of people living with dementia and promises to improve the care and investment in dementia services.

The Health and Social Care policies relating to dementia (*Dementia Strategy (2009), Prime Minister's Challenge on Dementia 2020 (2015), NHS Plan (2019)*) all recognise the contribution of NHS staff to the provision of dementia care and the aspirations to improve quality of care and outcomes. The improvements can only be achieved through engagement and involvement of the workforce and provision of effective educational opportunities (Surr *et al* 2017). This study explores the educational opportunities experienced by participants and the effects of those opportunities, focusing on the perspectives of decision-making in dementia. Shared decision-making is a crucial aspect of dementia care and it is important that best interests decisions are made for people with dementia in a person-centred way (Daly, Bunn and Goodman 2018). This study therefore addresses two important and inter-related topics that continue to appear in current debate.

1.2.1 Definitions of dementia

It is important to define dementia to appreciate the impact of dementia on the person and their carers. There are different ways to consider dementia; as a disease or as a disability, and the way dementia is defined can have an impact on how people think about and interact with people living with dementia (Love 2017). The biomedical model has been the dominant discourse on dementia and has significantly shaped practitioners' responses. The biomedical model contextualises dementia as a progressive neuro-degenerative cognitive disorder and focuses on deficits and underlying pathology, often overlooking the fact that the person can and should be an active partner in the treatment process (Cahill 2022). Shakespeare, Zeilig and Mittler (2019) suggested that dementia is a multi-dimensional phenomenon, and requires a response that addresses different aspects, including clinical, psychological, social, and political. From a definition viewpoint, it is worthwhile then to consider dementia from a biomedical perspective and from a social perspective.

Dementia is commonly defined through diagnostic criteria, for example the Alzheimer's Disease International Report define dementia as a group of symptoms that happen because of a disease (Webster 2021). Dementia is most often used as a descriptor for a collection of symptoms that are caused by structural changes of the brain. It is a clinical state where the symptoms of cognitive decline manifest, including memory loss, loss of judgement, language, motor skills and intellectual function, which in turn leads to a deterioration in independent daily function (Ash 2014). Alzheimer's Disease was the term utilised in the past for most dementias (Kitwood 1997) but it is becoming better understood that Alzheimer's Disease is one form of the four main types of dementia: Alzheimer's Disease (AD), Vascular Dementia (VaD), Lewy Body Dementia (LBD) and Frontal Temporal Dementia (FTD) (Cunningham *et al* 2015). There is a difficulty in understanding exactly what dementia is, especially because there are over 100 causes of dementia symptoms (Birchenall and Adams 2011). With similarities to other terminal conditions, dementia is now being viewed as a progressive condition requiring appropriate palliative care (Rahman 2017).

The International Classification of Diseases (current version 11 (ICD 11) (World Health Organisation (WHO) 2022) and the Diagnostic and Statistical Manual of Mental Disorders version 5 (DSM-5) (American Psychiatric Society (APS 2013) are the most used systems for diagnosing a dementia (Naik and Nygaard 2008). A dementia diagnosis, as per both ICD-11 and the DSM-5 is a condition primarily or secondarily affecting the brain (WHO 2022). The ICD-11 categorises the varieties of dementia, though dementia is defined as a decline in memory, primarily the inability to learn new information, a decline in other cognitive abilities characterized by deterioration in judgement and thinking, such as planning and organizing, and in the general processing of information. It also refers to emotional changes, social behaviour, apathy and stipulates that the changes must have been present for at least six months for a confident clinical diagnosis. Specific sub-types of dementia consider the overall diagnostic criteria with additions that may be unique to that sub-type, such as duration and acuity of onset (WHO 1992). DSM-5 defines the presentation of dementia as a person having evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains of learning and memory, language, executive function, complex attention, perceptual motor and social cognition. The cognitive deficits interfere with independence in everyday activities and are not explained by delirium or other reversible causes (APS 2013).

The medical model is a model of health which suggests that disease is detected and identified through a systematic process of observation, description, and differentiation, in accordance with standard accepted procedures, such as medical examinations, tests, or a set of symptom descriptions (Swaine 2011). Samei Huda (2019) argues that the medical model is sometimes mis-represented as a 'disease-based' model in respect of a diagnosis being separate from other diseases and optimal health, and therefore that management of patients focuses on biological processes ignoring psychosocial factors. He defends the medical model as a system to help identify clinical problems, one which integrates the effect of culture, social factors, personal circumstances and beliefs, diet, upbringing, and so forth on health and illness.

In his text, *Dementia Reconsidered* (Kitwood 1997), Tom Kitwood acknowledged the profound and lasting effects that dementia poses on our political, economic, and social life but he also suggested that dementia was viewed through the lens of the medical model, framed as an 'organic mental disorder', which caused psychiatry and other disciplines to treat dementia in a narrow way, ignoring the larger human issues, such as how people treat each other. Kitwood (1997) introduces what he describes as malignant social psychology where people who are cognitively intact treat people with dementia in such a way that it strips them of their humanity; for example infantilising, disparaging, or ignoring people. Cuijpers and van Lente (2015) also describe the criticisms of the biomedical model as neglectful of the social components of dementia, affecting policy and research and negatively affecting the experience of living with dementia. They explain that according to the biomedical model, Alzheimer's Disease is a condition of a person, caused by deterioration of the brain, where there is currently no cure. The biomedical approach to deal with dementia is by medical control, where it should be diagnosed, managed, and treated by medical authorities. Chaufan *et al* (2012) expand on the challenges of medicalising dementia (specifically Alzheimer’s Disease) they suggested that it pits advances in biomedical research against the needs of an aging population, which means that the priority is to fund a cure, rather than to fund care. They concluded that the medical model led to a ‘cult of expertise’, where laypeople are excluded from participation in decisions and proposed that alternative framings of dementia are critical to address the needs and preserve the humanity of people living with dementia and their carers. In essence, Chaufan *et al* (2012) support the need to prioritise investment in care interventions, to help people living with dementia to live well today, rather than investment to prioritise future treatments and cures. This is a valid position, with the number of people living with dementia who have people caring for them, investment in ways to help them live well would help to alleviate the many challenges they face whilst hoping that treatments and cures can be found.

Keady *et al* (2013) suggested that the biopsychosocial model is applied to dementia to ground practice, generate clinical understanding and evidence-based decision-making. The biopsychosocial model is a model that considers the biological, psychological and social factors that contribute to a dementia diagnosis. The biopsychosocial model promoted through person-centredness takes a whole-person approach to understanding dementia and examines a wide range of factors likely to impact on the person's subjective experience, including influences from biology, society, economics, psychology and the environment (Hennelly *et al* 2018). Keady *et al* (2013) explain that the biological functioning of the brain and the individual's psychological response to this biology relies on the social domain to retain identity, positioning the individual with dementia as a person of worth and value. This echoes the paradigm presented by Kitwood in which the person comes first, using a richer range of evidence than the medical model, searching for human, rather than medical solutions (Kitwood 1997). It is therefore important to consider both the medical and the social definitions of dementia as important to the study, as it may help to explore how health professionals think about people living with dementia and particularly advanced dementia. Where symptoms are exacerbated and dependence on others in activities of daily living is increased, the inclination to see dementia as a problem to solve may outweigh the inclination to preserve the rights of the person living with dementia.

1.2.2 Progression to 'advanced dementia'

There are various tools for classifying the stage of dementia, most often used for measuring severity in clinical research and evaluating the efficacy of dementia drugs in clinical testing. The Global Deterioration Scale (GDS), the Clinical Dementia Rating (CDR), the Mini Mental Status Examination (MMSE), and the Minimum Data Set evaluate various areas such as cognition, function, and behavioural symptoms and each have advantages and disadvantages in their use (Choi *et al* 2016). In the World Alzheimer Report (2022), classification or staging of dementia is discussed in a series of essays, where it is suggested that the concept of disease stages has practical relevance for patients, families, and healthcare professionals (Gauthier and Rosa-Neto 2022). Reisberg *et al* (1982) suggested that the incidence of clinical complications, the extent of physical suffering, and the use of burdensome interventions in dementia are not well understood. More recently, Rahman (2017) claimed that there is a reluctance to view dementia as a terminal illness and as a result a lack of knowledge and targeted interventions to both recognise and manage the terminal phase, from both health professionals and informal carers.

Advanced dementia is now being recognised as a leading cause of death in the UK and across the world (Sampson *et al* 2018). The number of sub-types of dementia may be one reason why Mitchell *et al* (2009) suggested that the clinical course of advanced dementia has not been described in a rigorous, prospective manner. The Global Deterioration Scale (GDS) (Reisberg *et al* 1982) is one tool that delineates between dementia stages. Stages 1 - 3 are the pre-dementia stages, stages 4 - 7 are the dementia stages. Beginning in stage 5, an individual can no longer survive without assistance but stages 6 and 7 indicate severe dementia. In stage 6, the individual will be largely unaware of recent events and experiences in their lives and may require some assistance with activities of living. They may also have personality and emotional changes, such as delusional behaviour, obsessive symptoms, and agitation. Stage 7 is very severe cognitive decline (severe dementia), where all verbal abilities are lost over the course of this stage, basic psychomotor skills are lost and the brain appears to no longer be able to tell the body what to do (Reisberg *et al* 1982).

The Dementia Severity Rating Scale (DSRS) can be used by caregivers to assess the severity of different types of dementia, from the mildest to the most severe (Khan 2016). The DSRS uses a multiple-choice format to obtain information from the caregiver about the individual's ability to function in their home environment. The first six categories mirror the items in the

CDR and the other five items address language, recognition, eating, incontinence and mobility, rating from 0 to 51 (‘normal’ to ‘maximally impaired’).

Advanced dementia is often referred to as late-stage dementia and includes the severe and terminal stages of the disease (Long 2009). Mitchell *et al* (2009) conducted an 18-month, multicentre, prospective study of 323 nursing home residents with advanced dementia to characterize the residents’ survival, clinical complications, symptoms, and treatments and to determine proxies’ understanding of the residents’ prognosis and the clinical complications expected in patients with advanced dementia. Pneumonia, febrile episodes, and eating problems were found to be frequent complications in patients with advanced dementia. Features of advanced dementia include profound memory deficits (e.g., inability to recognize family), minimal verbal communication, loss of mobility and other activities of daily living, and urinary and faecal incontinence and the most common clinical complications are problems with eating and drinking and with infections (Mitchell 2015).

People with dementia may die from an un-associated condition, or from what is considered as end-stage, where the consequences of the dementia impacts all domains of their life and they ultimately die of the complications of the condition; immobility and loss of swallow reflex for example leading to infection that is fatal (Downs and Bowers 2014). The most common cause of death is pneumonia, but symptoms of severe dementia include cognitive problems, such as profound loss of ability to perform purposeful actions, functional impairments and non-cognitive symptoms often described as behavioural and psychological symptoms of dementia (BPSD) (Sandilyan and Dening 2019).

1.2.3 Stigma

The stigma associated with a dementia diagnosis is multi-factorial and the fact that stigma exists perpetuates negative connotations that contribute to the continued existence of the stigma itself. It is important therefore to consider stigma due to the association between dementia and the inevitable loss of decision-making capacity (Milne 2010). Stigma also relates to how the public view dementia, through a medical lens or through an impairment or disability lens. Viewed as a medical issue, there is less likelihood of preserving the rights of a person with dementia. ADI explored stigma in their 2019 report: Attitudes to Dementia, recommending that active measures be taken to reduce stigma to uphold the human right to full and equitable engagement and access in meaningful activities (ADI 2019). According to Goffman (1963 p. 14 - 15), stigma presents as three different types: abominations of the body, blemishes of individual character and tribal stigma but in all three types, the same sociological features are found. A person who experiences stigma has an ‘undesired differentness’ from what is anticipated, they exhibit traits that can obtrude itself upon attention and turn people away from them. Although there has been an increasing amount of research on dementia-related stigma, evidence-based approaches to reduce dementia-related public stigma is still lacking and therefore dementia is still stigmatized, leading to significant negative effects on the health and well-being of people with dementia and the people supporting them (Sarang *et al* 2019). The ADI (2012) report on stigma suggested that low levels of understanding perpetuate the stigma which is prevalent in most countries. As a result, people with dementia are often isolated, or hidden, because of stigma or the possibility of negative reactions. The belief that nothing can be done to help people with dementia often leads to hopelessness and frustration (Batsch and Mittleman 2012).

Approximately 90% of people who have dementia will experience Behavioural and Psychological Symptoms of Dementia (BPSD) at some point. It is not confined to advanced dementia, as it is experienced as part of the natural course of dementia (Cerejeira, Lagarto and Mukaetova-Ladinska 2012). However, it is recognised as detrimental to the condition, leading to deterioration and poor prognostic indicator and as such may contribute to the individual reaching the advanced stage (Tible *et al* 2017). BPSD is the recognised term to describe symptoms of disturbed perception, thought content, mood or actions that frequently occur in people with dementia (Marrie and Williams 2014). BPSD are numerous, complex, and multi-faceted and there are many ‘behaviours’ and ‘symptoms’ included within the term. Some of these include wandering, aggression, agitation, disinhibition, hallucinations and delusions and they are common symptoms seen in severe dementia (Sandilyan and Dening 2019). BPSD is deemed as problematic because it creates a potential risk to the person living with dementia, those around them or their carers. Carers often become exhausted from the challenges of managing BPSD and experience mental and physical ill health (Brodaty and Donkin 2009). This adds to the stigma because the carer burden is reported to be greater for carers of people living with dementia (Broadaty and Donkin 2011). Person-centred care interventions have showed immediate effects on reducing BPSD, such as agitation, neuropsychiatric symptoms, and depression, improving quality of life and cognitive function, thus person-centred interventions are a vital element in dementia care (Kim and Park 2017; Lee, Lee and Kim 2022).

1.2.4 Personhood and person-centredness

As dementia progresses and insight is flawed, decision-making can also present a challenge because, as highlighted by the Alzheimer’s Disease International (ADI) report, the person living with dementia may not be consulted in decisions made on their behalf by others (Batsch and Mittleman 2012). Many challenges stem from the difficulties in communicating with a person living with dementia because it appears that they lack insight into their condition (Howorth and Saper 2003). Part of the stigma of a dementia diagnosis is the loss of a sense of self, acknowledged within the ADI report, which suggested that in their encounters with their carers, healthcare workers, the media, governments, and society people with a diagnosis of dementia experience labelling, stereotyping, separation, status loss and discrimination; a significant influencing factor in the stigma associated with a dementia diagnosis. The ADI report also describes the consequence of an assumption of incapacity to make decisions, leading to a premature loss of autonomy and dignity, in turn fuelling the loss of self-esteem associated with stigma and dementia (Batsch and Mittleman 2012).

Harding (2012) discussed the apparent natural process of others having an influence on decisions because we are not atomistic individuals but part of social relations. She promotes taking a person-centred approach to autonomy to promote continued personhood. Kitwood discussed the concept of personhood as 'a standing or status that is bestowed upon one human being, by others in the context of relationship and social being' (Kitwood 1997 p. 8). He placed emphasis on the role of positive social interactions, authentic communication, and genuine relationships in dementia care (Tieu *et al* 2022). Personhood in dementia is concerned with preserving dignity and respect and supporting the sense of self of the person living with dementia. Donnelly (2019) suggested that people with dementia will have lived full and active lives, in which they have developed moral, political, social, religious, and other views; built a complex set of relationships; and acquired financial and other assets, which contributes to their personhood. Supporting personhood in dementia is the key goal of person-centred care (Hennelly 2018).

Person-centredness, according to Brooker (2007) means different things to different people in different contexts. She offers a definition of person-centred care that describes four elements: valuing people with dementia and their carers, treating them as individuals, recognising each person's experience and perspective, and recognising their need for an enriched social environment (p. 12). Kitwood (1997) described the biological and environmental factors that affect the person with dementia, explaining how each can influence the other. In respect of society, Kitwood described behaviour tendencies of others that are highly damaging to the person with dementia, for example disempowerment, stigmatization and infantilisation, and they amount to treating the person with dementia as less than human. Kitwood's solution to counter these behaviours was to use positive person work, which included recognition, validation, and facilitation, all promoting personhood of the individual with dementia. Working in a person-centred way across a whole organisation requires sign-up by leaders at different levels; at senior level for valuing people, in standard setting for individualised care and from those responsible for day-to-day provision of care for personal perspectives and supportive social environment (Brooker 2007).

Nandimath (2021) stated that there was a need for greater implementation of person-centred care to improve the quality of life of people with dementia but also acknowledges that there are challenges to its implementation from a lack of clarity, a lack of evidence, a task centred care culture and lack of resources. Ellis and Astell (2017) conducted a study to review interaction between care staff and residents with advanced dementia in one care home and found that in 24 years between their study and a previous study (Astell and Ellis 2006), little had changed in respect of the social environment and engagement for the residents were limited to episodes of personal care. The focus of their study was social interaction and their considerations in relation to this topic were that people with advanced dementia may be judged as having nothing to contribute and have lost the desire to participate in the social world, which exacerbates the reduced opportunity for interaction with others, individuals with advanced dementia are excluded from the social world and are not viewed as social agents. They recognised the links between these factors and the resulting accounts of 'burn-out' in care staff and a lack of motivation and education. Walmsley and McCormack (2016) support this notion, they suggested that professional carers of people with dementia, who are often constrained by the medical model are unable to offer quality person-centred care, due to lack of time. As a result they experienced moral distress as the stigma of aged-care is compounded and autonomy and wellbeing undervalued. Tieu *et al* (2022) suggested that person-centred care has become synonymous with an individualistic and consumerist notion of care, where recipients were viewed as consumers. However, this is inconsistent with the humanistic ideals that underpin the concept as it assumes persons are merely objects with particular attributes but lack the social, relational, and temporal dimensions of personhood. Tieu *et al* (2022) goes on to explain that the consumerist model of personhood is predicated on being an individual and having the capacity to exercise autonomy and self-determination. This ignores the fact that persons are also embedded within their social surroundings and undergoing significant development and change over the life course. When considering factors that affect best interests decision-making, it is important to acknowledge the changes that dementia brings and focus on preserving the person's sense of selfhood in person-centred care (Tieu *et al* 2022).

1.3 Decision-making

1.3.1 How we make decisions as capacitous adults

Making decisions is a normal part of life and most decisions made by adults are made independently, without significant involvement from anyone else (Manthorpe 2019). A decision is a deliberative process that results in the commitment to a categorical proposition (Gold and Shadlen 2007) and decision-making is a complex and involved process, explored, and debated from different perspectives, including philosophical, psychological, and neuroscientific (Pirtošek, Georgiev and Gregorič-Kramberger 2009). A neuroscientific perspective involves identifying the specific area of the brain that is activated when a particular type of decision is required (Swaab 2014). A psychological perspective considers how decisions are rendered under different conditions, including how information is considered, the level of importance attached to information and how short-cuts are used when making judgements (Hardman 2009). The philosophical elements of decision-making is explored by Steele and Stefánsson (2016) with normative decision theory, from which people can understand the behaviour and intentions of others.

If the brain is structurally damaged by the dementia, then decision-making will be affected from neuroscience, psychological and philosophical aspects. This all reinforces the fact that decision-making as a process is multi-faceted, complex, and not easily explained. Patients with dementia cannot be assumed to be incapable of making decisions. Patients with mild to moderate dementia can evaluate, interpret, and derive meaning in their lives. Even a patient with advanced dementia may have capacity to appoint a health-care proxy for example (Hegde and Ellajosyula 2016). Unfortunately, the decision-making process for people with dementia is fraught with difficulties that hinge on the lack of involvement of the person with dementia (Miller, Whitlatch and Lyons 2016). It is important to understand patient decision-making as this is affected with a diagnosis of dementia.

It is also important to consider nurses' decision-making as the study reviews perspectives when making decisions on behalf of a person living with dementia. Nurses' clinical decision-making is also a complex process with processes that develop over time as nurses acquire necessary knowledge, thinking processes and clinical experience (Gillespie 2010). Nurses make clinical decisions within a multi-layered context where each level potentially includes social, cultural, political, ideological, economic, historical, temporal, and physical factors that may influence clinical decision-making (Gillespie 2010). Nurses make a multitude of decisions daily in clinical practice that call for careful thought processes because the outcomes of the decisions may impact on the patient; it is complex cognitive work that demands flexibility and the less experience the nurse has, the less skilled they are in clinical decision-making (Manetti 2019). Procedural aspects of decision-making within legislation will be explored in chapter 2.

1.3.2 Dementia and decision-making

Other progressive and terminal diseases generally leave decision-making capacity unaffected until very late into the disease, giving the freedom to make informed decisions and retain control over one's affairs throughout the progression of the condition. This was supported in a study by Kolva, Rosenfeld and Saracino (2018), who found that half of the sampled terminally ill cancer patients experienced impaired decision-making capacity but 85% did have the ability to make a treatment choice. Dementia is different in that it potentially deprives the person of their capacity to make autonomous informed decisions perhaps even from mild to mid disease (or at least appears to) (Moye *et* al 2005; Torralva *et* al 2007). The individual is unable to maintain control of their own destiny and relies on others to make decisions on their behalf, be that health and social care professionals or family (Samsi and Manthorpe 2013).

If planning and reasoning is a neurological process, where specific areas of the brain are activated to act, the neurological damage associated with dementia will have a detrimental impact on the function of the brain. This is supported by Gleichgerrcht *et al* (2016) when they discussed AD. They confirm that decision-making involves memory, language, attention, visuospatial perception, and executive functioning and in AD, as the disease progresses, brain areas such as the temporal, frontal and parietal lobes are affected. This results in a progressive decline of memory functions as well as language and visuospatial abilities and executive function decline (p. 611). As dementia progresses and the level of brain damage increases, this loss of decision-making capacity is exacerbated. An example of this is the degree of apathy experienced by a person with Alzheimer's disease and the shrinking of the area of the brain associated with thought and reasoning (Swaab 2014).

There is a general assumption that the person with dementia is not autonomous because they are unable to make decisions; this understanding of autonomy means that health and social care professionals in particular feel justified in making decisions on behalf of the person with dementia (McCormack 2002). Although damage to the structure of the brain will impact on functioning, decision-making has, as mentioned previously, been largely ignored as a continued right of a person with dementia (Miller, Whitlatch and Lyons 2016). O'Connor and Purves (2009) recognised that all too frequently, there has been an implicit assumption underpinning interaction with people with dementia that they are incapable and that they have no insight into their own experience and cannot give informed consent, they asserted that the MCA (2005) advanced civil and social rights through protecting liberty and promoting self-determination for people with dementia.

It is also important to understand the concept of Advance Care Planning (ACP), which involves identifying an individual's preferences (in advance) about the care they would like to receive and the setting they would prefer to receive it (Exley *et al* 2009). According to NHS Improving Quality (2014), there have been several policy initiatives that identify the intention of government to offer a person more choice about their care, including NICE guidelines (2004), the MCA (2005), the End-of-Life Care Strategy (2008) and the NHS Next Stage Review (2008). However, ACP has happened infrequently for people diagnosed with a dementia, even though it should be initiated early in the diagnosis and follow a continuous and dynamic process between an individual and their healthcare professional (Piers *et al* 2018). ACP is a form of advance decision-making that is invaluable for people diagnosed with conditions that will affect their capacity to make autonomous decisions (Hayhoe and Howe 2011). Although ACP is not a central focus of this study, it does feature in relation to decision-making on behalf of others.

1.3.3 Mental Capacity Act (2005) and the Best Interests Standards

Prior to the introduction of the MCA, people's autonomy was not always respected and people were often 'written off' as being incapable of making a decision due to their diagnosis (Graham and Cowley 2015). The law left patients lacking mental capacity and their doctors in something of a legal limbo; no-one had legal authority to act as proxy and consent on behalf of the patient (Brazier and Cave 2011). The MCA was the result of many years of dedicated reform effort (Ruck-Keane and Auckland 2015) as it sought to provide a secure framework in which all parties concerned can make best interests decisions about care for people who lack capacity (Ryan *et al* 2009; Graham and Cowley 2015). Figure 1.1 presents a timeline of the development and progression of the legislation.

1986	•The Law and Vulnerable Elderly People (publication highlighting the need for reform)
1989	•Decision-making and Mental Incapacity: A Discussion Document (highlighting the need for reform)
1989	•Law Commission invited to investigate the law relating to incapacity
1991	•Law Commission Consultation Paper 119
1993	•The Law Commission Consultation Paper Nos. 128, 129, 130
1995	•The Law Commission. Mental Incapacity - item 9 of the fourth programme of law reform: mentally incapacitated adults
1997	• The Lord Chancellor's Green Paper: Who decides? Making Decisions on Behalf of Mentally Incapacitated Adults
1999	•The Lord Chancellor's White Paper: Making decisions : the Government's proposals for making decisions on behalf of mentally incapacitated adults: a report issued in the light of responses to the consultation paper Who decides?
2003	•Mental Incapacity Bill published
2004	•Joint Committee pre-legislative scrutiny
2004	•Re-named Mental Capacity Bill published
2005	•Mental Capacity Act (2005) received Royal assent
2006	•The Law Commission Post-legislative scrutiny reviewed how legislation is reviewed following implementation
2007	•MCA Implemented and Code of Practice Published
2007	•Deprivation of Liberty Safeguards introduced as an amendment under the Mental Health Act 2007
2008	•DOLS Code of Practice published
2008	•Government Approach to Post Legislative Scrutiny agreed to review legislation 3 years following implementation
2009	•DOLS implemented
2013	•The House of Lords Select Committee (HOLSC) was established to review MCA and DOLS
2014	•HOLSC Post-legislative scrutiny report published
2014	•Valuing every voice - Government response to HOLSC report
2015	•Law Commission commences a review of DOLS
2017	•Mental Capacity and Deprivation of Liberty - Law Commission recommendations and draft bill
2018	•Final Government Response to the Law Commission's review
2018	•Mental Capacity Act Amendment Bill
2019	•The Mental Capacity (Amendment) Act (2019) receives Royal assent
2022	•Liberty Protection Safeguards to be implemented and new Code of Practice to be published

Figure 1.1: Timeline of the MCA, Best Interests and Deprivation of Liberty

The detailed timeline in appendix 1 identifies the development of the legislation from its origins to the most recent amendments, which are yet to be implemented. The MCA (2005) was implemented in 2007 following a call for change in legislation that dated back almost 20 years prior. A lengthy consultation process and the publication of draft recommendations accompanied by pre-legislative inquiry concluded with its publication and implementation (Letts 2007). Post-legislative scrutiny that was directed through a separate process of law change resulted in reports of widespread failure to adhere to the MCA. Further consultation and amendments in response to the criticisms have resulted in the *Mental Capacity (Amendment) Act* (2019), with the changes due to be implemented in 2022 (Ruck-Keane 2019). This timeline demonstrates the complexity of the legislation and its development and the fact that continued focus on the function of the legislation is inevitable.

The best interests approach used within the MCA is considered as the most useful approach for making decisions on behalf of incapacitated adults, because it allows for integration of both patient autonomy as well as acknowledging family interests (Wade and Kitzinger 2019). The MCA *Code of Practice* (COP) (DCA 2007) recognised the challenges of defining what best interests are; it also recognised that every case and every decision is different and that the law cannot set out all the factors that will need to be considered in working out someone's best interests; there is no guidance that will apply to all cases in all settings. Best interests is not defined in the MCA 2005 but section 4 establishes a process (or checklist) by which a conclusion should be reached in determining what is in a person's best interests (Ruck-Keane *et al* 2019). This includes encouraging the individual's participation in the process or considering the individual's past and present wishes and feelings expressed when they had capacity. It also requires the best interests decision-maker to consider any values or beliefs that may influence the individual's decision if they had capacity and any other relevant factors that they would consider if they were able to do so. Any other significant person who has a vested interest in the incapacitated person's well-being has a right to be consulted as part of the best interests process and any decision should be delayed if there is a possibility that the individual may regain capacity to decide or should be the least restrictive option if the decision cannot be delayed (Office of the Public Guardian 2009). There should be no assumptions made about the individual's quality of life and no decision should be undertaken if it is motivated by bringing about the person's death (British Medical Association (BMA) 2019). If applied correctly, the MCA and BI standards have the potential to empower people with dementia (Illife *et al* 2015). Unfortunately, it is still misunderstood or misapplied and used against people (Burgess 2017).

1.3.4 Embedding policy into practice

Prior *et al* (2014) propose that health policy is not just a channel through which scientific evidence might flow, it is an active agent in the health care system of most countries and worth questioning how policy might get in to practice. The House of Lords Select Committee (HOLSC) (2014) compiled a report; post legislative scrutiny to establish how well the MCA was embedded in practice. It is suggested that it takes an average of 17 years for research evidence to reach clinical practice (Morris, Wooding and Grant 2011). Prior *et al* (2014) went on to say that policy rhetoric had little impact on the precise focus of interactions between health professionals and their patients unless it is encompassed within operational documents and unless policy is translated into a clearly structured set of activities, practice will remain sporadic, contingent, and piecemeal. It is worth considering then, how the introduction of the MCA was operationalised and whether this has had any influence on the criticisms identified the criticisms being practitioner knowledge and application of the legislation in practice (HOLSC 2014).

1.4 Defining knowledge

As part of the criticisms, not only from the HOLSC (2014) but also from other sources that will be identified within chapter 3, practitioner knowledge is one area where criticism has been directed. Therefore, it is appropriate to introduce the concept of knowledge at this point so that elements of knowledge can be further explored as the study develops. Bolisani and Bratianu (2018) explain that knowledge is an abstract concept without any reference to the tangible world, no clear definition and is a multi-field paradigm that is composed of rational, emotional, and spiritual knowledge fields. Indeed, Reed and Shearer (2011) align to this idea when they suggested that nursing knowledge is enriched by many patterns of knowing, not necessarily cumulative, unchanging, or unchangeable, but is relevant to the practice situation or problems to which it is linked. It is outside the scope of this study to explore the multitude of theories of knowledge but as knowledge of nurses is a focus of the study, it is important to identify a definition by which the knowledge was explored. Dombrowski, Rotemberg and Bick (2013) explain that there are three kinds of knowledge, that though interconnected have their own specific features: experiential, skills, and knowledge claims.

Simply put, skills are the ability of completing a task to an expected outcome (Kassema 2019) and experiential knowledge is understood as a way of knowing and understanding through direct engagement, which is carried and transmitted through actions, rather than communicated verbally (Nimkulrat *et al* 2020). Knowledge claims are what we know, or think we know and include both explicit and tacit knowledge. Knowledge claims enable us to learn from each other through an exchange of stated ideas that can be examined and discussed (Dombrowski, Rotemberg and Bick 2013). Explicit knowledge (also referred to as articulate knowledge) is typically acquired through formal education, writings, books, rule sets and legal code (Dampney, Busch and Richards 2007). Whereas tacit knowledge cannot be articulated and is a form of ineffable knowledge which is not expressed through language but through a lived experience (Zappavigna 2014). Hislop, Bosua and Helms (2018) suggested that explicit and tacit knowledge are two pure and separate forms of knowledge, where explicit knowledge is regarded as objective and can be codified in a tangible form, whereas tacit knowledge is personal, held by people, and may shape how they think and act and is almost impossible to codify.

Dalkir (2011) explained tacit knowledge residing in the heads of knowers and explicit knowledge being contained within tangible or concrete media. The argument that Dalkir (2011) proposed is that tacit knowledge that may be easily articulated by one person but may be difficult to externalise by another, so the same content may be explicit for one person and tacit for another. Also, highly skilled, and experienced individuals may find it harder to articulate their know-how, whereas novices are more able to verbalise what they are attempting to do because they are following a how-to process. If this definition is applied in the study then the knowledge of nurses can be explored from a tacit/explicit dichotomy and the considerations proposed within those definitions will help to extract meaning from the responses.

1.5 Rationale for this study

In reviewing research conducted in relation to the MCA (2005) and best interests, it became apparent that further research is required to understand continuing practice and inform the development of guidance in the application of the legislation. Best interests decisions are a significant factor in the MCA (2005) and in professional practice and it has been highlighted that there are improvements required (HOLSC 2014). Appendix 2 gives some examples of how practitioners' understanding of the legislation continues to be criticised by professionals on social media. Analysis of how nurses deliberated about best interests will be informative and helpful, particularly if there are recommendations to be made that will guide and improve practice. This study continued from previous studies where issues of best interests have been explored, specifically the practice of best interests determinations and how knowledge and understanding is demonstrated through that practice. It will investigate how the horizon of knowledge, understanding and interpretation of capacity and the Best Interests Standards (in relation to advanced dementia) has changed since the review of the legislation that suggested that practice was impaired.

Graham and Cowley (2015) suggested that it is impractical to expect practitioners to know every section of the MCA and be able to quote it verbatim or 'cherry-pick' what they need to know and apply it without due consideration, but they should practice understanding and pay due regard of the uniqueness of individuals through applying the 'spirit of the MCA'. This is what the research aims to do; to explore perspectives of nurses in respect of the MCA and best interests of a person living with advanced dementia, to consider if the 'spirit of the MCA' is evident in their perspective. As communication is a recurring aspect of the MCA (2005) and also as part of the legislation, Best Interests Standards, it is worthwhile exploring any connections between advanced dementia and communicating decision-making preferences where communication is judged as impaired.

1.6 Research questions

The over-arching question was:

- What factors do nurses consider when determining best interests for patients with advanced dementia?

Three sub-questions were utilised to explore the concept of best interests:

- How is knowledge of the Best Interests Standards demonstrated?

- What procedural and substantive considerations do nurses identify when making best interests decisions?
- What support mechanisms are helpful for nurses in relation to undertaking best interests considerations?

A case study approach will enable in-depth analysis of Best Interests as Standards and part of the MCA (2005) and as part of best interests decision-making. To describe and explain (parts of) social processes, doing a case study presents a unique opportunity to focus on social interactions and the developing meanings that participants in the system attach to each other, such as the different, and sometimes contrasting, views participants in a system have, and their diverging interpretations of events and conditions (Swanborn 2010). A case study provides the researcher with real life events in a meaningful and holistic way when the case is not distinctive in its context (Yin 2018).

1.7 Terminology

For clarity, it is important to differentiate between Best Interests and best interests within the thesis. When individuals lack the capacity to make an independent decision, the MCA decision-making (2005) supports them by allowing others to make decisions on their behalf in what is deemed to be their 'best interests'. The specific guidance on how this is undertaken uses identified actions, known as and referred to within this thesis as 'Best Interests Standards'. For the sake of brevity, the author will refer to the specific standards within the legislation as Best Interests Standards (BIS) and in general for the person as in their best interests. In this tone, the BIS may appear to be formally applied but the resulting decision may not promote the patient's actual best interests.

There are several terms stated within the thesis for a person living with dementia: patient, individual and person living with dementia. In general, the term 'patient' is used in relation to interaction or relationship with the nurse, as the ‘patient’ is the direct recipient of care. Individual or person living with dementia is used when discussing dementia in general, as ‘patient’ does not accurately describe every person experiencing the symptoms or effects of a dementia diagnosis. Service user is also a term that is used (most often in social care) that refers to recipients of social care services. This term is used within the thesis if the reference to support the point defines the person as a ‘service user’.

1.8 Outline of thesis

This thesis contains seven chapters, and each stage of the process is explained and explored in the corresponding chapter. The questions discussed in section 1.6 were developed to explore the context of nurses making best interests determinations for patients with advanced dementia requiring clinical treatment or intervention, which reflects the clinical situations that they may face. Figure 1.2 represents the structure of the thesis. Chapter one has introduced the study, giving the contextual background to the condition of advanced dementia and the reason that decisions may be required for the individual, with an explanation of the legislation that supports the decision-making process. Chapter two provides the background of the legislation and how it provides context to the study and chapter three is a review of literature that informed the study and helped to develop the research methodology. Chapter four then goes on to explain the methodology and the process of data collection, which was carried out over a ten-month period. The results are presented in chapter five and analysed in detail, aligned to the literature in chapter six. Finally, chapter seven presents an overall evaluation of the study, including the strengths and limitations of the study. Chapter seven also provides recommendations for education and training, practice, and future research, which will hopefully lead to improvements in patient outcomes where best interests decisions are involved. References and appendices are the final sections of the thesis.

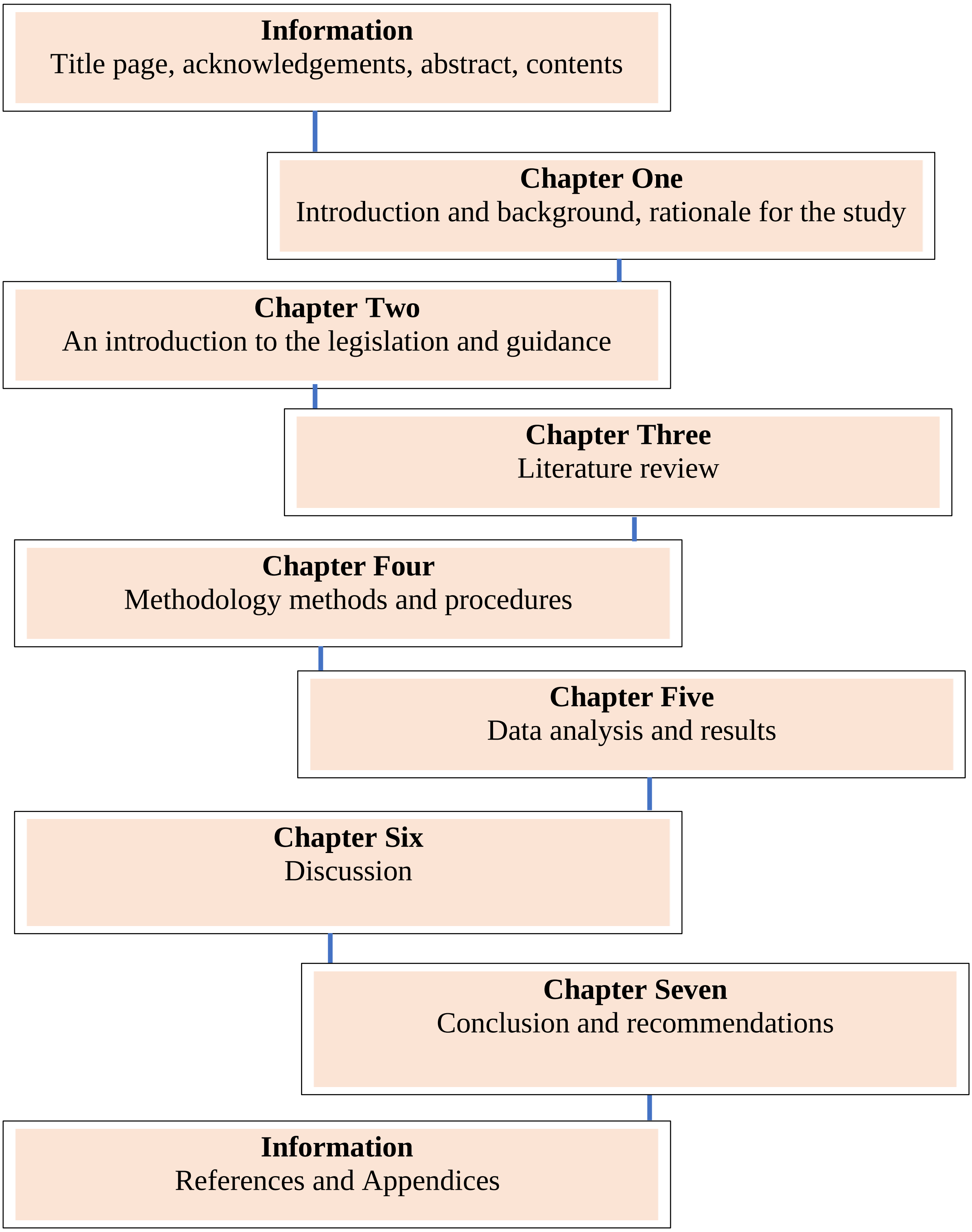


Figure 1.2: Structure of the thesis

1.9 Summary

Thus far, this chapter has considered the definitions of dementia from a medical and a social perspective and how a person is judged to be at an advanced stage of dementia. It has identified that individuals living with advanced dementia may experience cognitive decline to such a degree that they lack the capacity to make an autonomous and appropriately informed decision for aspects of care and treatment that may be required. In England and Wales, the rights of these individuals are protected by legislation that guides professionals and non-professionals alike in how to approach decision-making on their behalf. Unfortunately, there is a level of criticism directed towards health and social care professionals due to the lack of satisfactory application of this legislation.

The legislation specifies that a person should be assumed to have capacity to make a decision and should be supported to make a specific decision at the time it is required to be made. If the person is deemed to lack capacity, any decision made on their behalf should be in accordance with the best interests process, with reference to the BIS as set out in the legislation. The central aim of this study is to examine how successfully nurses undertake best interests processes and how they perceive the difficulties the process involves.

The challenges of dementia are widespread but interlinked with the sizeable and self-generating stigma that accompanies societies' perception of the condition. It is impossible to deny that dementia affects the individual physically and psychologically, as it is acknowledged as progressive and terminal. It also has an impact on the people delivering care, both formal and informal because of the challenges that the condition generates; mainly the potential to experience behavioural and psychological symptoms that are difficult to interpret and to manage.

The advanced and challenging symptoms contribute to the stigma associated with the condition and influence the perspective of caregivers. If the person is experiencing BPSD then they are considered as lacking the capacity to make any decision. Dementia, and more specifically, advanced dementia, can and does impact on the person's ability to maintain insight into their capabilities and as the condition progresses, the ability to maintain autonomy in decision-making is impaired. The progressive nature of dementia means that the individual with dementia will require decisions to be made on their behalf as their capacity to engage in decision-making dissipates. What is needed is an increased understanding of the potential challenges, mitigated by solutions of how these challenges can be addressed as they present themselves. The medicalisation of dementia, BPSD and the associated stigma are positively impacted by person-centredness. A person-centred approach may go some way to reduce stigma and increase confidence in the systems available to support the person living with dementia and their carers.

> '*Good practice is not about being told what to do and then going ahead and doing it. People and their circumstances are not only more complex than following such a superficial process, but actually deserve deeper and wider reflection in relation to their capacity, rights, choices and decision-making*.' (Graham and Cowley 2015 p. 16).

Chapter two will explore the legislation in greater depth and chapter three will explore the literature surrounding the legislation and its application.

Chapter Two
An introduction to the legislation and guidance

Introduction

This chapter examines the law and guidance and provides the background to the legislation that underpins the focus of the study. The *Mental Capacity Act* (MCA) (DCA 2005), the *Mental Capacity Act (2005) Code of Practice* (COP) (DCA 2007) associated with the Act, the *Best Interests Standards* as one of the five principles of the Act and the *National Institute for Health and Care Excellence* (NICE) (2018) guidance developed to support practitioners in the legislation's application are explained to give context to the study that explores nurses' knowledge and perspectives in relation to making best interests decisions. The research focus is best interests decisions for people with advanced dementia, but as the BIS are part of a wider approach to decision-making in the legislation, they cannot be understood properly in isolation from the other principles. Also, the other supporting documents guide the implementation of the legislation and therefore need to be considered alongside the BIS.

2.1 The Mental Capacity Act (2005)

Prior to the introduction of the MCA, those who had an impairment of the mind or brain were subject to inconsistent outcomes and decisions, as the assessment of mental capacity by health professionals could be subjective, biased and paternalistic (Marshall and Sprung 2016a). The law left patients lacking mental capacity and their doctors in something of a legal limbo; no-one had legal authority to act as proxy and consent on behalf of the patient and it was not until 1987 that this question troubled the courts (Brazier and Cave 2011). The MCA was the result of many years of dedicated reform effort, commencing with a Law Commission

Consultation Paper in 1991 (Ruck-Keane and Auckland 2015). The MCA sought to provide a secure framework in which all parties concerned can make best interests decisions about care for people who may lack capacity (Ryan *et al* 2009; Graham and Cowley 2015).

The MCA sought to change the way risk and benefit are assessed, to ensure that best interests decisions were not based solely on the clinical agenda (Marshall and Sprung 2017). Two fundamental aims of the MCA were to uphold an individual's right to autonomy, balanced with an Imperative to protect the interests of those unable to do so for themselves (Taylor 2016). It came into force in 2007 and applies to anyone in England and Wales aged 16 and above. Section 1 of the MCA sets out five 'statutory principles' or values that underpin the legal requirements in the legislation. The five statutory principles are shown in table 2.1.

Principle	
1	A person must be assumed to have capacity unless it is established that he lacks capacity.
2	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.
3	A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4	An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5	Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Table 2.1 The five principles of the Mental Capacity Act (2005) (DCA 2007 p. 19).

The presumption should always be that a person has the capacity to make all decisions for themselves. If the individual has an impairment or disturbance of the functioning of the mind or brain and it is therefore suspected that they lack capacity to make a decision, only then should their capacity be assessed (Forsyth 2007). This is known as the two-stage test of capacity (Nicholson, Cutter and Hotopf 2008). To assess the person's capacity to decide, they should be able to understand the information given to them, retain it for long enough to make the decision, weigh-up the information to consider the decision and communicate the decision by one of a variety of means, *table 2.2* (DCA 2007). At least with the MCA in existence decisions are intended to be respectful of autonomy, rather than medically driven as used to happen previously (Brazier and Cave 2011). This means that if the MCA is applied correctly, people are not assumed to lack capacity simply because of a diagnosis, and when they are assessed as lacking capacity for a particular decision at a specific time, best interests decisions should be determined at least partly by their preferences or values.

1	Does the person have a general understanding of what decision they need to make and why they need to make it?
2	Does the person have a general understanding of the likely consequences of making, or not making, this decision?
3	Is the person able to understand, retain, use and weigh up the information relevant to this decision?
4	Can the person communicate their decision (by talking, using sign language or any other means)?

Table 2.2 Assessing ability to make a decision (MCA Code of Practice 2007)

The focus of the MCA is to protect the decision-making rights of individuals who may have problems with capacity, though there is an acceptance that at times the ability to make an autonomous decision may be absent, therefore options are available to forward plan. The MCA defines the right to appoint a Lasting Power of Attorney (LPA), an identified individual given the legal right to make decisions on behalf of a person when capacity is deemed to be lost. There is also the right to make an Advance Decision to Refuse Treatment (ADRT); a legally binding request to decline specific treatments if the ability to make a contemporaneous decision is lost. A valid Advance Decision to Refuse Treatment (ADRT) has the same effect as a decision made by a person with capacity, which health professionals have a legal duty to respect. If the wishes of the person are ignored, it could lead to a charge of battery (Marshall and Sprung 2017). If this forward planning is not taken up, or is not possible due to a variety of reasons, such as capacity already being impaired or the ADRT not being relevant to the treatment being proposed, then the MCA accepts that decisions may need to be made on behalf of the person that lacks capacity. These decisions are expected to be made in the person's best interests and the MCA provides a checklist to ensure that a person's best interests have been considered. As mentioned, the aim of the legislation is to ensure that decisions made on behalf of patients lacking capacity are made in their best interests, or that it promotes the patient's good or wellbeing. To do this the legislation mandates a decision process/checklist, and a best interests decision is defined as one that is in accordance with this process.

The MCA was considered visionary only a decade or so ago, but it is now being challenged by an emerging new model of legal personality and legal capacity, connected with Article 12 of the United Nations (2006) Convention on the Rights of Persons with Disabilities (CRPD) (Series 2015). One group directly affected by article 12 yet featured little in article 12 of CRPD negotiations according to Series and Nilsson (2018), is people with dementia. The CRPD Committee examined reports and found that legal capacity to make a decision is removed once a person is considered to have impaired decision-making skills, which is discriminatorily applied to people with disabilities. This denial of legal capacity is based on a diagnosis of an impairment or where the outcome may have negative consequences and Article 12 does not permit such discriminatory denial of legal capacity (Series *et al* 2014). Critics of the best interest 'paradigm' have argued that it disproportionately and adversely affects persons who suffer from disabilities. Individuals with disabilities are regularly subjected to their decision-making abilities being questioned and assessed and second-guessed on grounds that they need to be protected from their own poor decision-making (Martin 2014). The CRPD endorsed a new approach to capacity in the form of a 'support paradigm'; instead of viewing mental incapacity as a deficit, any support necessary should be provided to the individual (with a disability) to ensure that they are able to exercise full legal capacity on an equal basis with others (Series 2015). Donnelly (2016) says that the MCA retains a degree of revolutionary potential, which should be further developed. Donnelly (2016) also advocates for the preferences, wishes and feelings of a person with impaired capacity receiving a higher degree of respect than has been the case under the MCA. Some elements of best interests reflect the interpretation of Article 12, according to both Donnelly (2016) and Bartlett (2020). Ruck-Keane and Auckland (2015) argue that best interests decision-making in the Court of Protection does go some significant way to being compliant with the CRPD as case law gives proper respect for the 'rights, will and preferences' of the individual lacking capacity.

The Law Commission (2017) devised the draft bill for Mental Capacity and Deprivation of Liberty and sought to draft legislation that was in the spirit of the CRPD, to ensure that wishes and feelings are given a particular weight in best interests decision-making by the recommended amendments to section 4 of the MCA. However, the revised Mental Capacity Amendment Bill did not include the Commission's proposed amendments (Series 2020). Bartlett (2020) acknowledges however that questions raised about CRPD interpretation have not been resolved and suggested that social reform is needed for compliance to be achieved in any new areas of law. He concludes by stating that the experience of implementing the MCA suggested that such social reform/compliance is not easily achieved. It appears that the MCA is deemed worthwhile, that it is historically valid, and although currently appropriate, further research and development is required to enhance its value and assure its compliance with disability rights law.

2.2 The Code of Practice

The COP (DCA 2007) was published in 2007 as the legislation was implemented and was a key part of the practical guidance needed to explain how the Act would operate on a day-to-day basis and offered examples of best practice to carers and practitioners. The COP has a statutory force, with section 42 of the Act requiring a COP for the guidance of a range of people with different duties and functions under the Act (DCA 2007). This means that specific people have a legal duty to pay regard to it when working with individuals who lack capacity, for instance attorneys, deputies, Independent Mental Capacity Advocates (IMCAs), researchers and anyone acting in a professional capacity for an individual lacking capacity. The COP describes their responsibilities when making decisions on behalf of individuals who lack the capacity to make decisions for themselves and any reason for departing from the guidance contained in the COP would require good reason due to the legal duty to pay due regard to the COP. There are no sanctions for a failure to comply with the COP but such failures can be used in evidence before a civil or criminal court (DCA 2007 p. 1 – 6).

The COP has not been without its criticisms. Research conducted in 2010 and published in 2012 by Williams *et al* recommended that the COP be revised to enhance specific information, such as unwise decisions and a lack of decision-making capacity or lack of insight, to include good practice examples and successful practices and to include more case examples or gaps in practice. However, it was not until a Law Commission review in 2014 that amendments to the legislation were recommended along with a new COP, as the current publication was identified as requiring a 'much needed review' (Law Commission 2017 p. 45). A consultation on a new COP was undertaken from January to March 2019 by the Ministry of Justice. The new *Mental Capacity Act Code of Practice* will be published to coincide with the forthcoming Liberty Protection Safeguards, currently scheduled for April 2022. There is an opportunity to consider any training or support required through the results of this study as it related to the existing COP and therefore the results may inform training requirements for the revised COP due to be launched.

2.3 The Best Interests Standards

The *Mental Capacity Act COP* (DCA 2007 p. 64) stated that:

> '*An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests*.' (section 1(5))

Best interests are not defined in the MCA. However, section 4 sets down a process (or checklist) by which that conclusion should be reached in determining what is in a person's best interests (Ruck-Keane *et al* 2019). This checklist can be viewed in table 2.3, which is an adapted list devised by Regan and Sheehy (2016): appendix 3 maps the detail of the checklist as outlined in the MCA (DCA 2005) and the COP (DCA 2007).

1	Encourage the individual's participation
2	Consult all those close to the individual
3	Consider the individual's views, whether expressed verbally or in writing, including their feelings, religious beliefs and past habits
4	Consider all circumstances, including emotional bonds and family obligations
5	Avoid making assumptions
6	Consider whether capacity will be regained in the future and whether this discussion could be delayed until then
7	Consider the potential decision the individual might have made if they still had capacity
8	Consider whether the least restrictive option has been taken in making the decision
9	If the decision is about life-sustaining treatment, ascertain that no one involved in the decision-making process has a desire to end the life of the individual and that no assumptions have been made about their quality of life

Table 2.3 Nine principles to guide best interest decisions (Regan and Sheehy 2016 adapted from DCA 2007)

The BIS checklist supports the belief that the MCA empowers people and places them at the heart of the decision-making process (Marshall and Sprung 2017). In other countries, such as Scotland, the USA, Canada and Australia, substitute decision-makers are nominated to decide on behalf of the person who lacks capacity and make decisions based on the hypothetical decision that the individual would have made, whilst taking the wishes and feelings of the person and others into account. There are subtle differences between these countries and the MCA best interests approach, according to Dunn *et al* (2010), as the MCA best interests checklist is entirely evidence-based. To support this assertion that the checklist is evidence based, appendix 4 highlights the evidence statements that align to each checklist criteria. The COP (DCA 2007) recognised the challenges of defining what best interests are. It also recognised that every case and every decision is different and that the law cannot set out all the factors that will need to be considered in working out someone's best interests. It also sets out some common factors that must always be considered when trying to work out someone's best interests:

> *'Working out what is in someone else's best interests may be difficult, and the Act requires people to follow certain steps to help them work out whether a particular act or decision is in a person's best interests. In some cases, there may be disagreement about what someone's best interests really are. As long as the person who acts or makes the decision has followed the steps to establish whether a person has capacity, and done everything they reasonably can to work out what someone's best interests are, the law should protect them'*. (COP (DCA 2007) p. 64).

The best interests process aims to promote personal wishes and feelings as central to the decision-making process and to provide protection to those who are vulnerable (Marshall and Sprung 2017). An Independent Mental Capacity Advocate should be appointed to examine the situation of individuals without capacity who have no-one suitable to represent them, they will provide information to make sure the final decision is in the person's best interests (DCA 2007 p. 96). In cases in which there is disagreement about precisely what constitutes those interests or where clarification of the legality of a proposed course of action is needed, the Court of Protection is empowered to make the required judgments (DCA 2007 p. 123).

The person who assesses the decision-making ability of a patient is not necessarily the person who then determines if the proposed care and treatment is in the patient's best interests (Griffith 2014; Griffith 2015). The COP (DCA 2007 p. 88 - 89) states that ultimate responsibility for working out best interests lies with the decision-maker but they will need to find a way of balancing concerns of others or resolving disagreements between themselves and others. The decision-maker will need to weigh up the views of different parties, depending on the circumstances of each case.

Herring and Foster (2012) suggested that the well-being of a person could not be assessed in isolation, and that it is only by considering the network of relationships within which a person lives that well-being can be properly considered. This notion is supported by a variety of literature; Dunn *et al* (2007) discussed the origins of best interests in common law and demonstrate that that the concept of best interests was shown through case law and developed in the same way. The situation prior to the MCA was one of substituted judgement, whereby the judge was required to consider the 'antipathies' and the 'affections' of the person concerned. Ruck-Keane and Auckland (2015) discussed how the Law Commission highlighted the difficulties posed by substituted judgement when making decisions for those who have never had capacity, as well as the effect it had of giving lower priority to the person's present emotions than those anticipated in the person had they had unimpaired capacities. The result of this long drafting process was the requirement that decisions should be made in their best interests, taking into account several relevant factors. When a person has been formally appointed as health and welfare attorney, or a court-appointed deputy do they have a legal right to make decisions on behalf of another and if the decision relates to life sustaining treatment, the attorney must have been appointed with additional powers to consent to or refuse life-sustaining treatment (court-appointed deputies cannot be given this power) (BMA 2019).

The BIS stipulate that all those close to the individual should be consulted in best interests decisions, which recognises the importance of family and carers in the process. The decision-maker should consider all circumstances, including emotional bonds and family obligations. Section 4 (7) of the Mental Capacity Act (2005) established anyone engaged in caring for the person or interested in his welfare, anyone named by the person as someone to be consulted, or any attorney or court appointed deputy should be consulted when determining best interests. This provides a legal right for relevant people to be consulted and may include family members, carers, partners, and others (Nicholas and Nicholas 2010).

People with dementia may have expressed their wishes about future place of care through advanced statements or family discussions at an earlier time when more able to consider and express their preferences (Lord *et al* 2016), which supports the idea of significant others being consulted and involved in best interests decisions as they can communicate these preferences on behalf of the person that lacks capacity. However, decisions remain the responsibility of the clinical team, or where the course of treatment or action being proposed is more likely to involve serious consequences for the person, it will become necessary for the responsible clinician to be the most senior clinician with overall responsibility for the patient’s care (BMA 2019).

The BIS Checklist included, but is not limited to, the risks and the burdens of the treatment. The court recommends the adoption of a balance-sheet approach, where the benefits should be entered followed by the dis-benefits (Griffith 2015). According to Kopelman (2007), when the BIS is seen in the context of its practical uses, it is a mistake to suppose that it permits whatever anyone wants it to mean. Practical uses of the BIS should incorporate what a reasonable person would want or how a reasonable person would balance burdens and benefits. Ruck-Keane and Auckland (2015) discussed several court cases where judges have presided over best interests cases and each made decisions specific to the circumstances, some where there was a focus on the preservation of life, others where patients previously expressed wishes carried more weight. The case law explored demonstrates the challenges of making best interests deliberations and the authors acknowledge that the MCA warranted amendment to encourage respect of wishes where they can be confidently ascertained and where compelling evidence should be required to go against those wishes.

2.4 Parliamentary, regulatory and professional views of the implementation

As mentioned in chapter one, the MCA received pre-legislative scrutiny prior to receiving Royal Assent in April 2005 and subsequent implementation in October 2007. In October 2004 the House of Lords Constitution Committee reported on the legislative process and suggested that Parliament frequently ended its legislative scrutiny at the point of Royal assent with little or no evaluation of whether the legislation had achieved its aims (UK Parliament 2013). The Law Commission published their report on the post legislative scrutiny project in 2006, recommending a more systematic approach to post-legislative scrutiny controlled by Parliament. In response to this, the then Government announced its acceptance of the Law Commission's proposals and published Post-legislative Scrutiny – The Government's Approach (Office of the Leader of the House of Commons 2008). This document proposed that a law should be reviewed by Parliament three years after it has been passed to see how it has worked out in practice and in some cases a parliamentary body such as the House of Lords may conduct further scrutiny.

The House of Lords Select Committee (HOLSC) was established in May 2013 to conduct post-legislative scrutiny of the MCA (2005), the task being to answer the question of whether the

Act was working as Parliament intended (HOLSC 2014). The post-legislative scrutiny (published 2014) highlighted the fact that the MCA was not fully embedded in practice and though some good practice was identified, considerable improvements were required to address the shortcomings of the implementation of the legislation. According to the report, the steps of capacity assessment and best interests set out in the principles of the legislation are rolled into one, therefore negating the empowering ethos and being outcome focused and decided on by professionals (HOLSC 2014). The report provides examples of where this has been the case from at least seven sources, such as the Law Society, the Downs Syndrome Association and the British Association of Social Workers. The criticisms purported by the different agencies were that the right to make an unwise decision runs counter to the prevailing cultures of risk aversion, over-protection and safeguarding (p. 43 – 44). This occurs when paternalistic models of care are favoured over a person being found to have capacity and making an unwise decision. The assessment of capacity should be a separate but integral aspect of best interests decision-making, meaning that working out best interests is only relevant when capacity has been assessed as lacking (DCA 2007). The report states that the assumption of incapacity and the decision are amalgamated and formulated on the basis of professionals' interpretations, rather than considered separately and criteria applied to establish a consensus of best interests (HOLSC 2014).

The report also suggested that best interests is probably the most abused and misunderstood phrase in health and social care and that it has too often been the vehicle for poor decision-making. The criticism was that the concept of best interests as defined by the legislation was not well understood, in part because it was at odds with the concept of best interests as it is used in a medical or clinical sense. The British Institute of Learning Disabilities (BILD) contributed to the HOLSC (2014) report and conveyed that though the definition of best interests and the centrality of the person's wishes, beliefs, values and history in the MCA is very good, best interests are too often interpreted in a medical/paternalistic sense which is not how it is set out within the MCA (BILD 2013). This means that the clinical factors lead the decision, rather than the past or present wishes of the person who is incapacitated, leading to a paternalistic decision. Families who disagreed with the decision being made found they were excluded on the grounds that "they are not acting in the best interests of the person whom they care for" (HOLSC 2014 p. 47). The BIS were used to justify decisions taken by local authorities about an individual's care, without carrying out the necessary consultations, and all too often against the wishes of the patient and their carers.

The Government was expected to respond to the recommendations from the post-legislative scrutiny; this was subsequently published in 2014 (HM Government 2014). The government response directly acknowledged the number of people living with dementia and that they are likely to benefit from the MCA at some point in their lives (HM Government 2014). They acknowledged that there was a challenge to ensure that people are empowered and supported to make decisions and that any decisions which must be taken by others on their behalf take into account their wishes, preferences and best interests (HM Government 2014). The solutions offered in the government response relied on the imminent legislation that was due to be introduced and guidance that was being disseminated, including the *Care Act (2014)*, which came in to force in 2015, the *Prime Minister's Challenge on Dementia* (DH 2012) and *Closing the Gap: Priorities for essential change in mental health* (DH 2014). For instance, the *Prime Minister's Challenge on Dementia* (DH 2012) identified dementia as one of the biggest challenges facing society and only through thorough implementation of the MCA would the challenge for people with dementia, their families and carers be realised (HM Government 2014).

The HOLSC report (2014) recommended that the professional bodies and Royal Colleges should emphasise that best interests determinations should be distinct from clinical practice. In response to this, the NMC revised the professional standards and within it, state that registrants should “Act in the best interests of people at all times” and “keep to all relevant laws about mental capacity that apply in the country in which you are practising” (acknowledging that there is different legislation in the four countries of the UK) (NMC 2018 p.8). This suggests that professional bodies and the Government acknowledge the importance of professional practice in relation to the MCA and best interests decision-making. However, the criticism was that considering best interests was through a clinical lens, despite the legislation stipulating that this should not be the case. Subsequent analysis of professional practice has not demonstrated any significant improvements in practical application of the legislation (Wade and Kitzinger 2019).

The Care Quality Commission (CQC), the independent regulator of health and social care in England, published a report in the state of health care and adult social care in England (2016). In respect of the MCA, the CQC found that some hospital and private care home providers were still not adequately implementing their responsibilities in relation to the MCA (2005) and whilst there were some examples of good practice, there were also examples of poor practice and that training and staff understanding were not good enough (CQC 2016). They found variable levels of practice in best interests decision-making and in particular that people living with dementia were often assumed to lack capacity and there was a lack of involvement of family members in best interests determinations (CQC 2016). This seems to echo the findings from the HOLSC report, that suggests that application of best interests is inconsistent and indicates indifference by professionals.

Part of the criticism focused specifically on the Deprivation of Liberty Safeguards (2007), which were introduced as part of (but later than) the MCA (2005). This specific criticism resulted in a Law Commission review at the request of the Department of Health. The review began in 2014 and completed with the publication of a report in 2017. During the consultation process, best interests assessors reported that they felt they were engaged in 'rubber stamping' Deprivation of Liberty Safeguards (DOLS) applications and family carers reported that best interests decisions by health and social care professionals were often made without reference to the wishes and feelings of the person at the centre of the decision, professionals often 'pick and choose' which factors of the best interests checklist to prioritise to suit their own preferred outcomes (Law Commission 2017). Again, a paternalistic attitude was identified, continuing to reflect the criticisms from the earlier reports.

The *Mental Capacity (Amendment) Bill* was introduced to the House of Lords in July 2018 where the Law Commission's recommendations were broadly followed, with some changes. The *Mental Capacity (Amendment) Act* received Royal Assent in May 2019 and reforms the process under the *Mental Capacity Act* (2005) for authorising arrangements enabling the care or treatment of people who lack capacity to consent to the arrangements, which give rise to a deprivation of their liberty. However, the new legislation is yet to be formally implemented (scheduled for April 2022). The Law Commission recommended amendments to the *Mental Capacity Act* (2005) and replacement of DOLS with Liberty Protection Safeguards (Series 2020). The reason for discussing this is concerned with best interests determinations. The Law Commission (2017) report recommended amendment of the MCA to give additional weight to a person's wishes and feelings through the draft bill, suggesting amended terminology specifically related to best interests. The actual amendment bill stripped out this content, potentially to be included in the (yet to be published) new *Code of Practice* (Ruck-

Keane 2019). This demonstrates that best interests remain a focus of the legislation and the agencies that promote consideration of the standards when applying the legislation.

2.5 National Institute for Health and Care Excellence (NICE) Guidance

The NICE guidance was published in year three of the doctoral study, so the review of the guidance was undertaken during the write-up phase, rather than in the design phase of the study. However, introducing and discussing the NICE guidance within this chapter is important because it strengthens the case for the significance of the legislation and how responding to the criticism was given serious attention by policy-makers. The fact that the guidance refers specifically to best interests also highlights the crucial role that best interests decision-making has in health and social care practice. In response to the serious issues identified with the practical implementation of the MCA and adding further momentum towards the need for improvement in practice, the Department of Health commissioned the NICE to develop further guidelines. Published in October 2018, the NICE guideline is the most current guidance around the MCA in general, although there are the Liberty Protection Safeguards (Law Commission 2017), which should come into force in April 2022, introduced under the *Mental Capacity Amendment Act* (DH 2019). The NICE guidelines (2018) aim to help health and social care practitioners to implement the principles of the MCA, to improve the quality of the decision-making support they provide. It was developed with reference to the best available evidence from research, expert testimony, expert consensus and developments in law. It also identifies where evidence is lacking and makes recommendations for future research (NICE 2018).

The guideline focused on the key areas of advance care planning, supporting decision-making, assessment of capacity to make specific decisions at a given time and best interests decision-making for people who lack the capacity to make a specific decision at a given time (NICE 2018

p. 7). It provides information on education and training content and stipulates that local policy should be developed to identify the tools recommended for assessment and support. The NICE guidance also makes recommendations for future research, including the effectiveness of different training programmes (p. 38) because there was no good quality evidence evaluating the effectiveness of training but evidence that informed the guidance suggested that practitioners did not always understand the requirements of the Act and that their practice did not always comply with the requirements. The guidance makes eight recommendations for future research. It recognised that a better understanding of how training increases compliance would help inform measures for improvement and made a recommendation for research in this area. Another recommendation for research was to explore the effectiveness and cost-effectiveness of using a checklist to support the best interests decision-making process. This recommendation was made because the evidence reviewed, though limited and of low methodological quality, suggested that the use of checklists could improve practice in relation to the best interests decision-making process and the outcomes of the best interests decision itself. These two research recommendations link back to two of the research sub-questions identified in chapter 1:

- What procedural and substantive considerations do nurses identify when making best interests decisions?
- What support mechanisms are helpful for nurses in relation to undertaking best interests considerations?

2.6 Philosophical background

2.6.1 Autonomy and best interests

Much has been written about the way that people who lack capacity (especially people with dementia) are treated in respect of autonomy and best interests considerations. For example, there is a significant risk of paternalism where clinicians are tempted to substitute their own judgment for that of a patient, particularly when they feel that they have a better insight into that patient’s medical needs than the patient themselves and they seek to ensure the best medical outcome (Sherwin and Winsby 2010). This opinion is supported further by Boyle (2010) who suggested that people with dementia were deprived of opportunities for exercising self-determination even when they had capacity or the ability to express a preference, particularly where there was conflict between a person and their carers over admission to care facilities.

Harding (2012) explored autonomy for people with dementia. She explained the differences between individual autonomy and relational autonomy and suggested that individual autonomy is problematic because people with dementia are (like all other people) not atomistic individuals. The fact that people with dementia rely on others for their care, limits their ability to effect change on their own lives and environments. There appears a natural process of others having an influence on decisions because of the social relations we are part of. However, the person with dementia could find themselves oppressed by the same such social relationships, particularly where carers are under strain from caring. The answer, according to Harding (2012) is to take a person-centred relational approach to autonomy to promote continued personhood. This meant that (as stipulated in BIS), the person should be considered alongside all relevant circumstances, including their relationships with others. Herring (2009) also discussed the law and dementia and recognised that the views of the individual can only inform considerations about the person’s best interests. He criticises the lack of relationality in best interests decision-making and suggested that the law looks at the person in isolation, as a rational being but ignoring emotion, personal identity, and narrative.

He takes a sensitive view of dementia, encouraging interaction with those that have lost competence by valuing the non-rational and listening to people with dementia.

Although personhood is not part of the BIS checklist, if there is evidence of the desire of others to preserve the personhood of the person with dementia, using Herring's (2009) view of considering emotion, personal identity, and narrative, then best interests will surely be enhanced. The cultural and social exchange and sharing that continues for people with dementia is perhaps the strongest indication that personhood and identity are not destroyed by dementia. If there is an understanding of the voice that people with dementia retain, and the possibilities for a more expanded understanding of personhood, then the doors are opened to a more powerful articulation of the rights of people with dementia and thus their ability to retain their humanity to the end of their lives (Shakespeare, Zeilig, Mittler 2019).

Donnelly (2019) suggested that people with dementia will have lived full and active lives, in which they have developed moral, political, social, religious and other views; built a complex set of relationships; and acquired financial and other assets. This is an important reason to consider these factors when making best interests decisions. Boniolo (2021) suggested that there are no strong reasons to claim that a person with dementia is different from the person they were before the disease; the person is the same as they were before. There is a responsibility to continue to respect them and the choices and decisions that they may have made. Hawkins (2014) however argues that when an individual undergoes a dramatic change (in the article that change is dementia), what is good for the person changes as well, and to understand what is good for someone it is important to consider their current state; that is what beneficence demands. Auckland (2017) suggested that, given the profound harm that tying a person with dementia to their previous wishes can do, it is essential that there are safeguards in place to ensure that only directives that are sure to be truly autonomous are upheld. She considered if any evidence exists that previous wishes may no longer be held by the individual, which suggests that confidence in the validity of previously held wishes appears to be as challenging as establishing best interests.

2.6.2 The philosophy of best interests

A number of authors have acknowledged that establishing what is in a person's best interests can be challenging, that there are many facets to a person's interests and they are as unique as the individual themselves (Herring 2015; Graham and Cowley 2015; Hubbard and Stone 2018). Herissone-Kelly (2010) suggested that the MCA has received little philosophical attention and questions best interests in respect of paternalism. He suggested that if judgements about what are in the patient's best interests are about what is good for them, rather than what they themselves may have chosen, then paternalism begins to loom. Coggon (2008) defends best interests as a construct for good decision-making, rather than as a concept. He suggested that, as a construct, it is a system of action-guiding principles that may or may not be relevant to the incident at hand to accommodate the different situations to be decided. If it were narrowed down to once concept, it would be too restrictive. Quigley (2008) supports Coggon's assertions and applies them to the judiciary, in that the BIS entreats medical professionals to think carefully before acting and the judiciary.

Kong (2017) suggested that the legal boundaries between capacity and best interests are blurred when relationships and their importance are considered and she argues that capacity assessments are not value-neutral, despite their air of objectivity. Donnelly (2009) suggested that best interests is inherently an elusive and, in some ways, an unsatisfactory concept. There is a dissonance between the original, objective, meaning of the term and its current meaning under the MCA. Although best interests is, to a degree, an indeterminate term, capable of assimilating shifts in meaning, there are still difficulties with retaining the same term but hoping that it will serve as a shorthand for something different. This is because decision-makers' intuitions associated with the old meaning will continue to assert themselves with the result that the underlying conceptual shift cannot be delivered upon (Donnelley 2016).

Jennings (2009) offers a critique of what he suggested is a hedonic legal standard of best interests, that it should be re-conceptualised away from a preoccupation with security, comfort and fulfilment of experiential interests in favour of semantic agency and memorial personhood. Semantic agency defined as making and experiencing meaning through touch, gesture and physical closeness with others and memorial personhood defined as continuing recognition of individuals living with dementia as members of a human moral community. Care-givers and social institutions have an obligation to provide the opportunities to sustain and conserve semantic agency and personhood for the person living with dementia, according to Jennings (2009), which recognised the significance of other people in preserving best interests, however they may be defined.

Fovargue and Miola (2010) acknowledged that best interests decisions can be made by an individual but in health care practice, they are more likely made by a team via a process of consultation and cooperation with a view to doing what the patient would have wanted rather than what the healthcare professionals think is medically 'best'. Although there is evidence to suggest that healthcare professionals possess the knowledge, skills, and expertise to result in decision-making that best suits the situation and promoted the most appropriate outcome, there are also schools of thought that lean towards the opinion that medical led decisions can be deleterious for the patient. For instance, a clinician may evaluate a patient's quality of life differently, and often as less desirable, compared to the patient's own evaluation of his or her situation, also the clinicians' decisions about the capacity of patients may be influenced by the clinician's own emotions and attitudes (Braun *et al* 2009). Healthcare professionals may follow their own agenda when considering decision-making capacity of patients; failing to afford patients the autonomy they deserve.

Dunn *et al* (2007) suggested that subjective determinations of best interests draw heavily on personal context and the outcome will be judged for that person. Clinical decision-making is complex and subjective and may preclude wider consideration of the patient's wishes and preferences; information from surrogates may be unreliable (Taylor 2016). This does buy into the fact that there is a level of subjectivity with best interests considerations and it is not entirely easy to not make assumptions. The influence of others in decision-making in general and in potential capacity and best interests considerations was acknowledged by Ryan-Morgan (2019) who discussed the variety of influences others have on individuals who face making a decision, how prospect theory can influence decisions and how 'knowing too soon' when examining an individual's capacity to make a decision can all impact on the capacity assessment and outcome. Harding (2017) also recognised the relational aspects that impact on considering best interests determinations and in respect of initial assessment of capacity. Series (2015) suggested that case law offers several examples of people who were found to lack mental capacity by assessors whom they did not like or trust – and thus refused to co-operate with – only to be found to have mental capacity by other assessors whom they felt less antipathy towards.

Hope, Slowther and Eccles (2009) questioned whether behaviour is a measurement of apparent wishes and feelings, which is not defined in the COP. If a person with dementia expresses their wishes in their behaviour, rather than language, this may not be taken into account. Lim, Dunn and Chin (2016) also say that the uniformity of best interests decisions varies across cases of incompetence. For instance, people who have never been deemed as competent (such as the severe learning disabled), or children who have not yet had the opportunity to develop their competence lack the capacity to express any preferences or wishes and so are viewed differently. Smith, Lo and Sudore (2013) also raise the issue of when previous wishes conflict with best interests in their article, written from an American perspective so not relating to the legislation. They recognised the impact that decision-making has on professionals when their professional duty of care is undermined by what treatment the patient may have expressed they did not wish to receive. Although there are ethical challenges that professionals in these situations may face, Smith, Lo and Sudore (2013) recommend an ethical framework approach to ease the potential burden. The ethical framework echoed the BIS but also considers other aspects such as how much leeway the person who is incapacitated gave surrogates to override the decision. Literature from the USA may not be completely applicable because the USA does not have legislation such as the MCA but it does reflect the ethical challenges of best interests determinations and is therefore useful to consider. Wilkins (2018) also recognised the challenges associated with best interests determinations and surrogate decision-making, suggesting that a narrative approach should be considered as it supports the involvement of the person with dementia. Wilkins (2018) recognised the deliberations of others to the debate of how decision-making should be conducted; that the burden-benefit ratio may discount any preferences of the person, that advance directives may not be a true representation of how the person might feel in the present moment and that conflicts are bound to arise for those involved in the process. The narrative process that is promoted, considers the participation of those with a vested interest in the well-being of the person with dementia, which echoes the standards in the BIS checklist of the MCA COP.

Kong and Ruck-Keane (2019) discussed the MCA and suggested that the way that it is currently set up gives the impression that a stark boundary exists between capacity and best interests, with capacity as a cliff-edge off which a person falls. When the person falls off this cliff edge, it encourages paternalism from others and may sanction a complete dismissal of the perspectives and values of the person at the heart of the decision (p. 127). Regan and Sheehy (2016) do convey that it is unreasonable to expect health and social care professionals to be familiar with the complexities of mental capacity law. They do also suggested that nurses have a central role in changing practice, so that best interests determinations are carried out where individuals are unable to consent to care; and that it should be standard practice for those involved in the individual's care. Kong and Ruck-Keane (2019) recognised the complexities in the legislation, primarily because of the role of relationships in decision-making and suggested that practitioners adopt an ethical framework to guide them through application of the legislation.

Greener *et al* (2012) also explored the values and perspectives of others in respect of best interests determinations, using a vignette to highlight issues. They suggested that there might be a clash of perspectives, where the decision-maker will need to make evaluative decisions to take account of the diverse values. They identified that the person with dementia might display behaviour that implies they now have a different view to what they have previously expressed, that the views of significant others may not be benign, that there may be conflict between professionals and family members. They recognised that BI standards is a combination of several approaches and has conceptual tensions, perhaps resolved through the application of a values-based medicine model. They also recognised that there was a need for better education about the MCA.

Kopelman (2007) gave the American perspective on the best interests standard, which was published as the MCA was implemented. Kopelman's article reflected some of the initial and more recent criticisms of the MCA and defends the 'true' meaning of the best interests standard. The comments were not in relation to legislation and considered best interests in both adults and children, suggesting that the best interests standard should be understood as an umbrella principle covering different kinds of usage. First, to express moral, legal and medical ideals that should guide choices. Second, it can be used in making practical and reasonable decisions about what should be done in a particular situation, given the available options. Confusing these two fundamentally different uses of the best interests standard has led, Kopelman (2007) suggested, to misguided criticisms, where some critics have argued that this standard requires someone to do what is ideal in all situations and then conclude that what is ideal is unknowable, unattainable, unrealistic, or too narrowly focused on the incompetent or incapacitated person's interests. Viewing the standard as always requiring what is ideal in making practical decisions not only confuses its different meanings but also is divorced from why it developed and how it is used. When it is considered how the standard is used to solve practical problems, it does not require what is ideal but what is reasonable.

A more recent but recurring criticism of the best interests standard concerns its vagueness, and thus the inadequate guidance it offers to care providers. Hope, Slowther and Eccles (2009) acknowledged that neither the MCA or the COP provide sufficient guidance to carers faced with difficult best interests decisions; that although the general approach is right, many of the details are wrong. Boyle (2011) suggested that there is a risk that any decisions made will reflect the interests of professionals and/or family members, rather than the person's best interests because the responsibility for establishing best interests lies with the decision-maker. The lack of an agreed definition of best interests, together with guidelines being inconsistent amongst professional groups, result in decisions being made in ‘murky waters’ (Lim, Dunn, Chin 2016). Taylor (2016) agrees with this when she states that the concept of best interests is ill defined and existing guidance for best interests decision-making is insufficient; there are ongoing inconsistencies in the interpretation of best interests and how it might impact on patient autonomy. Griffith (2015) states that a superficial reading of the standard title suggests that it imposes a duty to simply act in the best interests of people at all times, which is clumsy and could lead to an inaccurate interpretation of when best interests arises.

Heywood (2015) explores a variety of case law in respect of ADRTs and acknowledges the challenges that arise when there is a need to reflect on previously expressed wishes and whether these expressions would still be held if the person was able to make the decision in the here and now. Where there is any doubt about the validity of an ADRT, it must be resolved in favour of preservation of life. This is the point that Heywood refers to from the case law considered in his article. Wade and Kitzinger (2019) also referred to the courts to discuss the considerable challenges with how the legislation is applied in practice, stating that some of the language used in the legislation is difficult to define, such as ‘wishes and feelings’, as there is no guidance on what weight to give to any factor. They also suggested that it is unlikely that any two people will consider the same factors or give them relative importance and that it is more difficult to apply the legislation to a multitude of decisions which have significant consequences. In fact, there is criticism not only of individual practitioners in respect of how they consider best interests, but also of the courts when they must decide on referred cases. Analysis of some recent decisions of the Court demonstrates a confusing incoherence in the way in which the Court both obtains evidence from individuals lacking capacity and evaluates it when reaching decisions upon their behalf (Munro 2014). Taylor (2016) also acknowledges this when she intimates that clinical decision-makers may be ill-equipped to manage complexities in the law that even the courts appear to find challenging. So, if the Courts are finding cases challenging, individual practitioners will surely struggle too.

Best interests are related to well-being and beneficence, where consideration of social, emotional, ethical, and moral aspects of an individual's life is important (Regan and Sheehy 2016). However, many clinical situations lead nurses to carry out care that is felt to be in the best interests of individuals but that could be seen as unethical, for instance covert administration of medication (Regan and Sheehy 2016). Dunn *et al* (2007) suggested that the MCA's procedures relating to best interests prove problematic because there is no help with ethical dilemmas, it is largely instruction-based and there is no practical guidance to the process of determination. They do acknowledge that the MCA aims to clarify, codify, and regulate substitute decision-making in a framework that defines its scope and provides a mechanism for determination.

In complex clinical situations, it can be difficult for nurses to balance duty of care with respect for an individual's decision, especially where forgoing treatment may cause harm (Regan and Sheehy 2016). (District) Nurses must keep an open mind about a person's best interests while they methodically work through the checklist of factors, recoding their findings and using the balance-sheet approach as they proceed. The MCA does not have a hierarchy of factors and each factor carries equal weight (Griffith 2015).

Considering how people might have acted when they had capacity is integral to determining their best interests (Regan and Sheehy 2016). Hope, Slowther and Eccles (2009) suggested that best interests should be taken from what the individual might have written in a valid Advance Decision, rather than what the decision-maker deems as in their best interests, as it is more likely to be representative of what the person would have wanted and avoids bias on behalf of the decision-maker. Donnelly (2009) recognised that a carer may have a special understanding of the person who lacks capacity, but similarly they may be unable to be objective due to the emotional involvement in the situation, which might cause conflict between the involved parties. She suggested that the MCA envisages this but the COP makes no suggestion about how a divergence in opinion should be resolved, simply that the person making the decision needs to ‘work out’ what is in the best interests. Later, Donnelley (2016) explained that the MCA includes the beginnings of a support model, requiring that the person in respect of whom a best interests determination is being made should be permitted and encouraged to participate in the process and that their ability to participate should be improved and requiring consultation with relevant others to determine the person’s best interests and their wishes or feeling. Involving family and friends may confer practical advantages over the medicalised approach to support taken in the MCA literature – people’s decisions and social worlds extend far beyond the clinical (Series 2015).

Mackenzie and Watts (2011) discussed emotionality and neurodiversity within the realms of assessment of capacity and decision-making and suggested that the two factors need to be considered by those making decisions on behalf of another; that their emotional state and their neurodivergent condition will undoubtedly have an impact on any decision they may have made. Therefore, any past or indeed current wishes expressed might not be or might not have been a capacitous decision or may have been but are ruled out because of the emotionality or neurodiversity. This basically demonstrates that it is a difficult concept but that additional factors need to be taken in to account.

Morgan (2013) recognised that the best interests of the individual in question should take primary place and suggested that the MCA encourages discussion for determining best interests by involving a group of people with different emotional attachments to the individual with the intention of achieving a consensus. However, disagreements are likely because of these emotional attachments.

The Court of Appeal held that the use of the phrase best interests must be confined to an objective test to be used when considering the duty owed to a patient who lacks decision-making capacity. Limiting the application of best interests in this way reinforces the autonomy of the capable adult and their right to refuse treatment even when it would not be in their best interests to do so (Griffith 2014; Griffith 2015). Healthcare professionals are duty bound to adhere to the MCA (2005), which stipulated the steps to take to ensure that best interests are considered. However, there is the suggestion that the best interests principles expose the patient to risk; that even though the hypothetical 'reasonable person' is evaluated, patient preferences considered, and medical knowledge applied, the patient may still have the values of the physician imposed upon them (Defanti *et al* 2007).

Dunn *et al* (2007) discussed how best interests are about more than just the incapacitated person, Wade and Kitzinger (2019) state that the best interests approach is an exercise in being as person-centred as possible with all the uncertainties and difficulties that implies and Hope, Slowther and Eccles (2009) dispute that there is one specific approach in which to determine best interests, as judgements need to be weighed on to the importance of previous wishes as well as present experiences. When a decision needs to be made on behalf of a person who lacks capacity, more than one person will be involved in the treatment, with consultation between a range of people; people who know the person well and may have knowledge of their thoughts on the matter concerned (Griffith 2014; Griffith 2015; Regan and Sheehy 2016).

Munro (2014) discussed the finding of empirical research and suggested that the values attached to best interests decisions are often from wider social norms, the decision-maker's own values, what the incapacitated person may have wanted prior to losing capacity or the views of carers. Coggon (2016) suggested that the MCA demands that decision-makers give parity to patients' own values (if they can be established) and take patient-centred approaches in all cases. He argues that the law is clear but that interpretation and application is what is, in his words, erroneous. What is required is robust interpretation and application of the law where patients' values, alongside professional and public judgement must be taken seriously (Coggon 2016). Barton-Hanson (2018) supports this idea that the concept of best interests is unclear and that wishes, beliefs and values are not given primacy status, that the CRPD framework is not sufficiently recognised by the best interests model within the MCA, which therefore requires further reform.

Johnston, Banner and Fenwick (2016) examined how the wishes, feelings and values are respected in best interests decision-making processes and question how healthcare professionals can evidence a patient's wishes feelings and values when their expertise is in assessing medical best interests. They suggested that one way to fulfil the clinician's legal responsibility to take a patient's preferences into account is to utilise narrative medicine, which would lead to a more sophisticated judgement of best interests than the aforementioned 'balance-sheet' approach. Wade (2018a) also discussed what he believes should happen in respect of best interests with people in a minimally conscious state (not necessarily from dementia). He acknowledges that best interests are not focused on prolonging life, that evidence from a variety of sources is useful and that decisions are made by the clinical team without an advance decision or appointee and that courts cannot suggest clinically inappropriate treatments. Wade (2018a) recommended that regular best interests meetings should be held and conducted in line with the MCA COP, but also that the focus should be on the person and not on the investigation or treatment.

2.7 Summary

The MCA and the accompanying COP was years in development in response to protecting the rights of vulnerable people who lack capacity to make decisions about their health and wellbeing, property, and finance. It is recognised as a visionary piece of legislation and one that is echoed (albeit with subtle differences), in other countries around the world. Since its implementation in 2007, it has supported countless individuals, both professionals and patients. It defines who should be consulted in the event of a decision being made in a person's best interests. The application of the legislation is significantly criticised, even years after its introduction and in response to an official review, amendments were made to the deprivation of liberty safeguards, and a new Code of Practice is due to be published. NICE guidance was developed as a practical support for health and social care professionals, although this is very much a replica of the legislation with a more clinical focus. The development of the NICE guidance demonstrates the importance of the legislation in a clinical context, but it is difficult to determine how much more it is recognised since the original training and education linked to the initial implementation. This chapter serves to provide context to the subsequent chapter which explores the criticism of the legislation in greater depth.

Chapter Three
Literature review

Introduction

Literature reviews are essential when planning a research project. They place research findings into context and help the researcher to make a valuable contribution to their field (Winchester and Salji 2016). Chapter two examined the law and guidance and referred to the criticisms that have arisen regarding the inconsistent implementation of the legislation. This chapter discusses and reviews the literature that informed the study, relating to implementation of the legislation and practitioners' knowledge of the legislation. Despite the length of time that the legislation has been implemented, criticisms relating to the implementation remain and will feature in the review. A range of literature is drawn on to consider the broader issues of decision-making in dementia, which informed the study in a more general way as the best interests of people living with advanced dementia was a focus of the study.

Yazan (2105) writes that novice researchers should write literature reviews for their research project to help them to conceptualise their inquiry and design their research process. More generally, the literature review informs the methodology, identifies innovation, minimises duplication and ensures that professional standards are met (Maggio, Sewell and Artino 2016).

The aim of the literature review was to identify studies that focused on capacity and best interests for people with advanced dementia. A literature review question was established as: 'What is understood about nurses knowledge and application of the Best Interests Standards when making decisions on behalf of a person with advanced dementia?' This chapter will present how the literature review was methodically conducted to best answer the question or to identify gaps in the literature. From the interpretation of the literature presented, the context of the research will be clarified and what appears to be absent from the literature will complete the chapter.

3.1 Literature review process

In reference to the implementation of the legislation, the literature search was limited to the years 2005 to 2020, which reflects the age of the legislation. Initially, 2005 to 2017 was the date range, but the literature was revisited intermittently to identify more contemporary literature as the study progressed. The searches were restricted to English language and UK studies took priority. Although the planned study was to focus on the legislation from England and Wales, including international studies in the literature search criteria could be a good way to compare how the problem is perceived and managed at a local, national and international level (Aveyard 2019).

3.1.1 Inclusion and exclusion criteria

The Problem, Interest, Comparison, Outcome (PICO) tool is widely used to develop search strategies (Erikson and Frandsen 2018). The truncated approach of Problem, Intervention, Comparison as demonstrated in *Table 3.1* were the aspects of the PICO tool used to identify appropriate search terms (Erikson and Frandsen 2018). The problem, identified in the HOLSC (2014) report was best interests decision making, or knowledge and understanding of best interests. The area of interest was advanced dementia and the area of comparison was nurses' perspectives of the problem in the area of interest.

P(Problem)	**I**(Interest)	**C**(Comparison)
Best Interests Decision-making Knowledge Understanding	Advanced Dementia	Nurses' Perspectives Nurses' experiences

Table 3.1 – Adapted PICO tool to identify relevant terms

Stating the inclusion and exclusion criteria before conducting the literature review is important (Bettany-Saltikov 2012). Inclusion and exclusion criteria demonstrates the scope and detail of the review and provide vital information about the relevance of the review (Aveyard 2019). The search can then target the papers that will answer the question and exclude any irrelevant papers (Bettany-Saltikov 2012). The inclusion and exclusion for the review criteria are shown in table 3.2:

Category	Inclusion Criteria	Exclusion Criteria
Search of database	• English language • 1st April 2005 to 31st December 2017 • UK based studies • Peer reviewed	• Non-English language • Prior to 1st April 2005* • Non-UK studies with no links to capacity, best interests or legislative frameworks • Non peer reviewed • Literature reviews • Reports
Population	• Adults with dementia • Adults lacking capacity for medical decision-making • Health care professionals or family as surrogate decision-makers	• Focus specifically on under 18s
Intervention	• Best Interests decisions • Decision-making	• Not relating to best interests or decision-making for health or care requirements
Outcome	• Relating to clinicians' knowledge, experience, or perspectives of decision-making and/or dementia	• Not relating to knowledge, experience, or perspectives of decision-making and/or dementia

Table 3.2 – inclusion/exclusion criteria

3.1.2 Search strategy

Studies indexed in the following electronic databases were searched: PubMed, EBSCO (which included Academic Search complete, CINAHL, MEDLINE, PsychINFO), Proquest, Web of Science, Cochrane Library and Google Scholar, as they are considered as optimal combinations and searching databases alone is not enough to retrieve all relevant references

(Bramer *et al* 2017), therefore it is important to utilise additional methods. Medical Subject Headings (MeSH) were applied, combined with keywords, to increase precision and efficiency when searching (Baumann 2016). Boolean operators 'AND' and 'OR' were used to improve the search techniques, recommended by Bramer *et al* (2017), and detailed in table 3.3.

Source	**Search Strategy**	**Hits Received**
PubMed	dementia AND best interests AND knowledge	141
EBSCO	dementia OR Alzheimer's AND best interests OR decision making AND knowledge	363
Proquest	dementia AND best interests AND decision making AND nurses AND knowledge	6671
Web of Science	dementia AND best interests AND knowledge	529
Cochrane Library	dementia AND best interests	23
Google Scholar	dementia OR Alzheimer's disease AND best interests AND decision making AND nurses AND knowledge	626

Table 3.3 – keywords and Boolean operators search results

Grey literature was identified using Google and the identified search terms, through social media shared articles, through reviewing reference lists of identified studies and through searching for guidelines from National organisations, such as the Department of Health, Law Commission, Mental Health Foundation, and the Care Quality Commission. Grey literature is an important component of a literature review as it provides a more balanced picture to the reader by providing data not found within commercially published literature (Paez 2017).

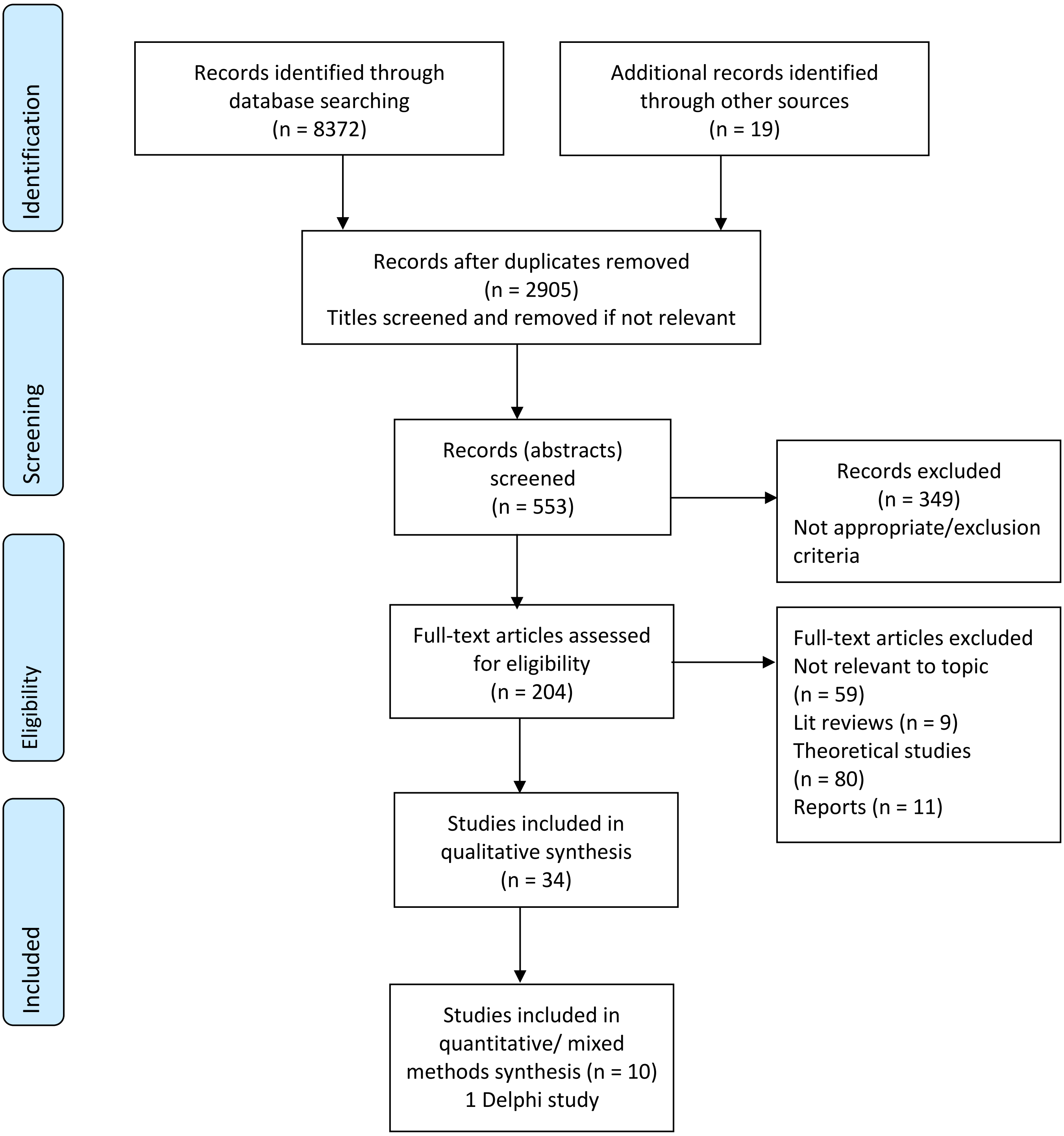
Thinking of keywords relevant to the question is essential to identify a comprehensive range of literature. It is useful to use synonyms, to consider different words that describe the topic and then use the appropriate combinations of keywords, refining them if the results are too many or too few (Aveyard 2019). The question for the literature review was 'What is understood about nurses knowledge and application of the Best Interests Standards when making decisions on behalf of a person with advanced dementia?' The keywords used were:

1. For dementia, key terms of "dementia" (MeSH) OR "Alzheimer's Disease" (MeSH) were used.
2. For best interests, recognised terms of "best interests" OR "best interests principle" OR "best interests standards" OR "best interests decision-making" were used.
3. For nurse, "nurse" (MeSH) OR "healthcare professional" were used.
4. For knowledge, "knowledge" (MeSH) OR "understanding" OR "perspectives" OR "experiences" were used.

3.1.3 Data screening

To ensure the review is valuable, authors should prepare a transparent account of what was done, why it was done and what was found. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) is a reporting guideline designed to address this (Page *et al* 2021). The PRISMA flow diagram in Figure 3.1 illustrates this. The screening process was conducted in stages and initially, 8,372 papers were identified. As expected, there was replication of results within and across the databases, so removal of duplicates and review of the titles resulted in 2905 being retained for deeper consideration. A review of the full title and journal title resulted in 553 articles for abstract screening. Screening abstracts is useful as it allows the researcher to quickly determine whether the paper is of interest or relevant to the literature review (Winchester and Salji 2016). At this stage, 204 were considered against the inclusion criteria for the final full text review. An additional 19 studies or reports sources were identified through a manual search of specific named journals or from the reference lists of other studies.

Figure 3.1 PRISMA Chart



3.1.4 Study details

Articles/studies were rejected as they did not meet the inclusion criteria once the full text was read. For example, one study was not useful to inform the development of the study as it focused on specific theoretical approaches to decision-making and did not relate to capacity assessment, best interests or the legislation. The articles that remained were assessed and a system was adopted for the review, where each paper was assessed for relevance and quality through critical appraisal and whether it was empirical or theoretical research. By identifying the strengths and weaknesses of the methods used in a study, it is possible to understand the contribution that the study makes in answering the research question (Aveyard 2019).

Research conducted prior to the implementation of the legislation was excluded from the initial review but through exploring the references of the included literature, some pre-dated studies were identified. The content of these studies was useful to inform the study. Literature reviews were included initially but then removed following feedback from the viva, as they did not inform the study and were useful only to identify primary research studies and as supplementary literature.

3.1.5 Critical appraisal of the studies

Research evidence, regardless of designs, demands due consideration of its quality prior to its utilisation in the clinical environment. To facilitate the process of critical appraisal, tools can identify if research is rigorous, reliable, unbiased, and methodologically appropriate by helping to question the literature in a structured and in-depth way (Aveyard 2019). There is an increasing recognition of the value of qualitative research, and as such more than 100 critical appraisal tools exist for qualitative research (Munthe-Kaas *et al* 2019). However, there is no clear guidance regarding which tool and approach to use, nor how or why to use them (Hong and Pluye 2019). Hawker *et al* (2002) provides a generic criteria for appraisal that could be applied to all studies, including qualitative and quantitative (Hong and Pluye 2019). Hawker *et al* (2002) suggested that qualitative researchers need to detail their methods and modes of analysis thoroughly if the research is to be easily located, highly graded, and incorporated into evidence-based practice. They developed a criteria for the abstract, introduction, method and data, sampling, data analysis and results, ethics, generalisability, and implications for practice. A protocol to assess these criteria (appendix 5) allows the reviewer to grade the included studies independently as ‘good’ (40), ‘fair’ (30), ‘poor’ (20) and ‘very poor’ (10). A summary of total scores (appendix 6) gives an indication of the strengths and weaknesses of each study according to Hawker *et al’s* (2002) criteria and protocol.

The Joanna Briggs Institute (JBI) (2007) critical appraisal tools were developed by the JBI and collaborators following extensive peer review and although designed for use in systematic reviews, they can also be used when creating Critically Appraised Topics (CAT), and as an educational tool (Lockwood, Munn and Porritt 2015). Hannes *et al* (2010) suggested that the JBI framework appears to be coherent due to its focus on congruity, it facilitates reasoning and critique about evidence-based healthcare (Pearson, Jordan and Munn 2012) However, the framework does lack the evaluation of generalisability (Hannes *et al* 2010), although generalisability is not the aim of qualitative research or case study research. The criteria in the JBI critical appraisal template (appendix 7) includes alignment between the methodology and research objectives, methods and analysis, the interpretation of findings and the philosophy and positionality of the researcher, as well as ethical considerations. The criteria were judged as yes/no/unsure and appendix 8 shows a sample of the critical appraisal of the studies identified in the literature search, using the framework.

3.1.5.i Methodological quality

Using both Hawker *et al* (2002) criteria and the JBI framework, it was evident that the studies included in this review were generally of good quality. The studies ranged between scores of fair at 260 and good at 360. Only two studies scored fair (Evans, Warner and Jackson 2007; Howarth *et al* 2014), mainly due to a lack of detail for the review criteria. All other studies reviewed scored good, with 19 scoring full marks of 360.

3.1.5.ii Abstract and title

The Hawker *et al* (2002) tool refers to a structured abstract with full information and a clear title. All reviewed studies used clear and appropriate titles and all provided a formal abstract apart from one study by Alonzi, Sheard and Bateman (2009). Andrade (2011) provides a list of qualities for an abstract, as the abstract sets the tone for the rest of the paper and should be properly representative of the entire paper. There were 25 studies that followed a variation of the background, methods, results and conclusions structure suggested by Andrade (2011).

3.1.5.iii Introduction and aims

Hawker *et* al (2002) asks if there is a good background and a clear statement of the aims of the research. All but six studies were clear about the purpose of the research study and included aims or questions for the study. Four studies provided background to the studies but no specific aims were presented (Alonzi, Sheard and Bateman (2009); Dunn *et al*; Samsi, Manthorpe and Rapaport 2011 and Boyle 2013). Rowley *et al* (2013) and Howarth *et al* (2014) provided no background or aims.

The JBI (2007) framework asks if there is congruity between the stated philosophical perspective and the research methodology. Philosophical perspectives are the starting point from which assumptions about the research are based. They influence the researcher’s role and how the study is conducted. The underpinning framework has implications for how quality is assessed, how values and ethics are viewed and the type of knowledge that is produced (Illing and Carter 2019). In some qualitative studies the philosophical assumptions are made explicit by the researcher, in the description of the characteristics of qualitative inquiry. In some studies, they remain hidden from view but can usually be deduced by the discerning reader in the themes, the quotes of participants, the stated biases of the researcher, or the emerging design (Cresswell and Poth 2018). Qualitative research is commonly, although not exclusively underpinned by interpretivism, which assumes that people seek understanding of the world in which they live by developing subjective meanings of their own experiences (Petty, Thomson and Stew 2012).

Eleven of the studies were quantitative or mixed method in design, only two specifically stated that they were mixed methods (Luke *et al* 2008; Marshall and Sprung 2016b). Although 33 studies were qualitative, only eight specifically stated they were qualitative in design. Considering Allwood's (2012) assertion that any research philosophy can underpin qualitative or quantitative research, they should not be assumed as being interpretive. One study utilised a phenomenological approach (Samsi and Manthorpe 2013), which is a strand of interpretivism (Saunders, Lewis and Thornhill 2018). Four studies explained their use of grounded theory (McDonald 2010; Dunn *et al* 2010; Gough and Kerlin 2012; Brown and Marchant 2013), where the underlying philosophical assumptions seem to echo postpositivist presuppositions (Rieger 2018) and postpositivism is part of an interpretive framework (Cresswell and Poth 2018). Emmet *et al* (2013), Boyle (2013) and Poole *et al* (2014) all used ethnography in their studies, another methodology that is typically, though not always aligned to interpretivism to satisfy the qualitative and inductive nature of ethnographic enquiries (Hayre *et al* 2022).

Of the 25 qualitative studies that did not explicitly state the underpinning philosophy/methodology, 10 aligned to interpretivism. For example, (Rogers and Bright 2018) specified their research objectives to understand factors that influence practitioners' decisions, the differences between professional groups and how often individuals are judged to have capacity or not (p. 76). This exploratory study aligns to one definition of interpretivism that interpretivist researchers collect what is meaningful to their research participants (Saunders, Lewis and Thornhill 2018). There were studies that were more challenging to align to a specific philosophy, for example Carpenter *et al* (2014) could be positivist in that it used binary logistic regression, linear regression analysis and statistical inference to estimate the effects of an experiment are key to the rigor of positivist research (Park, Konge and Artino 2020). The study also used open questions and vignettes to investigate professional judgements in social care, which infers interpretivism. This aligns to Allwood's (2012) point that assuming interpretivist philosophy is unconvincing.

3.1.5.iv Method and data

Chenail (2011) discussed qualitative research methodology regarding the methods utilised to address new types of research problems. He suggested that the researcher should explore an optimal array of methodological choices to meet the needs of the design's concept and then clearly explain or defend what methodologies and procedures were used to accomplish each aspect of the design. This approach will meet the needs of the study coherently and effectively. The Hawker *et al* (2002) tool asks if the method is appropriate and described clearly and the JBI (2007) tool asks if there is congruity between the methodology and question and between the methodology and the methods.

Although 26 of the reviewed studies did not explicitly state the methodology and instead referred only to the specific methods utilised, they did use appropriate research designs for their chosen aims. Of the quantitative studies, all data was collected and analysed using standardised measures, such as Cairns *et al* (2011) who used Kappa values, which is a robust statistic useful for either interrater or intrarater reliability testing (McHugh 2012). Chapman (2020) used *P* value statistics where, according to Andrade (2019), findings should be interpreted in the context of the study design, including the nature of the sample, the sample size, the reliability, and validity of the instruments used. Chapman (2020) stated that the questionnaire used was generated through consultation and was therefore valid and relevant. Of all the studies reviewed, two reviewed documentation or files, 33 utilised just interviews or just questionnaires, one used both questionnaires and interviews. Three studies used interviews or questionnaires with focus groups. Observations were used by five studies, four of which were alongside interviews and there was one Delphi study. A total of eight studies utilised vignettes alongside other methods. There is no objective hierarchy of evidence and methods, as each choice must be based on the research question and an assessment as to whether the chosen method provide data that can answer the question; the 'fit' between the question and the method (Busetto, Wick and Gumbinger 2020).

Cliff and McGraw (2016) used interviews alongside vignettes to examine the factors that influence mental capacity assessments in home healthcare settings. The purpose of the vignette was to ask participants how they would approach the assessment of capacity in a particular situation. Rogers and Bright (2019) also utilised interviews and vignettes but they took the opportunity to defend the use of vignettes as the most suitable method for the study. Livingston (2010) used focus groups and interviews to identify common difficult decisions made by family carers on behalf of people with dementia as well as facilitators and barriers to such decisions. The focus groups were used to generate a list of common areas in which family carers reported making difficult decisions and the interviews discussed personal accounts of making those decisions. Emmet *et al* (2013) utilised ethnographic observations, interviews and focus groups in their study to evaluate assessments of residence capacity on hospital wards. Observations were used to capture interactions and events between health and social care professionals, people with dementia and their carers. Interviews were used to assess personal experiences, understanding and knowledge of the MCA. Focus groups were used to consider hypothetical cases derived from the observations and discussed how decisions might be improved. The methods chosen in these examples demonstrate the point made by Busetto, Wick and Gumbinger (2020) that chosen methods must provide data that can answer the question.

3.1.5.v Sampling

Emmel (2013) suggested that sampling in research refers to defining a population from which a sample will be drawn and of which the sample will be representative and can be measured. He also suggested that the term sampling is not fit for purpose, that sampling in qualitative research is best described through inverting these 'rules' and thinking about measurement in very different ways. This may explain why there is no reference to sampling in the JBI (2007) tool. The Hawker *et al* (2002) tool does however ask if the sampling strategy was appropriate to meet the aims of the research, with details of the group and response rates. The sampling methods used, where specified, were snowball sampling (Samsi and Manthorpe 2013; Marshall and Sprung 2016b). Snowball sampling happens when the researcher accesses informants through contact information that is provided by other informants and is arguably the most widely employed method of sampling in qualitative research (Noy 2008). Purposive sampling was also used by seven studies including Livingston *et al* (2010); McDonald (2010); Clerk *et al* (2018); Scott *et al* 2018). Purposive sampling is used to select specific kinds of people that are most likely to yield appropriate and useful information and therefore need to be included in the sample (Campbell *et al* 2020).

Sample sizes ranged between 6 (Murrell and McCalla 2016) and 279 (Manthorpe and Samsi 2015). The studies with small samples acknowledged the sample size as a limitation in their study, although qualitative studies can justify small sample sizes to support the depth of analysis required (Vasileiou *et al* 2018). Manthorpe *et al* (2011) also acknowledged their sampling limitations through the potential of bias among those who agreed to participate. They considered whether the participants were atypical, or how their expressed views applied in practice. Participants were from a variety of fields in health or social care, people with dementia and/or their carers. Only three studies focused solely on nurses as participants (Samsi *et al* 2011; Manthorpe *et al* 2014; Marshall and Sprung 2016b). A robust recruitment plan enhances trustworthiness and overall research success (Negrin *et al* 2022). Livingston (2010) described in detail how participants were recruited to their study and Rogers and Bright (2019) referred to inclusion criteria for their study, leading to BI assessors, mental health assessors and DOLS signatories. Walji *et al* (2014) also specified their inclusion criteria. All reviewed studies explained how participants were recruited, albeit some briefer than others (Carpenter *et al* 2014; Howarth *et al* 2014).

3.1.5.vi Data analysis

Saldaña (2020) suggested that data analysis is one of the most elusive practices in qualitative research, as each project is contextual and case specific. With a unique analytic signature, the researcher should strategically scrutinise the data for patterns, categories, themes, propositions, and new theories. The Hawker *et al* (2002) tool considers if the description of the data is sufficiently rigorous, which should indicate the strategic scrutiny. The JBI (2007) tool asks if there is congruity between the methodology and the representation and analysis of data, which questions whether the context of the research is apparent.

All the quantitative and mixed method studies presented a clear description of how analysis was carried out and used appropriate statistical tests to compare variables. For example, Willner *et al* (2011a, 2011b, 2012) used analysis of variance, McNemar tests, thematic analysis and Student-Neuman-Keuls test, which are some of the major tests that can be done using Statistical Package for Social Sciences (SPSS) (Rahman and Muktadir 2021). SPSS is a program that is user-friendly and easily applicable in any kind of quantitative analysis, the statistical method of analysing numerical data in a more mathematical way (Rahman and Muktadir 2021). In each study there was a rationale for the analysis approach utilised, which demonstrates the contextual/case-specific technique recommended by Saldaña (2020).

Thematic analysis (TA) was the approach used by 24 studies, for example Samsi and Manthorpe (2013); Brown and Marchant (2013) and Boyle (2013). TA does not come with a predetermined theoretical framework, which offers the ability to develop rich, detailed, and nuanced analysis, although it can lead to poorly constructed and executed analysis (Trainor and Bundon 2021). TA can be applied across a range of theoretical frameworks and research paradigms and is flexible in terms of research question, sample size and constitution, data collection method, and approaches to meaning generation (Braun and Clarke 2017). This flexibility was demonstrated by Samsi and Manthorpe (2013) who used phenomenology, Brown and Marchant (2013) who utilised grounded theory and Boyle (2013) who utilised ethnography. Of these studies, only Samsi and Manthorpe explained their process of thematic analysis but all explored the themes and used direct quotes to support findings. Livingston *et al* (2010), Harris and Cohen Fineberg (2011), Walji *et al* (2014), Cliff and McGraw

(2016) and Manthorpe and Samsi (2016) briefly explained their use of the stages of TA, other studies simply explored the themes generated.

Framework analysis (FA), a comparative form of thematic analysis , was used by 3 studies (Wilson, Seymour and Perkins 2010; Samsi, Manthorpe and Rapaport 2011; Manthorpe and Samsi 2015). Framework analysis is designed to identify, describe, and interpret key patterns within and across cases of and themes within the phenomenon of interest (Goldsmith 2021). FA stages are data familiarisation, framework identification, indexing, charting and mapping, and interpretation. Wilson, Seymour and Perkins (2010) Samsi, Manthorpe and Rapaport (2011) and Manthorpe and Samsi (2015) all stated that they used this 5-stage approach and explored the themes but not the process.

3.1.5.vii Ethics

In qualitative research, there is an in-depth data collection process with a select few participants with whom the researcher interacts over an extended time-period. This commands ongoing ethical decision-making by respecting research participants, addressing issues related to informed consent, anonymity and confidentiality (Farrugia 2019). The Hawker *et al* (2002) appraisal tool asks about confidentiality, sensitivity, and consent as to how ethical issues have been addressed and the JBI (2007) tool asks if the research is ethical according to current criteria and if there is evidence of ethical approval by an appropriate body.

Ethical processes were not discussed in all the studies reviewed, although most academic journals that publish studies with human participants require evidence of ethical approval (Newson and Lipworth 2015). Some studies were also part of large studies, where ethical approval could be assumed. For example, Samsi, Manthorpe and Rapaport (2011) and Manthorpe *et al* (2011) were part of EVIDEM programme of research, which was a five-year programme specifically designed to influence services for people with dementia and their carers (Manthorpe *et al* 2013). Willner *et al's* (2012) study was supported by a small grant from the Welsh Office for Research and Development in Health and Social Care but explicit approval was not discussed in the article. Similarly, Rowley *et al* (2013) did not discuss ethical approval but the study was requested by the hospital ethics committee, so it was assumed that ethical principles had been followed. There were eight studies that did not state that ethical approval was obtained, nor could they be assumed in the same way as those that referred to larger programmes. All other studies explicitly stated that ethical approval was received and some explained processes in detail, for example Emmett *et al* (2013) discussed continuous consent and confidentiality with a clear explanation of both.

3.1.5.viii Results

Reay *et al* (2019) discussed how researchers can present their research findings in an article and supported allowing authors to experiment with different ways of showcasing findings to match with their epistemic orientations and preferences. They acknowledged the affinity between different approaches in presenting findings and the nature of the data available but concluded that employing different ways to present findings enables authors to reveal specific aspects of their work. The Hawker *et al* (2002) appraisal tool asks if there is a clear statement of the findings, which demonstrates a flexible approach to how they are presented. The JBI (2007) tool asks if there is congruity between the methodology and the interpretation of results as well as whether conclusions drawn in the research flow from the analysis of the data. This suggests a more structured approach to presenting findings is warranted.

All the studies reviewed presented their findings appropriately and identified their perceived value of the findings in relation to practise. Specific findings of each study are discussed further on in this chapter, aligned to the themes that best matched the identified findings.

The findings of qualitative studies are inductively derived from the data, which is presented as evidence to support the findings and the quality and quantity of the evidence persuades the reader that the findings are trustworthy (Merriam and Tisdell 2016). Of the qualitative studies, all but two used statements or quotes from the interviews to support the findings (Phair and Manthorpe 2012; Brown and Marchant 2013). However, the two that relied on narrative description of the themes gave in-depth detail of the issues identified from the interviews and cases. One study that was brief in its description of the findings was Rowley *et al* (2013) which presented findings in tables and concluded that the Trust required an intervention to enhance the knowledge of the staff. The tables showed exact test scores for each directorate and each question.

Merriam and Tisdell (2016) state that a study should provide a balance of description and interpretation; giving sufficient description to help the reader understand the interpretation and vice versa. The JBI (2007) tool asks if participants and their voices are adequately represented in the study, which is demonstrated by using quotes within the findings and the studies that presented supporting quotes from participants to aid understanding of the interpretation were robust with their approach. For example, Scott *et al* (2018) presented two overarching themes and utilised quotes from participants to clarify the interpretation of the themes. Carter *et al* (2018) also took this approach, using participants responses to support the interpretation of three themes. Mixed method studies also utilised direct quotes to enhance understanding of the themes (Luke *et al* 2008; Manthorpe *et al* 2009).

3.1.5.ix Transferability or Generalisability

Generalisability refers to whether the results from one study can be applied to wider or different populations and although some argue that generalisability in qualitative research is not meaningful, results can be generalisable by concept if applied flexibly (Braun and Clarke

2013). The JBI (2007) does not question generalisability in the appraisal tool, which may indicate that it is not meaningful but the Hawker *et al* (2002) tool asks if the findings are transferable/generalisable to a wider population. All the studies were conducted in the UK so as the legislation is for England and Wales, this may increase generalisability of the studies. Some studies referred to the potential for generalisability when identifying their limitations, mainly due to small sample size recruited or because of the geographical area in which the research was conducted (Willner *et al* 2012; Phair and Manthorpe 2012; Emmett *et al* 2013). Walji *et al* (2014) discussed how the presence of a shared narrative among the participants of their study may increase potential generalisability, recognising that the findings could apply in different contexts as the participants shared experiences even though their roles differed. Only two of the studies reviewed did not acknowledge the limitations of their study (Livingston *et al* (2010; Clarke *et al* 2015). All other studies recognised limitations in their studies and some listed limitations in detail. For example, Manthorpe *et al* (2011) discussed limitations of sampling in case study research and the risk of bias and Shepherd *et al* (2018) discussed selection and response biases because the survey they designed was self-completed.

3.1.5.x Implications and usefulness

LoBiondo-Wood and Haber (2018) suggested that the final steps of evaluating research are refining practice and generating future research, which are presented in the discussion and recommendations. They suggested that the greater the risk involved in making a change in practice, the stronger the evidence should be to justify the benefit of implementing the proposed change. The JBI (2007) tool does not ask about informing policy or practice but the Hawker *et al* (2002) asks how important the findings are to inform policy and practice. The ways in which the reviewed studies were relevant to the proposed research study are considered later in this chapter but all the studies considered what was potentially useful for practise alongside the limitations of the studies.

Some of the studies indicated a lack of knowledge of the legislation, leading to inconsistencies in practise in respect of capacity assessments and best interests determinations (Evans, Warner and Jackson 2007; Luke *et al* 2008; Manthorpe *et al* 2014). Even where there is knowledge, some gaps in knowledge remain and there is a risk of poorer outcomes for patients impacted by the legislation (Manthorpe *et al* 2009; 2011; Willner *et al* 2012; Heslop *et al* 2014). Staff also want additional education and training on the legislation as they self-identify reduced knowledge and confidence in applying the legislation in practice (Alonzi, Sheard and Bateman 2009; Wilson, Seymour and Perkins 2010; Samsi, Manthorpe and Rapaport 2011). Alternative approaches for training are recommended by some studies, for instance, moving away from the traditional 'taught away day' sessions (Gough and Kerlin 2012; Phair and Manthorpe 2012; Willner *et al* 2013; Manthorpe *et al* 2016). There are also studies that recognised the need for further research, such as McDonald (2010) recommending further analysis of the factors that influence decision-making and the context of risk and Emmett *et al* (2013), identifying the need to test their recommendations and clarify the issues they raised in their study.

Samsi *et al* (2011) specifically identified the relevance of their study to clinical practise, stating that specialist nurses offering support to carers and to people with dementia may need greater familiarity about legal provisions if they are seeking to maintain and develop their role and that enhanced knowledge may assist them in providing such specialist advice. Their study identified that participants had received limited training and felt less confident with the legislation as a result. Willner *et al* (2011a; 2011b; 2012; 2013) also devoted a section of their articles to implications, suggesting that their 2011b study provided some reassurance of knowledge and that participants would consult with others in respect of decision-making. They also identified gaps in knowledge as other studies had (Willner *et al* 2011b; 2012; 2013). Although the JBI (2007) appraisal tool does not ask about implications, it does ask if there is a statement locating the researcher culturally or theoretically and if the influence of the researcher on the research and vice-versa addressed. This could be established through reflexivity of the researchers, which according to Busetto, Wick and Gumbinger (2020) is sensitivity to the background and experience of the researcher(s) involved in data collection and analysis (professional experience or gender, age or ethnicity). In Poole *et al*'s (2014) ethnographic study the authors stated they were aware of their own personal and professional backgrounds, which would colour judgements about observations and emerging data. Walji *et al* (2014) also acknowledged their interest in the study and the potential for bias due to this. Both provided mitigation for their potential influence in results interpretation. In most of the studies, the professional background of the researchers was stated at the outset, as were potential conflict of interests but there was less detail about personal influences evident throughout the research.

3.2 Findings from empirical research studies

3.2.1 Findings

The empirical studies identified from the search varied in topic and methodology and there was limited empirical research specific to best interests decisions and nurses. The identified studies were divided into two themes:

- Knowledge, understanding and application of the MCA
- Best interests, DOLS and general decision-making

Figure 3.2 shows the two themes and the common or individual elements of each theme.

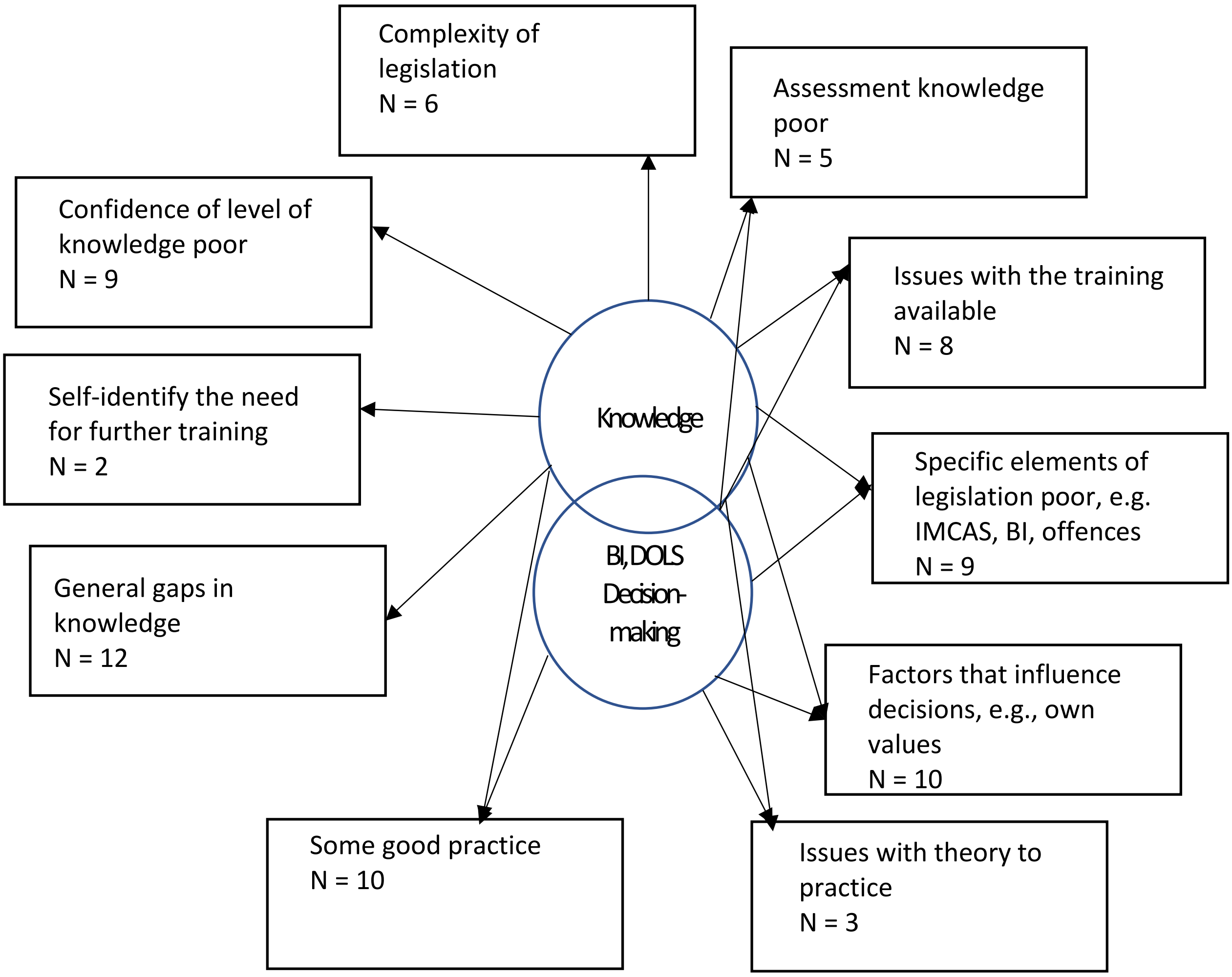


Figure 3.2 The two themes and the common or individual elements of each theme

3.2.2 Knowledge, understanding and application of the MCA

There were 28 studies in the review that focused on knowledge of the MCA and/or BIS and the application of this knowledge in assessment or decision-making processes. The studies did not necessarily focus on nurses or people with dementia but with care home staff or social workers and people with a learning disability (LD). They were included in the review due to their focus on knowledge in relation to the MCA and best interests. Overall, the various research studies conducted since the inception of the legislation, as well as more general research on best interests, have shown that knowledge of the legislation falls below the expected standard. From the studies within this theme, 22 discussed the lack of knowledge, gaps in knowledge, low confidence in the legislation and a need for additional education, training and awareness in the legislation, from the implementation of the legislation, following the HOLSC report and more recently. The consensus from the research is that education and training is required to address poor knowledge and understanding of the legislation, the terminology and how the fundamental tenets of the legislation should be applied.

Evans, Warner and Jackson's (2007) study was early in the implementation of the legislation but suggested that additional training was required for the MCA as they had shared a 4-question questionnaire with 86 doctors, nurses and paramedics who are often required to make rapid decisions when patients refuse treatment. The findings showed that they did not know how to assess capacity, only 10% knew how to properly assess capacity (using lenient criteria). This was a small study carried out very early in the life of the legislation but demonstrated that knowledge of capacity issues were low when explicitly tested using formal questions.

Luke *et al* (2008) conducted a mixed-methods study to examine attitudes to the MCA's Independent Mental Capacity Advocate (IMCA) service. Referrals made to the service between 2006 – 2007 were reviewed and then doctors and nurses from four hospital were interviewed. While aware of the potential benefits of the IMCA service, clinicians were generally negative about the contribution advocates could make to medical care and thought they could only contribute to decisions in a limited way. Clinicians seemed to feel that the IMCA role was unnecessary, given that decisions are made in a patient's best interests and they were more likely to support the role in discharge decisions. The study suggested that clinicians' ambivalence to the role suggested that they fail to pay due regard to the IMCA service as a statutory measure to safeguard patients' interests. It corresponds to the later HOLSC (2014) criticisms that suggested that the involvement of IMCAs is inconsistent and indicates clinician's lack of knowledge of the legislation as well as initial perspectives of others' roles in decision making.

Alonzi, Sheard and Bateman (2009) conducted a quantitative study that sought staff views on whether they needed further training and guidance on the MCA, the implications for practice showing the importance of gathering and analysing the views and needs of healthcare staff when developing guidance. The research was designed to support the implementation of the MCA and included community nurses as participants, responding to a questionnaire. Staff who participated in the study indicated that they wanted to receive further guidance on 12 areas relating to the MCA, the most significant of these being assessing capacity, help with decision-making and best interests. The authors of the study then produced guidance on the MCA in response to the identified topics.

Manthorpe made several appearances in the literature search, as lead author or co-authors. Manthorpe *et al* (2009) conducted a study in 2008 with 15 adult safeguarding leads, well placed to comment on the early implementation of the legislation. Participants were asked to estimate their level of confidence about their knowledge of the MCA, where they were (actual) and where they should be (appropriate for their role) and all but one felt they should be more informed. There were concerns that the legislation was not widely known and about how it would be incorporated into everyday practice. The study was limited in number and to just one London borough, but it suggested that the participants incorporated the principles of the MCA into their practice and systems of work even though they would welcome updating and guidance on the MCA. The second part of the study in 2010 with 12 adult safeguarding leads further investigated whether the expectations had been borne out in practice and whether any new areas of concern were emerging. In 2010, the participants were more enthusiastic about the legislation in supporting decision-making, protecting people from abuse and achieving good outcomes for those who lacked capacity. There were no great differences between the views of those interviewed in the second phase. All participants had substantial experience and expertise, which may have explained their favourable views of the MCA (Manthorpe, Samsi and Rapaport 2013).

McDonald (2010) conducted a grounded theory study as part of a programme of research into the early impact of the MCA on decision making. Participants were asked to select a case that was current and to compare practice with a similar case concluded before the legislation came in to force. Participants were purposively sampled from people working with older people with dementia and semi-structured interviews were used. The consensus achieved from the study suggested that legislation alone cannot fundamentally change the way that social work professionals respond to older people without further analysis of the factors that influence decision making in the context of risk. It also suggested that social workers felt that the legislation had forced them to take a legalistic and actuarial approach to decision making and had created barriers to the rights of older people. This study explored perspectives of the legislation and how it impacted on practice.

Wilson, Seymour and Perkins (2010) reported on the findings from a study with 26 staff members working in palliative and neurological care centres. Semi structured interviews were used to gain an understanding of knowledge of the MCA in line with ACP. Findings showed that staff generally had a good understanding of issues around capacity but felt unclear about some of the terminology, which impacted on their confidence. Scope was also provided for staff to consider best interests but some were unclear about when it was necessary to record these decisions and when it was not. Staff wanted clarification about when it was necessary to record decisions made in a person’s best interests.

Samsi *et al* (2011) conducted a study to explore the experiences of specialist community nurses providing information about the MCA and supporting people with dementia and their carers. Interviews were used with 15 Admiral nurses to enquire about their experiences of explaining the legal framework to carers of people with dementia and expectations of the legislation. There was limited confidence in knowledge and use of the legislation, although there was speculation that this would improve with more frequent use. The study was conducted in 2008, so relatively soon after the implementation, but it set out the scene of limited knowledge and confidence, even from specialist nurses. It was useful to the review as it focused on the legislation and dementia, although it did not focus specifically on best interests. There was a phase 2 of this study carried out in 2010, where participants were revisited two years after the implementation of the legislation. The overall aim of the second part of the study was to explore participants' understanding of their practice experience of the implementation of the MCA and their reflections of any change in nursing practice, as well as the challenges they faced in everyday practice and whether the expectations of the MCA had been met (Manthorpe, Samsi and Rapaport 2014). The findings showed that the MCA was better embedded in practice than two years previously and there was greater understanding of the principles of the law. Regular training and case discussion could enable participants to tackle issues with not only finance but also with decision-making.

Samsi, Manthorpe and Rapaport (2011) completed a qualitative study with Age Concern staff and found that most had a lack of confidence in providing detailed advice about the legislation and that knowledge was varied. The study was part of a wider body of research focusing on implementation of the legislation, practitioner's experiences and the legislation's relevance to older people with dementia. This was a small study, with nine participants and showed that some had knowledge of most areas of the legislation, whilst others had only minimal knowledge. In respect of training, some participants had undertaken in-house training and others had attended more detailed training. The article did not stipulate specific numbers or percentages of responses. The discussion section recognised the limitations of the study in respect of the numbers of participants and the area in which they worked. In respect of training, good practice was highlighted through sessions that incorporated practical case studies to demonstrate transferability to day-to-day work and with training being an ongoing process with regular opportunities to update information and enable discussion of cases.

There were four separate studies in 2011a, 2011b, 2012 and 2013 by Willner *et al.* One study aimed to assess the extent of knowledge of the MCA among new recruits in an NHS Trust (Willner *et al* 2011a). A questionnaire with 16 true/false questions was returned by 116 participants who ranged from health care assistants to consultants. They were used around a 10-minute presentation on the induction programme of new staff. The results gave grounds for both optimism and concern as there was a relatively good understanding of some aspects of the MCA and discernible improvements following training but there were also limitations in understanding both before and after the training event. There were no differences between non-clinical staff, naïve clinical staff that had not received training and clinical staff that had received training. Willner *et al (*2011b) conducted another study to evaluate the knowledge of mental capacity issues in 40 health and social care professionals. The study used interviews and scenarios based on actual cases to elicit participants' understanding in relation to best interests decision making. The results were similar between the health and social services staff and identified fourteen areas of concern, with significant gaps in knowledge such as recognising that capacity was an issue, that specialist assessment was required where capacity was in question, and a failure to identify that a best interests decision was needed. The subsequent 2012 study by Willner *et al* also identified several gaps in the knowledge of participants around mental capacity issues. Participants were qualified nurses working in specialist residential care settings catering to people with intellectual disabilities. They received the same interview used in the previous study and there were no differences in interview performance between three groups, who performed better than generic NHS staff but worse than community teams for people with intellectual disabilities (CTID). The study showed that staff had only a limited understanding of mental capacity issues and their confidence in their own knowledge may not be a good guide to their ability to deal with issues that might arise in practice.

The 2013 study conducted by Willner *et al* was also completed with 86 practitioners enrolled in MCA training, working in specialist areas (such as learning disabilities) and demonstrated more consistent practice in line with the MCA (2005). Basic or advanced training was delivered to inform and make practitioners aware of the of the law to link theory to practice. Findings showed little difference between those that attended the basic training and those that attended the advanced training. Findings also showed that knowledge improved following formal training in respect of responding to scenarios, but nine areas remained where there were significant gaps in knowledge. The consensus appeared to be that experience in dealing with capacity issues trumps any training received as those staff who worked in areas where capacity issues are endemic performed better than those who were not exposed to capacity issues as frequently. Participants did learn from the training and gains were retained up to 7 weeks later. Participants did have insight into their difficulties as scores decreased when participants realised that they were not well equipped to deal with the issues presented to them.

Gough and Kerlin (2012) reviewed MCA training in residential homes in their 2012 study, using interviews and focus groups with residential care home staff. The purpose was to explore and inform services of the issues associated with applying the knowledge and skills learned on MCA training into the workplace. It was conducted in an area where good practice had been identified and commenced with baseline data from an approved audit, followed by a focus group of nine and in-depth interviews with four participants who were all residential care home managers. The audit identified some gaps in understanding of the MCA, with some participants not seeing the relevance of the training because their units did not take residents who lacked capacity. The focus groups and interviews revealed perspectives about the training offered to care homes. Participants felt that training was not integrated and was delivered in isolation, that training presented issues with time and cost as the managers had to release staff and fund training and that managers were unable to establish if the training had any impact. This study also recognised the complexity of the legislation, which is a common theme in other studies. The recommendations were to integrate training with other topics to give the legislation relevance and to support managers to utilise e-learning with workplace discussions to address issues with cost and time. The authors recognised that gaining perspectives of recipients of the training would be beneficial so that gaps could be identified and practice informed. This study was useful to inform the literature review as it focused on gathering perspectives of staff through interviews and focus groups and it considered barriers to effective training, which impacts on practice.

Phair and Manthorpe (2012) identified that few studies have investigated the operationalisation of the MCA in hospital settings. They conducted a case study review of hospital policies and practices in one NHS Trust in England in relation to safeguarding the rights of vulnerable patients and staff's knowledge of the MCA. Interviews were undertaken, incorporating a discussion of a vignette and the findings revealed limited confidence and knowledge about the MCA and uncertainties about its relevance to clinical practice. There was limited realisation of staff responsibilities and how the MCA might uphold the rights of vulnerable patients. Training on the MCA had not made a great impression on staff and hospital policies were inconsistent. The study was not an official research study and was also limited as it focused on one Trust and therefore may not be generalisable to other hospitals or other providers of health and social care. It did however suggest that there are opportunities to refresh MCA and safeguarding training strategies that should be accompanied by changes to culture and attention to the coherence of different procedures. The formal testing of staff knowledge in this study was in the form of a survey, completed by 42 staff in clinical settings and knowledge varied, all were aware of the MCA and all but one had received training on it. Of the responses to the question about whether they understood the principles of the MCA, 61% were only slightly confident that they did so. A small minority were confident that they could determine what was in someone's best interests, half of the participants were only slightly or not at all confident. The training was described by participants as theoretical, lasting for just 45 minutes and 'bolted on' to issues around consent. Skills and competencies were not taught nor practiced, and mandatory training updates did not include the MCA. In interviews, the participants felt that the MCA was not embedded into practice. Most participants lacked knowledge, confidence or feared that the MCA was too bureaucratic to use to make best interests decisions. Participants were encouraged to offer ideas about how to improve the application of the MCA in practice, some suggestions were to create competency-based assessments, merging consent and MCA training and applying training to specific clinical settings. These recommendations will be revisited in the conclusion.

Emmett *et al* (2013) also conducted a study around discharge decisions for patients with dementia. They found that professionals from both health and social care professed to understand the need to respect unwise decisions but putting it into practice appeared problematic. Also, the legal standards under the MCA were perceived and implemented in varied ways in practice, between the different professional groups and between individuals practising within those professional groups.

Research by Manthorpe *et al* published in 2011 and 2016 has been referred to widely in many subsequent research studies. Care staff were interviewed in two phases and the findings published at two separate intervals. The first phase of the five-year study consisted of qualitative interviews to identify challenges staff face when they come across issues of mental capacity when working with people with dementia. It commenced with an audit of knowledge and familiarity with the legislation during the first year of its implementation and continued with a focus on exploring training, understanding, expectations, knowledge and use of the legislation. Senior carers and care home managers were recruited to the study and both rated their confidence in their knowledge of the legislation as low and there were mixed levels of awareness regarding details of the legislation. Even where it was apparent that they had a level of knowledge, it was not clear whether they were aware of the details of the specific aspects or if they had 'common sense knowledge' of them. There was an ethos of working in the spirit of the MCA and the principles of the legislation were congruent with their expressed practice values. Person centred care, mentioned in other studies, was a concept that was thought to be promoted through the desire to apply the legislation in practice. This study took a case study approach, and this was acknowledged as a limitation to the study.

The second phase of the study took place in 2012, published in 2016 and the published study acknowledged the (then recent) criticisms. The researchers attempted to contact all participants from the first phase in 2008 but this was not entirely successful, only 13 of the original participants were contactable. Similar semi-structured interviews were utilised in the second phase with 32 staff. Responses collected in phase one and phase two were compared to establish any changes in views. The study found that not all staff members were aware of the MCA and some were not generally aware of the legal framework they were working under. Some staff struggled to articulate the fundamentals of their practice. In phase 2, participants were asked to provide their opinions of any training they had received, and some responded that they had received no training and did not know about the legislation. Some staff recollected the paperwork that they used but could not remember the specifics around the training they had received. Managers were the most confident in their knowledge of the MCA and they considered that knowledge to be from discussions with other professionals. The person-centred care ethic was also identified in the findings from phase two as was the discussion of the principles without consciously acknowledging the legal and moral imperatives of the legislation through legal terminology. Between the two phases, there were continuing challenges of using the MCA, including the absence of understanding wilful neglect and ill treatment and ‘common sense’ responses seemed to be standard. The overall study is quoted in many subsequent studies and the authors consider that the findings may be food for thought for trainers and to consider the negotiations surrounding decisions and choices that take place between residents, care workers, families and other professionals.

Manthorpe, Samsi and Rapaport published another study (2012a) interviewing 17 staff from 23 carers’ organisations known to have an information and advice role. They found that participants’ experiences of using the MCA varied; centring mostly on the information and advice sought by clients or offered to them. This was another study that recommended ongoing training, local coordination and auditing of effectiveness of training interventions.

Rowley *et al* (2013) conducted a relatively large quantitative study with 249 10-part questionnaires with doctors, nurses and allied health professionals. The questionnaire was designed to gauge the participants' level of knowledge to imply its appropriate implementation. They expected a high level of knowledge and imposed a 70% pass mark but only 24% scored 70% or above and responses showed variable knowledge with no professional group appearing any more knowledgeable than another. There was an overall low standard of knowledge in the Trust and therefore it was concluded that the MCA was not being effectively implemented in the Trust. Measures to improve awareness and knowledge were subsequently instigated to empower staff with improved knowledge, including resources and educational sessions.

Heslop et *al* (2014) completed a review of deaths of people with a LD and related the review to a lack of adherence to the MCA. The Confidential Inquiry into Premature Deaths of People with Intellectual Disabilities (CIPOLD) did not set out to evaluate MCA adherence but it was apparent that when implemented effectively the MCA afforded good protection to vulnerable people that lacked capacity to decide about their healthcare and a lack of adherence to the MCA was a contributory factor in several deaths. Best interests determinations and assessments of capacity were the two main factors that contributed to premature deaths. Decisions were made on prejudice, a lack of information about the person or a lack of holistic assessment of the person's situation, which related to two of the BI standards: no assumptions or bringing about the person's death. Heslop *et al* (2014) recognised the potential personal agenda influencing best interests decision-making. The decision not to initiate life sustaining treatment and instead allow the patient to return home for 'TLC (tender, loving care) was taken by a clinician according to his/her own personal views' (Heslop *et al* 2014 p. 372) in apparent isolation and ignored due process stipulated by the MCA (2005).

This acknowledges the potential for best interests decisions to be influenced by personal values. Although CIPOLD related directly to people with an LD, the consequences of failing to adhere to the MCA may be a risk for other vulnerable groups and so the findings are important to consider.

A study by Walji *et al* (2014) identified that there has been limited previous studies in the area and interviewed seven clinical psychologists for their experience of implementing the MCA. The research identified the importance of finding solutions to current problems with the implementation of the MCA, such as training gaps and misunderstanding of the legislation in relation to its complexities, such as best interests decisions. The researchers acknowledged that findings could not be applied to all clinical psychologists but that errors in understanding could have significant clinical and legal ramifications. The study recommended that appropriate training could further enhance confidence and clinical practice.

Manthorpe and Samsi published another study in 2015, considering the knowledge of the offences within the MCA. The study comprised of interviews of 279 practitioners over a period of 3 years to explore how the MCA was being implemented in community-based dementia care. The findings suggested that knowledge of the offences within the MCA was partial to non-existent and as clinicians may be called upon to provide evidence of whether a victim or perpetrator lacks decision-making capacity, they need to be aware of the criminal offences. This study was the first on the offences of the MCA in practice and it focused on dementia and knowledge of the MCA and so was pertinent to inform the literature review.

In 2016 Cliff and McGraw published the results of their study that examined the factors that influenced mental capacity assessments and the perceptions of generalist nurses and allied health professionals. Although this study focused on capacity assessments rather than best interests determinations, it considered both influencing factors and perspectives of the staff involved and was therefore useful for the literature review. Semi-structured interviews were conducted, supported using a vignette and the themes identified were patient, team, staff and environment factors and family influences. These factors ranged from the type of condition the patient had (patient), family involvement in the situation (family) and the setting that the assessment took place (environment), aspects of interprofessional assessment (team) and how experienced the assessor was in capacity assessment (staff). The study acknowledged that capacity assessments, particularly in home care settings were inherently complex. The study was also useful in respect of the recommendations, providing educators and managers with an opportunity to develop systems to support practitioners to manage the challenges faced when conducting capacity assessments. This includes encouraging interprofessional working and utilising the knowledge, skills, and experience within the interprofessional team.

Marshall and Sprung conducted a mixed method study, using a survey questionnaire with 60 community nurses and nine were interviewed further to explore their experience in using the MCA in practice (Marshall and Sprung 2016b). Most of their participants had received training but still felt that they would benefit from additional training. Confidence was not rated highly and there was no significant increase in confidence relating to years of experience in their role. There were varied responses from 11 direct questions about the MCA. although only eight out of 60 participants answered all of the questions correctly in their research, overall scores were not clear in the article. However, most of the participants felt that the MCA was embedded in their everyday practice.

Murrell and McCalla (2016) conducted a small-scale qualitative research study using interviews with social workers and found that there was varied knowledge and in some cases was fairly limited. Many of the participants dealt with cases involving people living with dementia, so this study was related to both knowledge of the legislation and dementia. This study echoed criticisms in the HOLSC (2014) report, particularly with the principles of the legislation being rolled into one. The study found that best interests determinations merged with the capacity assessment; the wishes and feelings of the person was considered rather than an assessment of whether the person had the capacity to decide, and they give an explicit example where a participant demonstrated this. Although the study identified varied knowledge, it also identified some valid concerns that practitioners experienced, which demonstrated insight into the practicalities of using the legislation in practice. Their recommendations are similar to other studies, with joint working, peer review, team meetings and sharing difficulties and feedback to facilitate practice learning.

A cross-sectional survey conducted by Shepherd *et al* (2018) used a series of vignettes where participants were asked to identify the decision-maker in each scenario. There were 127 participants, from a range of professions, including nurses, allied health professionals and social workers. There was a broad spectrum of understanding about the legal frameworks, although there was a high level of discordance between the responses and overall, the participants demonstrated a lack of knowledge about the legal frameworks. The findings suggested that greater education and training is required.

Finally, Chapman (2020) considered nurses in their study that explored how well LD staff knew the MCA. This was a quantitative study using 12 item multiple choice questions that reflected the five principles of the MCA. The study acknowledged the existing evidence that the MCA is not empowering vulnerable people and the lack of knowledge in healthcare professionals but suggested that there is sparse knowledge that investigates staff knowledge of the MCA. The research is part of a wider programme evaluating the effectiveness of a new web-based assessment tool and was carried out in a large mental health and learning disabilities Trust where mandatory training on the MCA is required every three years. The study found that there was a high level of variability in MCA knowledge across the individual professions, with qualified staff scoring higher than non-qualified staff, even though both groups of staff have a responsibility to apply the legislation in practice. The fact that the study recruited 76 percent of the workforce was a strength of the study and the questionnaire was a valid and reliable tool to test knowledge. The shortcomings identified highlighted areas for potential improvement, particularly in non-qualified staff whose knowledge was of a lower standard than qualified staff. Training needs to extend beyond theoretical knowledge and direct staff in how to apply their knowledge to positively influence practice and the quality of care that patients experience.

From this theme, it was evident that knowledge about the legislation is variable and practitioners are self-aware in respect of their limited knowledge. Education and training was identified as a gap in several studies, implying that practitioners needed access to training in a more consistent way to give them the confidence to use the legislation in practice. In answering ‘What is understood about nurses knowledge and application of the Best Interests Standards when making decisions on behalf of a person with advanced dementia?’ there are gaps as studies focused on MCA and not specifically best interests. However, knowledge is variable in all fields of practice, nurses included.

3.2.3 Best interests, DOLS and general decision-making

Aside from studies that focused on knowledge relating to the MCA and best interests, there were 17 studies that focused on the Best Interests Standards or, best interests when considering Deprivation of Liberty Safeguards (DOLS) or decision making in general. Two studies identified good practice in BI decision-making (Carpenter *et al* 2014 and Rogers and Bright 2019), two identified inconsistency in the application of the legislation (Williams *et al*

2012; Clerk *et al* 2018) and two identified that support or training was required (Samsi and Manthorpe 2013; Cairns *et al* 2011). This adds further weight to the need for support, education, and training in MCA, BI and supporting decision-makers as best interests is a challenging concept to determine.

Each of the studies in this theme discussed aspects of the Code of Practice, such as knowing the person's wishes or the circumstances of the situation (Livingston *et al* 2010; Scott *et al* 2018), whilst others mentioned the need for education and training (Samsi *et al* 2011; Manthorpe *et al* 2014; Howarth *et al* 2014, Poole *et al* 2014) or the need for support with using the legislation (Carter *et al* 2018). This strengthens the assertion that best interests are derived from sources external to the legislation and that ongoing education, training and support is fundamental to its implementation. These studies informed the design of the study in respect of perspectives of dementia and interpretation of the best interests of people with dementia.

Dunn *et al* (2010) explored a grounded theory study design using observations and semi-structured interviews to understand how support workers made substitute decisions. The data suggested that support workers draw on the personal decisions that they make in their own lives as a starting point for thinking about how to make substitute decisions. In so doing, support workers believe that residents might be helped to live 'a life like ours' and that the quality of residents' day-to-day lives enhanced. The recommendations argued for a reconfiguration of the MCA's regulatory framework to be more carefully tailored to the realities of the everyday support of adults with intellectual disabilities, who were the recipients of the substituted decisions in the research project.

Livingston *et al* (2010) also focused on carers making decisions for people living with dementia using focus groups and interviews. The study aimed to identify common difficult decisions made by family carers. There were 43 participants in the focus groups and 46 in the interviews. The study acknowledged the MCA (2005) although it was not directly exploring the application of the legislation. The results highlighted the difficulties in making proxy decisions and specifically discussed legal-financial matters, non-dementia and dementia related health care, and care homes. It also identified strategies that helped with the implementation of decisions, which included knowledge of previous views, clear prognostic information and family support. The family carers interviewed expressed that they had not been informed about certain treatment interventions, which could be deemed as contravening the MCA and BI standards, validating the criticism by the various agencies. The barriers to and facilitators of decision-making was particularly useful as it considered aspects such as family conflict and resistance to care interventions, knowing previous wishes and supportive documents such as Lasting Power of Attorney. These aspects are encompassed by BI standards and should therefore be considered by healthcare professionals in their role as decision-maker.

Cairns *et al* (2011) conducted the first study that examined the interrater reliability of DOLS judgements. They asked lawyers, psychiatrists, Best Interests Assessors and IMCAs to make binary judgements about whether situations in 12 detailed vignettes amounted to a deprivation of liberty. The study aim was to gauge the level of agreement between assessments of liberty made by lawyers and different groups of mental health professionals. Professionals were asked to outline reasons leading to each judgement from a range of clinical presentations. The findings primarily raised concerns about the DOLS legislation but even professionals with high levels of expertise found themselves in the same position. The authors questioned whether training could improve the reliability of assessments.

Harris and Cohen Fineberg (2011) conducted a study relating to practitioners' understanding of best interests determinations. The discussion was based around processes and practice as well as knowledge/understanding so has been discussed within the theme of BI. This study was conducted before the HOLSC report and acknowledged that the legislation was still relatively new. There were 11 face-to-face interviews with nurses, social workers and occupational therapists and the questions focused on 'what is your understanding of the MCA best interests concept?' and 'how do you think the best interests portion of the legislation is meant to be implemented in a multidisciplinary team?' Therefore, the questions focused on the process of best interests determinations and relied on participants to reflect on their experiences of the process. The results demonstrated that there was variable understanding of the MCA and best interests with almost half of participants demonstrating a lack of clarity of the concept of best interests. There were inconsistencies in understanding and conceptualising best interests and there was no indication that the participants were using the BIS checklist. There were no clear examples of the inconsistencies in the article. The participants were clear about establishing the preferences of the person for whom the decision needed to be made and they emphasised the importance of advance planning. The small sample was identified as a limitation and the limited empirical research to inform best practice was recognised. The study recommended further training as the authors suspected that practitioners are adopting mechanisms for best interests decision-making that prevailed prior to the MCA, where perceived outcomes and perceptions of risk were the focus. This study was useful as it considered the process of best interests decisions and how they are conducted.

A Samsi and Manthorpe (2013) study considered the challenges of best interests decisions and how these challenges were identified, with interviews of 12 people with dementia and their carers. The interviews took place four times over one year to ascertain experience of decision-making, how decisions were negotiated and how dynamics changed. Carers reported that they struggled with weighing up what was in their relative's best interests and how to determine their relative's capacity. The recommendations included practitioners supporting carers with advice in a timely manner around issues such as LPA and advance planning. The theme of advance planning and its importance was echoed in other studies, reflecting the best interests principle of establishing prior wishes and preferences of the individual.

The Mental Health Foundation (MHF) conducted a report in conjunction with two Universities, funded by the Department of Health (Williams *et al* 2012). It was a national study and suggested that triggers for assessment, the assessment process, making best interests decisions, involving the person in the decision-making process and the outcomes of decisions all fell below expected practice. This was the first large-scale national research to explore professional practices in best interests decisions made since the introduction of the MCA; it was completed in 2011 and published in 2012. This study on 'Making Best Interests Decisions' was rigorous in design; it used purposive sampling as participants were invited from a range of areas that were representative of ethnicity, socio-economic and living conditions. The MHF study utilised a mixed methods approach, combining an online survey, telephone survey and face to face interviews to maximise the available data and therefore enhancing the validity of the study, providing triangulation; where combining several qualitative methods allows for one method to compensate for the weaknesses of another (Gray 2014). The aim of the study was to provide a picture of practice according to the main contexts and types of decisions being made and the processes of determining best interests, including barriers and obstacles that face all those involved in best interests decisions.

Although the study focused on all people affected by capacity assessments and subsequent best interests determinants, it found that 40% of the cases discussed related to people living with dementia. The findings suggested that decision-making capacity of people with dementia was often conflated with their executional capacity. It appeared that people with dementia were disadvantaged in relation to capacity assessment and best interests processes, in comparison with other client groups. Best interests processes were necessarily prolonged at times, there were ‘protective’ admissions to care homes and decisions about the best interests of people with dementia were often tied up with concerns about the best interests of their families (Williams *et al* 2012).

Manthorpe, Samsi and Rapaport (2012b) Purposive sample of 123 dementia care professionals working in community and care home settings were interviewed (2007–2010). Across the board, there were a few individual examples where, despite personal experiences, participants claimed that the Act had made no impact on their professional role or decision making, or giving advice on, planning, or stating personal wishes.

Another study that recommended the MCA be applied with particular focus to socio-cultural aspects was Boyle (2013) who conducted a qualitative study of observations and interviews with 21 couples (people living with dementia and their carers). The observations found that female carers were more facilitative of decision-making with their male spouses and that male carers were less facilitative, limiting the autonomy of their spouse. Boyle suggested that this gender disparity should be recognised by health care professionals who may be supporting the person with dementia to minimise any potential ‘gender power difference’ within families. This was useful in respect of factors that might influence the perspective of the person making a best interests decision, that gender may be a factor and should be considered in the design or choice of data collection tool.

Brown and Marchant (2013) conducted a qualitative study, guided by grounded theory reviewing 16 complex cases. The study analysed characteristics from the cases submitted including decision-making for people with learning disabilities across the lifespan. Best interests was only clear in one case, it was disputed in one case and not properly assessed or deemed as ‘complicated’ in the others. There were 30 issues that created complexity, such as the difficulty in assessing capacity, unpredictable conditions (e.g. addictions) and tensions with establishing best interests. In respect to best interests, the study identified that some practitioners passed responsibility for the decision to a medical professional, thinking that it was the correct procedure. This study suggested that some of the criticisms could be because cases requiring consideration under the MCA do not fit into the linear, cognitive model of decision-making. The study recommends that the guidance needs to address the ways that concerns are formulated, and how difficulties should be deliberated and brought before the court. Again, this study was useful to inform the design of the approach to data collection, considering complexity as it reflects real-life decisions made by health care professionals.

Carpenter *et al* (2014) used vignettes to consider the factors that affect BIAs judgements of DOLS, the levels of confidence in making the decisions and whether case law was used as a reference. This study used randomised vignettes with randomised factors in each. Participants were asked whether they considered the situation a deprivation of liberty and indicate how confident they were about it on a scale of 1 – 10. They were then asked whether recent case law had affected their decision and if so, in what way. Two local authorities were recruited to the study and 93 participants responded. The participants consisted of experienced professionals: nurses, social workers, and occupational therapists. Overall, the judgements were made with a high level of confidence and there were no statistically significant differences associated with the variables of gender, age, ethnicity, and profession, with the exception of number of years in post. DOLS were generally welcomed albeit with concerns about the clarity of making judgements.

Howarth *et al* (2014) utilised a mixed methods study to explore if people with dementia experienced forced care and discussed the concept of the MCA in the discussion. The survey was given to staff in the first section of training and there were 86 staff that returned the survey who worked in older adult care homes or in people's own homes. The survey included a definition of forced care and asked staff to report the frequency with which they used the examples of forced care indicated. The results suggested that forced care is used, in the form of helping someone to eat and drink or preventing someone from leaving a building. It was the first survey on the use of forced care and the authors felt that it raised concerns. This is perhaps similar to the criticisms raised about the failure to appropriately apply the MCA and BI standards; that the concept and practice of forced care may indicate a lack of insight into the legislation that governs care interventions. The authors raised concerns about the frequency in which capacity assessments and best interests determinations were reported and questioned the level of training staff have.

Poole *et al* (2014) completed a qualitative study that related to people living with dementia and hospital discharge. This ethnographic study related directly to the MCA and BI standards and people with dementia being discharged from hospital into alternative care settings than from which they were admitted. The study, which included 92 interviews with key stakeholders concluded that capacity assessments were complex, and that more training was required as well as more advocacy for people with dementia. Basically, the findings demonstrated that the ethical aspects of beneficence outweighed the rights of the person with dementia in that professionals and carers were concerned about risk, which determined the decision. The researchers acknowledged that this was an understandable concern for decision-makers as ultimately, they wanted the person to be safe, but the ethical dilemma was posed where it was undermining self-determination. This study considered other studies that have explored the practical application of the MCA but do not explore hospital discharge. The implications for practice here being the need for more specific training around the importance of functional as opposed to outcome assessments of capacity and the need for further research to establish how change can be achieved.

Clarke *et al's* (2015) study was not specifically related to the MCA, BI or dementia but the MCA was mentioned in the study, with respect to the compliance with the CRPD. Best interests were discussed in respect of the formalised process of decision-making. The study did not focus on MCA assessments or BI meetings but the routine clinical practice of a team. The study consisted of an observation of a multi-professional team over three months and a retrospective study of records, of which there were a range of patients, of various ages with mainly cancer or stroke but there were some patients with neurological conditions, including dementia. Only a small number of the patients had no capacity or unclear decision-making capacity. The discussions concerning CANH for patients lacking decision-making capacity were complex and multi-faceted, including topics such as risks, burdens and benefits, treatment goals, ethical values and interested parties. The study did not address the multiple decision-makers or decision points, which is acknowledged as part of the limitations. The observed team utilised principles of beneficence and non-maleficence in group reasoning, linking back to the ethical principles of their routine practice and the complexity of decisions that needed to be made.

A Delphi study completed by Clerk *et al* (2018) considered the application of the MCA and DOLS with practitioners from a range of professions, including GPs, nurses, social workers, physiotherapists and occupational therapists. A Delphi study gathers the views of experts on an area of interest (Barret and Heale 2020) and this study's aim was to generate a consensus of opinion with the first round including 98 participants from six professional groups. The authors suggested that application of the MCA is complicated and nuanced, requiring time for reflection to avoid paternalistic clinical interventions. The authors also felt that a Delphi study was uniquely suited to the application of the MCA and DOLS and that the findings presented a more developed understanding of the complexities and challenges faced by practitioners. The Delphi study found that participants did not respond consistently to the scenarios used but disagreed most significantly when patient decisions conflicted with clinical advice. In the first round, there was a fair degree of consensus about the need for a best interests assessment but a small group of professionals made up of nurses, OTs and physiotherapists were of the view that best interests decisions should be made for patients regardless of whether they had capacity. They were of the view that the decisions made by patients in these situations were detrimental to their wellbeing and therefore unwise. Round two sought to refine the findings from round one and the questionnaire was reduced to three scenarios, focusing on the one with least consensus. In this round the point at which the assessment is triggered was identified inconsistently by participants. The study identified that practitioners struggle to identify when to assess capacity and when an unwise decision conflicts with clinical advice. The analysis of the study suggested that a lack of understanding underpinning the law and the complexity surrounding issues such as capacity, best interests and DOLS was evident and further research is need to understand the challenge of transferring aspirations into practice to achieve a more comprehensive consensus in health and social care.

Carter *et al* (2018) also conducted a study specifically around advanced dementia to inform education and further research. The study used semi-structured interviews to evaluate the preparedness of family carers in making best interests decisions relating to advance care planning on behalf of people with advanced dementia. Part of the study was a Randomised Control Trial (RCT) where nursing home resident records were reviewed to identify the family member who was the principal decision-maker. The themes identified from the interviews were around knowledge and understanding of dementia, accessing support from others and the caring experience (including being the decision-maker). The authors felt that the findings had implications for nursing practice and the education of healthcare staff and service users. The findings identified the need for peer support for family carers to prepare them for best interests decisions and that training was needed for healthcare staff to facilitate the decision-making processes. This research was not focused on nurses' decision-making but the factors that influence carers' decision-making was valuable to compare findings.

Scott *et al* (2018) conducted a qualitative study, using interviews looking at decision making for people with dementia and advanced kidney disease. They conducted sixty semi structured interviews with multi-professional team members across nine renal centres in the UK. The themes identified from the secondary analysis of data were factors taken into consideration during decision making and the process of decision making itself. Best interests meetings were generally favoured as long as they involved family members and there was significant focus placed on advance care planning. This study did not consider the criticisms directed towards the application of the MCA but did consider the factors that professionals examined when deciding whether dialysis was an appropriate intervention for the person with dementia. Aspects such as co-morbidity, social support, quality of life and the feasibility of treatment were factors that informed clinicians' decisions. This study was useful to inform the review as it explored factors that influence best interests considerations.

Lastly, Rogers and Bright (2019) used vignettes to investigate the approaches of different groups of assessors to the MCA assessments required as part of DOLS. Three groups were interviewed about the factors that may influence their capacity assessments. Most assessors did not refer to the two-stage test of capacity and they suggested that judging a person's ability to weigh-up information is a subjective and value-based exercise, which is given pseudo-objectivity by the language of the MCA. There were elements of good practice identified by this study, including the importance of relationship building, having access to full information and taking practicable steps to support the person to make their own decision. The authors felt that the findings were relevant to those working in health and social care for designing and delivering training, to policy makers involved with reforming DOLS regulations and to other countries with similar legislation.

With this themes, it was apparent that best interests processes are challenging and complex, not something that practitioners are highly confident in and again, education and training would be valuable to increase confidence and improve practice. In answering 'What is understood about nurses knowledge and application of the Best Interests Standards when making decisions on behalf of a person with advanced dementia?' there are gaps as the studies focused on a range of practitioners as well as carers. Many decisions relating to best interests focused on deprivation of liberty, although there were some that focused on clinical aspects of care or more routine day to day decisions. It appears that regardless of the decision to be made, there are challenges for decision-makers and influencing factors relate to establishing what the 'incapacitated person' would want or how the decision-maker might expect them to decide.

3.3 Support mechanisms

Effective training and support on the MCA (2005) and how to apply its principles in practice is essential and a better understanding of what training and support increases compliance with the legislation could improve outcomes for people who may lack capacity to make a decision. The literature has identified gaps in education and training and that confidence in MCA and best interests is not correlated with experience but that direct experience does enhance confidence. Therefore, it is worth exploring what other support mechanisms are evident in the literature. Dunn *et al* (2007) suggested that empirical research is required to further explore the concept and procedures of best interests. This was at the outset of the implementation of the legislation, yet more contemporary literature still recommends that further studies are required. In reviewing the exiting literature Marshall and Sprung (2016a) established that real-life scenarios are advantageous to allow people to link theory to practice. The top five categories reported by Marshall and Sprung (2016b) that enhanced confidence in assessing mental capacity were the benefit of having previous experience and having a good knowledge of the MCA, having enough time, receiving support from a colleague and good knowledge of the patient. Conversely, the factors that reduced confidence were a lack of time, not knowing the patient well, a lack of previous experience, fear of getting it worse and a lack of knowledge of the MCA (p. 617).

Martin (2015) acknowledged that GPs struggled with some decisions for patients with advanced dementia and would benefit from a clinical decision-making model incorporating the principles of best interests decision-making. Wade and Kitzinger (2019) also gave some guidance about the process of best interests, to facilitate an appropriate outcome in line with the legislation. They suggested, with reference an aide memoire that formal and lengthy best interests meetings could be relatively rare. The aide memoire discussed initiating the process, recognising need, preparation (information about the person), preparation (clinical information and organisation), and lastly, the meeting.

The evidence reviewed in the development of the NICE (2018) guidance often referred to training and support, very few studies looked at this area but some evidence suggested that practitioners did not always understand the requirements of the legislation and that their practice did not always comply with the requirements. There was no good quality evidence evaluating the effectiveness of training and support in relation to the legislation. (NICE 2018 p. 37). The NICE (2018) recommendations for research are: training and support for practitioners, interventions to support and improve decision-making capacity for treatment, advocacy and support for decision-making, mental capacity assessment tools, and the components of a mental capacity assessment. The recommendations for training and support are detailed and suggested that service providers develop policies and tools to support practitioners and ensure that practitioners undergo training to help them apply the MCA and COP. They suggested that training be tailored to the role and responsibilities of the practitioner, for all levels and fields of staff and include topics such as the principles, consent, communication approaches, role clarity (including IMCAs), ethical issues, aspects such as Advance Planning, LPAs and ADRTs, best interests decisions, and signposting (p. 8).

3.4 Gaps in the literature

Before the MCA was implemented, the MHF completed a study to explore decision-making by people who may lack capacity to consent to acts of care and treatment (Myron *et al* 2008). The findings included an overwhelming desire amongst staff for more training and guidance on the issue of mental capacity and its assessment. The concept of best interests was the most common reason given by staff to initiate a capacity assessment and it was suggested that this confusion about the order of assessment of capacity and initiation of best interests consideration would be reduced by the implementation of the legislation. The key recommendations were to implement a coherent strategy for training, support to apply the legislation in everyday practice and more resources in place to support service users to make their own decisions. A study by Manthorpe, Rapaport and Stanley (2009), also conducted before the implementation found that legislation was widely regarded to be a way of empowering people, although the potential for coercive decision-making, particularly in best interests was also acknowledged. Subsequent studies conducted continued to correlate with these studies completed before the legislation was implemented.

The empirical data reviewed in the literature review considers whether knowledge of the MCA and BIS is sufficiently developed in practitioners who have a responsibility to apply the legislation in practice. The consensus appears to be that it is not (Willner *et al* 2011; 2012; 2013; Phair and Manthorpe 2012). It also appears that, despite the age of the legislation, application in practice remains an issue. There are studies that explore what professionals think about the legislation but few that explore thought processes when applying the legislation in practice, or to certain cases. There is the case for more research to be conducted (Poole *et al* 2014).

Taylor (2015b) acknowledged that there is limited knowledge by practitioners of the MCA, that there are persistent gaps in knowledge, and in respect of best interests, there is a lack of clear understanding from both health practitioners but also within the legal profession. She suggested that MCA training needs to be reviewed so that it builds knowledge and that further research is conducted to understand the factors that influence practitioner behaviour in relation to upholding individual rights to autonomy. Emmett *et al* (2013) recognised that there is a lack of judicial guidance and a lack of research on how current standards are applied.

In respect of gaining perspectives of nurses on their considerations in relation to best interests decision-making, empirical studies from Luke *et al* (2008) and McDonald *et al* (2010) considered the perspectives of professionals in relation to decision-making. Of all the empirical studies, three focused on nurses alone, so the gaps are nurses specifically. What also appears to be missing from the research is how knowledge might be demonstrated through the responses to situations or in practice. There has been scant documentation about how mental capacity is assessed and the process by which best interest are determined (Regan and Sheehy 2016), which could be considered as evidence of existing knowledge of practitioners. The study by Shepherd *et al* (2018) suggested there is confusion and uncertainty about the role of best interests in research involving adults who lack capacity and they judged ambiguity in the answers to their survey as discordant with the legal frameworks and therefore a failing in knowledge. Wade and Kitzinger (2019) offer reasons why the legislation has been poorly applied, they suggested that it is difficult to understand, there is ignorance of the law, a fear of allowing death and uncertainty about validity of ADRTs.

3.5 Summary

In this chapter, the search question and strategy was defined and inclusion/exclusion criteria specified to generate the literature. The literature was then critically appraised to establish its value in establishing what is understood about nurses knowledge and application of the Best Interests Standards when making decisions on behalf of a person with advanced dementia. The literature review demonstrated that there is a paucity of research in respect of nurses' experience of best interests considerations for patients with advanced dementia. In summary, the literature review identified that:

- The BIS within the MCA was both warranted and honourable in intention but the lack of an agreed definition resulted in inconsistencies in decision-making.

- The approach to best interests decision-making by professionals remained inconsistent, leading to poor outcomes for the individuals who should benefit from the legislation.
- The inconsistencies in practice stemmed from a lack of knowledge and understanding of the legislation and its application in practice.
- The lack of knowledge and understanding was evident across all fields of health and social care, except for professionals who work in specialist areas.
- The values attached to decisions are influenced by wider social norms and the values of the decision-maker.
- There is a lack of contemporary empirical research on the perceptions of people involved in or affected by best interests decision-making processes.

The discussion around best interests tends to be about notions of welfare and well-being (Herring and Foster 2012). The COP acknowledges that best interests is difficult to define and even though it sets out mechanisms to attempt to ensure that factors are considered when approaching a situation, there is no definitive way of ensuring that the decision made is indisputable by some agent. The fact that the approach suggested in the COP is one of flexibility reinforces the suggestion that the best interests approach is inconsistent by its very nature. It is impossible to apply identical application of guidelines to diverse situations, therefore the decisions made were equally ambiguous; no-one can say for sure that they are truly in the best interests of the patient for whom they are made. The literature provided evidence that there was a lack of confidence with various professionals in applying the legislation in practice and with best interests as part of the legislation, the lack of confidence is reflected in the BIS. There was also evidence that professionals lack comprehensive knowledge of the legislation, for instance a lack of clarity of the concept of best interests. However, there was little evidence about how well nurses understand and apply the BIS, what factors they considered when they made best interests decisions and how their perspectives of advanced dementia related to these decisions.

Appendix 9 gives details of the literature reviewed for the study. In reviewing research conducted in relation to the MCA (2005) and best interests, it was apparent that continued research is required to inform continuing practice and guidance in the application of the legislation. Best interests determinations are a significant factor in the MCA and in professional practice and it has been highlighted that there are improvements required (HOLSC 2014). Analysis of best interests determinants will be informative and helpful, particularly if there are recommendations to be made that will guide and improve practice. The proposed research continues from previous studies where issues of best interests have been explored and it will investigate if the horizon of knowledge, understanding and interpretation of capacity and best interests.

The consensus from both the literature, and more contemporary research suggested that best interests determinations do not adhere to the legislation with appropriate regard. For instance, best interests decisions are often clinically driven, professionals pick and choose when to involve family members and the principle is often used as a tool to justify safeguarding decisions (HOLSC 2014). The literature review identified that there is little UK research in understanding or knowledge of the legal frameworks underpinning best interests decision-making by health and social care professionals. Although healthcare professionals are deemed to have the medical knowledge and expertise to influence decisions made in the best interests of patients (Wrigley 2007), the practice surrounding best interests decision-making is criticised as paternalistic and exclusive, placing vulnerable people on the periphery of the decision-making process (HOLSC 2014). It is apparent that more contemporary research is required to inform continuing practice, guidance in the application of the MCA

(2005) and, as part of that legislation, the BIS as well as education and training needs in the legislation. The existing literature supports the development and implementation of legislation to support best interests determinations for incapacitated adults but acknowledges that the body of research is scant (Series 2015; Emmett *et al* 2013; Wade 2019). The best interests approach is criticised as being inconsistent and there is a suggested lack of knowledge of the legal frameworks (HOLSC 2014).

The proposed research will build upon existing research to carry forward previous studies where issues of best interests have been explored and it will add to the body of knowledge about the influencing factors relating to nurses' perceptions of their practice in best interests decision-making for people with advanced dementia. It will do this by identifying emerging issues through exploring knowledge and practice discussed in interviews, where nurses identify the factors that inform their decision-making on behalf of patients that lack capacity to complete the decision-making process themselves (namely, those with advanced dementia). The next chapter will explain the methodology used to answer the research question that was confirmed from the methodical search of the literature and how the study was planned and conducted.

Chapter Four
Methodology, methods and procedures

Introduction

Research methodology is the foundation upon which the research is built. It is a systematic way to analyse and investigate a problem and therefore it is necessary for a researcher to design a methodology for the problem chosen and the questions posed, and to know both the methodology and the methods necessary for the research (Rajasekar, Philominathan, Chinnathambi 2013). To provide rigour and reliability in research and generate results that are practically applicable, it is important to consider research design seriously and attentively (Gorard 2013). The literature identified in chapter three was primarily qualitative in nature and used methods for data collection such as interviews, focus groups and questionnaires. Vignettes were also prominent in the literature search, as a platform to generate questions for the interviews or questionnaires. The various designs and methods that were prevalent in the literature informed the design of the study as the approaches were found to have been valid and effective to explore the concept of MCA and best interests. There were limitations with each of the studies but the integrity with which the limitations were presented helped to inform the design of this study with the intent to minimise the limitations where possible. This chapter outlines the methodological approach followed to address the research questions that were developed in response to the literature review and the identified gaps. The research design will be identified and discussed, including details of the methods utilised, the tools for data collection, sampling strategy and the steps taken to analyse the data. Ethical considerations, validity and reliability of the study will be considered, and the chapter will conclude by summarising the key aspects of the methodology and reflecting on the whole process.

4.1 Considerations from the literature review informing the research

The literature review confirmed Shepherd *et al's* (2018) assertion that there is little UK research in health and social care professionals' understanding or knowledge of the MCA in relation to best interests decisions. Expert evidence in respect of best interests will inevitably play an important role in health and welfare decisions. However, under the Best Interests Standards (BIS) introduced by the MCA, it cannot be determinative (Donnelly 2011). Healthcare professionals have the clinical knowledge and expertise to influence decisions in the best interests of the patients that they care for, but it is worth considering if nurses have insight into the challenges they might anticipate in respect of decision-making and how they attempt to resolve the challenges.

Previous studies have shown that knowledge of the concept of what constitutes best interests is limited, for many professionals groups, not just nurses. In contrast, this study views nurses' knowledge from a different perspective; it aims to explore the factors that contribute to nurses' decision-making when evaluating what is in the best interests of a patient with dementia. Patients encounter nurses in a different way to other healthcare professionals, unlike other clinical staff, nurses have an almost constant presence with patients in their care and are in the same territory with each other (Quinn 2022). For this reason, it is worthwhile to explore nurses' perspectives in relation to the patients with advanced dementia and how they consider their best interests. The gaps identified in the research were the lack of contemporary empirical research in perceptions *of* and experiences *in* decision-making for incapacitated patients. For instance NICE (2018) recommended more research on whether a person's cultural background, ethnicity or religion influences best interests decisions or capacity assessments (p.38). This study addressed this gap by exploring nurses' perceptions of decision-making on behalf of people living with advanced dementia.

4.2 Research question

As mentioned in chapter one, when research in relation to the MCA (2005) and best interests was reviewed, it became apparent that continued research was required to understand practice. How nurses deliberate about best interests in dementia and their understanding and interpretation of capacity is an important concept to explore.

The over-arching question of the study was:

- What factors do nurses consider when determining best interests for patients with advanced dementia?

The literature that suggested knowledge is poor in relation to MCA and best interests focus on a legalistic interpretation of the legislation. In contrast, this study focuses on broader knowledge of best interests and application of that knowledge; knowledge that would be defined as tacit rather than explicit. Two further questions were also utilised to explore the how well nurses understand and apply the BIS and what their concerns about applying them are:

- What procedural and substantive considerations do nurses identify when making best interests decisions?
- How is knowledge of the Best Interests Standards demonstrated?

As the literature also identified that education and training was inadequate and that professionals themselves had identified the need for additional education and training, a third sub-question arose:

- What support mechanisms are helpful for nurses in relation to undertaking best interests considerations?

4.3 Research paradigm

Paradigms are patterns of beliefs and practices that provide lenses, for viewing and interpreting significant substantive issues to the discipline (Weaver and Olson 2006). Or, as described by Kivunja and Bawa Kuyini (2017), a conceptual lens through which a researcher determines the methodological aspects of their research project to determine which methods will be used and how the data will be analysed. Indeed, one of the first requirements when planning research is to establish which paradigm and subsequently which methodology or strategy can best answer the research question according to Welford, Murphy and Casey (2011). A researcher needs to ensure that aims and methods are integrated with the epistemology and ontology and using an established paradigm can be beneficial for ensuring congruence (Houghton, Hunter and Meskell 2012). Weaver and Olson (2006) further define paradigms as sets of philosophical underpinnings from which specific research approaches (e.g. qualitative or quantitative methods) flow and they explain that the main paradigms that have been used for nursing research are positivist, postpositivist, interpretive and critical social theory. There are differing views of research paradigms, with some researchers considering more than the four proposed by Weaver and Olson according to Welford, Murphy and Casey (2011). Cresswell and Poth (2018) for instance mention interpretive frameworks of postpositivism, social constructivism (interpretivism), transformative, pragmatism and critical theories or theories of race, feminism, queer and disability.

4.3.1 Interpretivism

In respect of research paradigm, the preferred approach was interpretivism, as from the paradigms available, interpretivism more closely matched the aims of the research. A traditional view of interpretivism is that it is a blanket term for a collection of 'qualitative' approaches that share the philosophical belief that human behaviour can only be understood when the context in which it takes place and the thinking that give rise to it are studied (Parahoo 1997). The view of qualitative approaches and interpretivism as synonymous or interchangeable terms is defended by Bhattacherjee (2012) and continued by Parahoo (2014). However, Denzin and Lincoln (2017) state that qualitative research has no paradigm that it is distinctly its own and that multiple theoretical paradigms claim use of qualitative research methods and strategies. Bhattacherjee (2012) suggested that if researchers believe that the best way to study social order is through the subjective interpretation of the participants involved, then they are applying an interpretivist paradigm. The interpretivist paradigm tries to understand what the subject is thinking or the meaning they are making of the context, to understand the viewpoint of the subject being observed, rather than the viewpoint of the observer (Kivunja and Bawa Kuyini 2017). Denzin and Lincoln (2013) state that all research is interpretative, guided by a set of beliefs and feelings about the world and how it should be understood and studied (p. 19). They combine the interpretivist paradigm with constructivism, which is also supported by Cresswell and Poth 2018). In social constructivism, according to Cresswell and Poth (2018) individuals seek understanding of the world in which they live and work by developing subjective meanings of their experiences, which are varied and multiple and lead the researcher to look for the complexity of views. They explain further that researchers 'position' themselves in the research, acknowledging that their own background shapes their interpretation and that researchers make an interpretation of what they find, shaped by their own experiences and background. The research aim, as defined in this chapter is to explore the factors that nurses consider when making best interests decisions for people with advanced dementia. It aims to explore their knowledge of the concept of best interests and the processes they are aware of to define them, the support mechanisms they identify and to understand the viewpoint of the research participant, developing subjective meanings of their experiences, which aligns to the interpretive or social constructivist paradigm.

4.3.2 Ontology

Cresswell and Poth (2018) discussed four philosophical assumptions in relation to research: ontology, epistemology, axiology and methodology. They explain that the ontological issue relates to the nature of reality and when researchers conduct qualitative research, they are embracing the idea of multiple realities. The interpretivist paradigm has a relativist ontology (Denzin and Lincoln 2017; Levers 2013), which means that there is no shared reality, only a series of different individual constructions. Relativism is one of two ontological positions: realism and idealism and relativism is considered a nuanced perspective stemming from idealism (Ormston *et al* 2013). Many contemporary qualitative researchers share the view that the social world is different to the natural world because human beings have agency and therefore have choice about what they do, rejecting the idea that fixed ‘laws’ govern the social world as they are thought to govern the natural world (Ormston *et al* 2013).

Kivunja and Bawa Kuyini (2017) suggested that assumptions about the nature of reality are crucial to understanding the meaning of the data that is gathered and how the researcher makes meaning of the data. They say that the ontology seeks to determine the real nature which constitutes themes that are analysed and makes the researcher ask questions such as whether reality is out there in the real world or a construction created in a person’s own mind, the result of individual’s cognition. They add that the assumptions about reality help the researcher to orientate their thinking about the research problem and how it is possible to answer the question. The interpretative approach, and the relativist ontology were both appropriate for the planned study as the research aim was to explore perspectives of individuals, to consider the factors that might influence practice, as their practice has the potential to be influenced by their own experience.

4.3.3 Epistemology

The epistemology modifies the methodology and justifies and evaluates the knowledge generated (Petty, Thompson and Stew 2012). Epistemology refers to the assumptions about the best way to study the world and whether an objective or subjective approach is best to study social reality (Bhattacherjee 2012). Interpretivism acknowledges a subjectivist epistemology where the knower and the participant co-create understandings (Denzin and Lincoln 2017) and the researcher needs to be aware of the impact his or her perceptions can have on the research (Houghton, Hunter and Meskell 2012). Interpretive researchers view social reality as impossible to abstract from social settings and rather than hypothesis testing, reality is interpreted through a ‘sense making’ process (Bhattacherjee 2012). Because of the assumptions that individuals develop their own subjective meanings of their experiences (as in interpretivism), knowledge of the reality involves understanding the multiple views of people in a particular situation (Petty, Thompson and Stew 2012).

Ormston *et al* (2013) suggested there are three epistemological issues to consider, the way in which knowledge is acquired, the relationship between the researcher and the researched and what is considered as truth. The first issue of how knowledge is acquired relates to the inductive or deductive reasoning and though simplified, qualitative research is often depicted as an inductive process. This process occurs through a ‘bottom-up’ process where the world is observed and evidence is collected to build theories, rather than a deductive approach where a hypothesis is developed, and evidence is collected to support or refute the hypothesis. The second issue relates to objectivity and subjectivity of the researcher, where some researchers consider that an objective approach is achievable if the researcher adopts a model where the phenomena being researched is independent of the behaviour of the researcher. Other researchers believe that people are affected by the process of being studied and that the relationship between the researcher and the social phenomena is interactive, the researcher cannot be neutral and cannot therefore be objective. This is supported in some ways by Welford, Murphy and Casey (2011) who consider the epistemology of some qualitative methodologies as being both subjective and objective, particularly with interpretivism or constructionism. The third epistemological issue according to Ormston *et al* (2013) is the focus on what it means to accept claims as accurate or ‘true’ and the more appropriate approach for the study of the social world is the assertion that reality can only be gauged in a consensual, rather than an absolute way.

Taking into account these three issues, the epistemology of a qualitative, interpretative approach with a relativist ontology is likely to be subjective as the phenomena being explored is observed and evidence collected to build theories that are derived from the subjective experience of the participants, developing understanding and meaning from multiple perspectives.

4.3.4 Axiology

Axiology addresses questions related to what is valued and considered to be desirable or ‘good’ for humans and society (Biedenbach and Jacobsson 2016). It refers to the ethical issues that need to be considered when planning a research proposal and considers the philosophical approach to making decisions, defining, understanding, and evaluating behaviour relating to research (Kivunja and Bawa Kuyini 2017). Cresswell and Poth (2018) state that qualitative researchers make their values known in a study and that this is the axiological assumption; the researcher openly discusses the values that shape the narrative and they include their own interpretation in conjunction with those of the participants.

Berger (2015) suggests that axiological components of research involve reflexivity and positionality, where reflexivity is the process of internal dialogue and positionality being part of the reflexive process, considering personal characteristics, biases, ideological stances, and emotional responses to the participants that impact the research. This supports the idea that axiology relates to the values of the researcher and how these values influence the interpretation of the study. Dawes Farquhar (2012) explains that interpretive researchers believe that values help determine what are facts and the interpretation that are drawn from these facts and that they acknowledge the potential for bias but explain and address it as a feature of the research. This supports Berger's (2015) point that the reflexive process produces subjective knowledge that is created through recognition of one's own situatedness in the study. Axiology has relevance to qualitative research as it provides the foundation for understanding the process of the addition on knowledge involved in scientific inquiry and has a direct bearing on the ethics of the research (Given 2008).

4.4 Qualitative research

Qualitative research uses words as data, collected and analysed in all sorts of ways (Braun and Clarke 2013). Qualitative research can be referred to as a family of methods in which some members are more compatible with each other than with other methods but there is no 'one-size-fits-all' to make the definitional task easier (Padgett 2012). It is concerned with participants' own experiences of a phenomenon; therefore, methods should be chosen that facilitate open expression, without constraint and interviewing is one of the frequently used methods for gathering experiences, perceptions, opinions, feelings, and knowledge (Austin and Sutton 2014). Improved understanding is achieved by the iterative process of qualitative research in which the researcher gets closer to the phenomenon studied (Aspers and Corte 2019). Cresswell and Poth (2018) suggest that qualitative research is conducted to explore a problem, to develop a complex and detailed understanding of an issue by talking directly to people and allowing them to tell their stories, unencumbered by the literature or what the researcher expects to find. Padgett (2017) agrees that talking directly to people helps to delve inside the 'black box' of practice and in this way qualitative methods are an obvious choice, where the topic may be little known, a topic of sensitivity and depth and where the intention is to explore the 'lived experience'. The aim of the research described in this thesis met all of these criteria, in that the topic was sensitive (relating to people with advanced dementia requiring invasive treatment), the literature had exposed that there was a lack of contemporary research in the area and both the lived experience, and the innermost components of practice were sought. It was also sensitive in that it addressed issues that related to participants' professionalism and professional identity. Therefore, a qualitative, interpretive approach was an appropriate choice, as this methodology centres on the way in which people make sense of their subjective reality and attach meaning to it; it centres upon understanding rather than explaining (Holloway and Galvin 2016).

Qualitative research thus contrasts with quantitative research, which is concerned with the systematic and scientific investigation of phenomena and the relationship of one particular phenomena to another via the use of observations, analysis, hypothesis and measurement (Maltby *et al* 2010). Quantitative approaches are generally aligned with a positivist paradigm (Soo Park, Konge and Artino Jr 2020). Although Cohen, Manion and Morrison (2017) state that it is misguided to only equate positivism with quantitative approaches, they also say that positivism is less successful in its application to the study of human behaviour. A quantitative study looks for differences or relationships between phenomena that vary, whereas qualitative research considers the human element, perceptions and meanings that are derived from something (Maltby *et al* 2010).

The study aligns with qualitative rather than quantitative research as it aims to explore the 'lived experience' of best interests decision-making; the lived experience being how nurses' perceive the intricacies of the process through reflection on a situation where a decision is required. Highlighting the participants' own experiences of a phenomenon, encouraging an in-depth discussion of processes, leading to the extraction of meaning in context is an illustration of how a qualitative approach is compatible with the research questions.

4.5 Case study Research

4.5.1 Origins of case study research

Case study research has a history within anthropology, as far back as the nineteenth century (Johansson 2007), with the training of lawyers in the USA, and in Europe with the study of working families in France (Thomas 2021). The case study approach was increasingly adopted in the UK in the 1970s in disciplines such as public policy, as social scientists saw case study as a way to obtain comprehensive accounts of social phenomena from participants (Fàbregues and Fetters 2019). A diverse group of researchers has since contributed to the development of case study research, which has resulted in a variety of definitions and approaches (Harrison *et al* 2017).

Case study research is referred to as both a method and a methodology (Harrison *et al* 2017). Yin (2018) refers both to case study as a method and to methodological approaches without entering the debate into which case study falls. Within this study, case study is understood as a methodology, as it aligns to the interpretation from Cough and Nutbrown (2012) who suggest that the methodology persuades the reader of the connection between the research questions and the methods used to operationalise the generation of data. This means that case study is the approach used to connect the development of the research questions, the tools used to collect the data and the analysis of said data.

4.5.2 Definition of case study

Case study research is now one of the most frequently used qualitative research methodologies in educational research (Yazan 2015). The claim that the notion of 'case' in case study is complicated, ill-defined and the subject of debate (Johansson 2007) is supported by Sandelowski (2011) who states that the distinction between case study and 'not case study' research is partly a consequence of researchers deciding what that term will signal to the audiences they wish to reach. Each of the main texts on case study research (e.g. Yin and Stake) have little in common with the others (Swanborn 2010). Stake (1995) asserts that a case is studied when it is of very special interest and when the aim is to look for the detail of interaction with its contexts whilst Yin (2018) says that a case study provides the researcher with real life events in a meaningful and holistic way when the case is not distinctive in its context. A popular definition of case study research is that given by Robson and McCartan (2016 p. 150):

> *"Case study is a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real-life context using multiple sources of evidence".*

Cresswell and Poth (2018) suggest that the case study approach best fits the needs of the researcher who is attempting to develop an in-depth description and analysis of a case or multiple cases to illustrate the complexity of the issue. In respect of the proposed study, the phenomena of interest is the perceptions of nurses and the aim is to explore and perhaps understand those perceptions of advanced dementia when best interests decisions need to be made.

4.5.3 Benefits and criticisms of case study

Case study allows researchers to focus on complex situations while taking the context of the situation into account (Casey and Houghton 2010) and the complexities involved in best interests decisions are evidenced in the literature (Gough and Kerlin 2012). Case studies draw on the ability of the qualitative researcher to extract depth and meaning in context (Padgett 2017), which aligns to what Tellis (1997) suggests is one of the three tenets of the qualitative method: describing, understanding, and explaining. Conducting a case study presents a unique opportunity to focus on the developing meanings that participants in the system attach to each other, such as the views participants have, and their interpretations of events in context (Swanborn 2010). In respect of strengths of a case study approach, Luck, Jackson and Usher (2006) suggests that it fosters integration of research strategies and enables a rich and detailed description of the unit of interest due to the multiple data collection methods that can be used to explore the case.

These data collection methods/sources of evidence include (but are not limited to) documentation, archival records, interviews, physical artifacts, direct observations, and participant-observation and participant responses to a research activity instrument (Baxter and Jack 2008; Alpi and Evans 2019). Vignettes are data collection tools that provide supplementary and complementary data during a research process, where other tools such as observations or interviews are not conclusive (Barter and Renold 1999; Erfanian *et al* 2019). Vignettes are a versatile research tool in terms of their style, and if used in conjunction with other data collection methods such as interviews, they offer an additional advantage of obtaining other information from participants (Skilling and Stylianides 2020). This aligns to Alpi and Evans' (2019) assertion that responses to a 'research activity instrument' are a key data source. Baxter and Jack (2008) define each data source as a puzzle piece that that is converged in the analysis process, promoting a greater understanding of the case.

Case study research is not without its critics or its limitations (Crowe *et al* 2011). The volume of data is difficult to organise and analyse and there is sometimes a temptation to veer away from the research focus (Health and Twycross 2017). It is thought to be more subjective than other qualitative methodologies and as the ‘unit of measurement’ is not static, it can be difficult to replicate and therefore lacks scientific rigour (Crowe *et al* 2011). Flyvbjerg (2006) dismisses as misunderstandings the criticisms that case study research cannot be generalised or develop propositions, that it generates hypotheses but not theory, that the knowledge produced is less valuable because it is context-dependent and that it confirms the researcher’s preconceived notions. Johanssen (2007) also rationalises these misunderstandings by explaining that the case study researcher’s interest lies in understanding the case, rather than generalising the findings and that any generalisation occurs in a naturalistic way through the audience using analytical reasoning to apply to a general context. Issues of rigour and bias are addressed through the researcher planning their study by applying the usual caveats for rigour and validity (Riege 2003; Luck, Jackson and Usher 2006).

Duff (2012) explains that case study research seeks depth, rather than breadth and it yields insights into potentially wider relevance and theoretical significance because its goal is to particularise and not universalise. This means that by its very nature, case study research focusing on a specific phenomenon may generate findings that offer insight and understanding into a wider context than its original focus. This is supported by Riege (2003) who suggests that design tests intended to test rigour may supress the discovery of new meaningful insights of case study research and not maximise the quality of the research.

4.5.4 Philosophy of case study research

Philosophically, case study research is versatile and can be orientated from a realist or a positivist perspective, through to a relativist or interpretivist perspective (Crowe *at* al 2011; Harisson *et al* 2017). Yin (2018) admits that his book on case study research is orientated towards a realist perspective but accepts that case study research can excel in accommodating an either a realist or a constructivist approach. The philosophical position of this study is aligned with the interpretivist paradigm and therefore emphasises the importance of understanding meaning, context and process relating to perspectives surrounding best interests decision-making by nurses. Rashid *et al* (2019) suggests that a qualitative case study assumes a relativist ontology and a subjectivist epistemology, the aim being to achieve a deep understanding of the social phenomenon under study and recognising the importance of the participants' subjectivity as part of the process. This qualitative research case study is an approach to research that seeks out understanding of nurses' experiences and perceptions in best interests decision-making in the context of advanced dementia. The data resources used allow multiple dimensions of the experience to be revealed and understood and exploring the responses would provide information about processes related to a theoretical issue, the definition asserted by Yin (2018).

4.5.5 Case study design

Alpi and Evans (2019) suggest that case study methodology is evolving and regularly re-interpreted. Johansson (2007) also suggests that the kind of case on which the case study is based may change over time in the view of the researcher, the audience, or the research process. Although the central tenet to case study research, according to Crowe *et al* (2011) is the need to explore an event or a phenomenon in depth and in its natural context, which is why it remains naturalistic research rather than experimental. Carolan, Forbat and Smith

(2016) agree that the literature demonstrates a lack of clarity and guidance in designing and reporting case study research and they provide a model to approach the design, as do Rashid *et al* (2019). Rashid *et al* (2019) discuss four phases, including the foundation phase, the prefield phase, the field phase, and the reporting phase, whilst Carolan, Forbat and Smith (2016) discuss three stages of situating the research, determining the components of the design and data analysis. The elements of each of these models are similar in nature, as presented in table 4.1 below:

<table>
<tr><th>Carolan, Forbat and Smith (2016)</th><th>Rashid <i>et al</i> (2019)</th></tr>
<tr><td>Three Stages: <i>situating, determining components, data analysis</i></td><td>Four Phases: <i>foundation, prefield, field, reporting</i></td></tr>
<tr><td>Situating:
Philosophical approach
Researcher situating themselves
Ethical considerations</td><td rowspan="2">Foundation:
Philosophical considerations and paradigms
Inquiry techniques consideration – qualitative/quantitative
Research logic consideration – inductive or deductive (including theoretical frameworks)</td></tr>
<tr><td rowspan="2">Determining components:
Defining the case and its context
Purpose and conceptual framework
Choice for sampling and data sources</td></tr>
<tr><td>Prefield:
Decide – is case study the right approach?</td></tr>
<tr><td rowspan="3">Data analysis:
Congruent with the philosophical approach?
Case-based or variable analysis-based?
How is data integrated during data analysis and interpretation?</td><td>Case study protocol – question, method, permission, ethics, interpretation, and assessment</td></tr>
<tr><td>Field:
Contact – sampling
Interact – collecting data</td></tr>
<tr><td>Reporting:
Case study reporting – a sound structure for reporting, including descriptions</td></tr>
</table>

Table 4.1 – Carolan, Forbat and Smith (2016) and Rashid et al (2019) models of case study research design.

Both models require philosophical congruence, ethical practice, consideration of the case and its context, reliable sampling and data collection methods and clear analysis and presentation of findings. The anticipated research study has followed each of these steps, demonstrated within this chapter in respect of philosophy, ethics, sampling, data collection and proposed data interpretation.

Yin (2018) recognised that a traditional case study has not usually included the idea of having a formal design but he suggests that a case study should be stronger and easier to do if it has a formal design. In case study research, Yin (2018) claims five components of a research design as being especially important. These components were used to develop the study (see table 4.2):

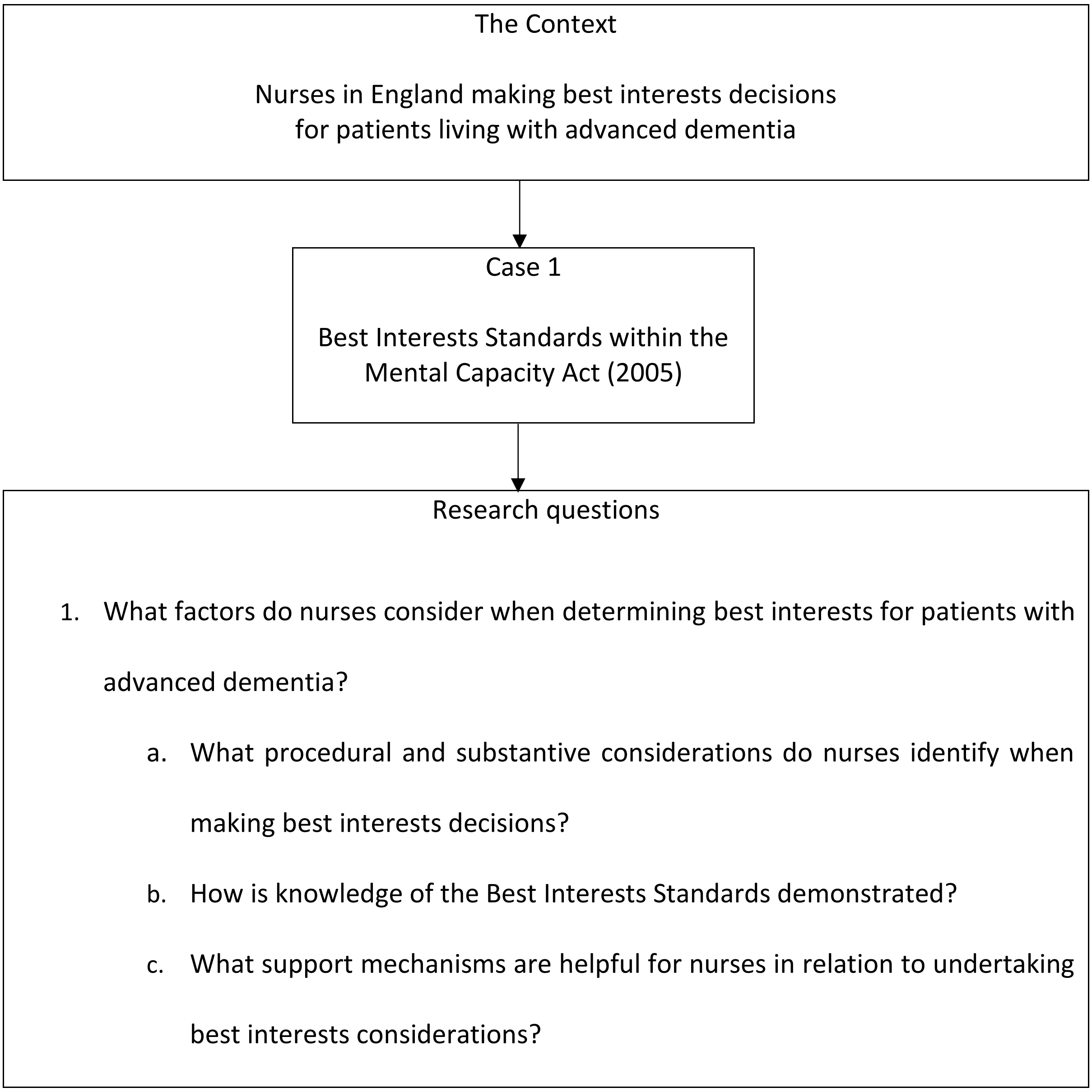
Component	Study details
1. A case study's questions	What factors do nurses consider when determining best interests for patients with advanced dementia? • What procedural and substantive considerations do nurses identify when making best interests decisions? • How is knowledge of the Best Interests Standards demonstrated? • What support mechanisms are helpful for nurses in relation to undertaking best interests considerations?
2. Its propositions (if any)	From the literature: • The MCA legislation is complex • Knowledge and confidence of practitioners in the MCA is poor • There are issues with applying theory to practice with the MCA • There are issues with education and training with MCA • There are examples of good practice • Certain factors influence best interests decisions
3. Its case(s)	• Best Interests Standards within the Mental Capacity Act (2005)
4. The logic linking the data to the propositions	• Data collection techniques that have the potential to reflect the propositions: • Offer the opportunity to demonstrate knowledge and confidence, apply theory to practice, discuss education and training opportunities, consider the complexities of the legislation, present factors that influence best interests decisions
5. The criteria for interpreting the findings (Yin 2018 p. 27)	• Devise an analytic strategy that puts information into different arrays, such as themes and sub-themes, place evidence in a matrix, create visual displays, sequencing information ○ Follow the theoretical propositions ○ Review the data to identify patterns ○ Use a descriptive framework ○ Consider rival explanations that threaten the original propositions

Table 4.2 – Yin's five components of case study research design

In a case study, the researcher is idiographically exploring the lived experience of the participants, which means that they are studying the uniqueness of individuals, in contrast to the nomothetic approach where large groups of individuals are studied (Barlow and Nock 2009). Adequate contextual description is required to understand the setting or context in which the case is revealed (Hyett *et al* 2014). Carefully formulated research questions informed by the literature and a prior appreciation of the theoretical settings and issues are important in defining the case (Crowe *et al* 2011). However, defining the unit of analysis (the case) and the boundaries of the case is a problem which confronts researchers from the outset (Yin 2018). Stake (1995) agrees, suggesting that the case will not be seen the same by everyone and Baxter and Jack (2008) explain that determining what the unit of analysis (case) is can be a challenge for both novice and seasoned researchers. The case (or object of study) should be fixed or defined and can be a person, a group, a program, an institution, a community, or a specific policy. The key to identifying the case is that it can be defined or described (bounded) within certain parameters, such as the place, the timeframe or on occasion, certain people involved in the case (Cresswell and Poth 2018). The unit of analysis can be individuals or groups (Yin 2018) and the bounds of the case can be an event (Casey and Houghton 2010). Merriam and Tisdell (2016) concur, suggesting that the unit of analysis characterises a case study, rather than the focus of the study.

Stake (1995) describes three types of case study, intrinsic, instrumental, and collective. An instrumental case best describes the proposed study, where a question needs to be answered and the question may be answered by studying a particular case. Yin (2018) presents four types of design for case studies, a single case (holistic), a single case (embedded), a multiple case (holistic) and a multiple case (embedded). If a researcher wants to study a specific phenomenon arising from a particular entity, then a single case study will allow for an in-depth understanding of the phenomenon (Heale and Twycross 2017). Thomas (2021) suggests that the single case could be the classic form of the case study but that the focus should be on the characteristics that give it interest. The study of more than one case dilutes the overall analysis due to resource limitations (Cresswell and Poth 2018). This supports the decision to design the study as a single case study as the common topic comparisons were made against was the BIS.

Yin (2018) determines the rationale for a single case study to capture circumstances of an everyday situation. For this study the situation was best interests decisions from the perspectives of registered nurses, the circumstances were the contextual factors such as knowledge and understanding of the Act and factors that influence the nurses' beliefs about patients with advanced dementia. Embedded subunits should be within or part of the original single case (Yin 2018) and an embedded single case study was considered. However, best interests is one of five principles within Mental Capacity Act (2005), which would mean the MCA would be the case and best interests the embedded sub-unit. As best interests was the primary focus a single case approach was adopted and is summarised in figure 4.1:



The Context

Nurses in England making best interests decisions
for patients living with advanced dementia

Case 1

Best Interests Standards within the
Mental Capacity Act (2005)

Research questions

1. What factors do nurses consider when determining best interests for patients with advanced dementia?
    a. What procedural and substantive considerations do nurses identify when making best interests decisions?
    b. How is knowledge of the Best Interests Standards demonstrated?
    c. What support mechanisms are helpful for nurses in relation to undertaking best interests considerations?

Figure 4.1 Summary of single case study plan

Yin (2018) describes case study as exploratory, descriptive or explanatory and suggests that a good case study researcher should pursue theoretical propositions and take advantage of the benefit of them whether for an exploratory, descriptive or explanatory reason. Inductive research is slightly more common than deductive research in case study, as the aim is to generate theory from the data and exploration and understanding is the focus (Dawes Farquhar 2012). When formulating case studies, this study reflected the guidance around exploratory case study as perceptions and experiences of nurses were being explored and the expectation was that the links to exploratory case study would become evident as the study progressed. The literature established that the use and application of the principles of the MCA (2005) was imperfect and required considerable improvement, which if taken broadly constitutes descriptive research; the 'what is going on' (de Vaus 2001). The case study approach would facilitate an in-depth analysis of the BIS as an aspect of both the MCA (2005) and decision-making. This study aims to further consider the descriptive aspect but potentially the explanatory aspect by utilising the case study approach, which provides an opportunity for one aspect of a problem to be studied in some depth (Bell and Waters 2014).

4.5.6 Case study research in nursing

Nursing research often uses case studies, and it is particularly useful when examining nursing practice given the complex elements which influence care delivery (Casey and Houghton 2010). Anthony and Jack (2009) summarise the experts in case study and discuss how qualitative case study methodology has been used to describe, explore, understand, or evaluate phenomena of interest to nursing, including experiences and perceptions of individuals or a collective.

Baxter and Rideout (2006) designed a qualitative intrinsic case study to explore the decision-making activities of nursing students, specifically factors that enhance or impede clinical decisions. They utilised journals and interviews and analysed inductively, referring to Merriam and Yin to guide the methodology. The case under study was the decision-making actions of nursing students providing care in an inpatient surgical setting. The findings were surprising in some respects but also identified the complexity and stressful nature of decision-making and the implications were in curriculum design.

Keady *et al* (2013) used a collective case study design, as per Stake's approach to explore the physical components attributed to physical domain in the bio-psycho-social model of dementia care. The case was instrumental in design and used comparative analysis to review the data. The instrumental and collective case studies revealed that the physical components co-existed alongside each other and queried if the interplay between the biological, the psychological, the social and the physical provide a platform for establishing person-centred dementia care. The use of a collective case study provided an innovative framework for investigating the research questions.

Kilpatrick (2013) designed a descriptive multiple case study using interviews and observations to describe how acute nurse practitioners affect perceptions of team effectiveness. They defined the case as the setting that the nurse practitioners practised and bounded the case by the limits of service, the reporting structure. They utilised purposive sampling and recruited participants from a range of health and social care professionals. They described Yin's approach to case study and devised a conceptual framework to present their findings. They concluded that the study had enabled an in-depth description of perspectives of providers, adding to understanding, which fulfils the brief of case study research.

These examples demonstrate how case study has been effectively used in nursing research in the areas of dementia, decision-making and exploring the perspectives of nurses. The case study method has implications for advancing nursing research, particularly nursing theory development and the generation of patient-sensitive nursing interventions (Zucker 2001).

4.6 Sampling and Recruitment

4.6.1 Sampling

Yin (2018) proposes that once a case is defined, other clarification becomes important. Defining and bounding the case can be difficult as many points of interest and variables intersect and overlap in case study research. Bounding the case is essential to focusing, framing, and managing data collection and analysis and involves being selective and specific in identifying the parameters of the case, including the participants and the process to be explored (Harisson *et al* 2017). The population for this case study was accessed from a Higher Education Institution (HEI) in the West Midlands, where the researcher was employed. Working in a Higher Education Institute (HEI) provided access to healthcare professionals from a wide area with varied levels of expertise, skills and knowledge. The ability to recruit from a large group of nurses provided the opportunity of purposive non-probability sampling. Non-probability sampling is common in small-scale research, as there is generally no intention to make a statistical generalisation to any population beyond the sample surveyed (Robson and McCartan 2016). Purposive sampling provides a wide range of non-probability sampling techniques for the researcher to draw on (Sharma 2017).

Purposive sampling is typically used in qualitative studies (Suen, Hang and Lee 2014) and happens when the participants' characteristics are defined for a purpose that is relevant to the study (Andrade 2021). Researchers who use purposive sampling carefully select participants based on study purpose with the expectation that each participant will provide unique and rich information of value to the study (Suen, Hang and Lee 2014). The researcher decides what needs to be known and sets out to find people who can and are willing to provide the information by virtue of knowledge or experience, which involves identification and selection of individuals or groups of individuals that are proficient and well-informed with a phenomenon of interest (Etikan *et al* 2016).

Purposive sampling is used when particular people are chosen because they provide the best perspectives on the phenomenon of interest (Gray 2014). The sample were students on post-registration courses at the University as they were accessible for invitation to participate and fulfilled the criteria, which were:

- Registered Nurse

- Some experience of working with patients living with advanced dementia in their post-qualifying career.

The reason for the inclusion criteria was primarily linked to the research aims and to the community of practice: the researcher is a registered nurse and was interested in exploring the thoughts of other nurses. The participants were also approached because they met the recruitment criteria of being registered nurses with some experience of nursing people with advanced dementia, or with an interest in dementia. Purposive sampling can be highly prone to researcher bias and it can be difficult to defend the representativeness of the sample (Sharma 2017). The findings of a study based on purposive sampling can only be generalised to the population from which the sample is drawn and not to the entire population (Andrade 2021).

Sample generalizability depends on sample quality, which is determined by the difference between the characteristics of the sample and the population the sample was selected from. The less representative the sample, the less generalizable the findings (Check and Schutt 2012). They recommend adhering to a set of guidelines to ensure that a purposive sample adequately represents the setting or issues studied; make sure the informants are knowledgeable, willing to participate and representative of a range of perspectives and that the researcher continues to interview until they learn little that is new from each subsequent interview (saturation) and they achieve an overall sense of the concept (completeness). Etikan *et al* (2016) suggest that purposive sampling does not need a set number of participants and Suen, Hang and Lee (2014) state that sample size is determined by data saturation, which seemingly aligns to what Check and Schutt (2012) recommend. Sharma (2017) proposes that the various purposive sampling techniques have different goals and can provide researchers with the justification to make generalisations from the sample that is being studied.

In respect of case study research, Thomas (2021) suggests that ‘samples’ and all the assumptions about them are not necessary in case study research. The point is not to find a portion that shows the quantity of a whole as the aim is not to represent the wider population. He suggests that the population is more of a selection and should show the quality of the whole. This is also supported by Check and Schutt (2012), who state that although purposive sampling does not produce a sample that represents some larger populations, it can be exactly what is needed in a case study of a clearly defined and relatively limited group.

4.6.2 Recruitment

The HEI was an appropriate site to establish a purposive sample of registered nurses who at some point have nursed patients living with dementia, which was the only pre-requisite. Cohen, Manion and Morrison (2017) state that the quality of a piece of research stands or falls by the suitability of the sampling strategy, meaning that credibility is reduced if the sampling strategy is not carefully formulated. Therefore, to enhance rigour, care was taken to clearly identify the research participants as nurses who were studying at the HEI. Appeals for participants were initially made via posters (appendix 10) displayed in post-registration sessions and on the virtual learning environment. A sample size of thirty participants was initially identified, with the possibility of increasing numbers if data saturation was not achieved. Participant information and consent are discussed in 4.9. Sample size in qualitative research is generally smaller to enable the depth of case-oriented analysis (Vasileiou *et al* 2018). It is a challenge with interviews to establish when data saturation has been achieved. If participants are individuals and are contributing to the research in isolation, then it is expected that their responses will be as individual as they are. Data saturation is defined within the literature as further data collection and/or analysis being unnecessary based on the data that have been collected or analysed thus far (Saunders *et al* 2017).

Tran *et al* (2016) suggested that data saturation is an elastic notion, there is no quantifiable guide on participant number and new data will always add something new, but there are diminishing returns. This becomes apparent to the novice researcher as the data is transcribed, interpreted and analysed. Data saturation and its meaning becomes clearer as the value of the participants responses begins to take shape, making the concept of data saturation more concrete. Ishak and Bakar (2014) define saturation as the point at which no new information is awarded to the researchers by any new participants or if repetition of stories occurs among participants. Prior to the interviews, it appeared that data saturation would be a difficult concept to judge; however, in practice, transcribing and analysing the data in parallel with conducting the interviews meant it became more obvious, with the value of the participants' responses beginning to take shape, making the concept of data saturation more concrete and recognisable.

4.7 Data collection

Each case should have a pre-defined boundary which clarifies the types of evidence to be collected and the priorities for data collection and analysis (Crowe *et al* 2011). Data collection was completed in 3 ways:

- Participant details
- Vignettes
- Semi-structured interviews

4.7.1 Participant details

The participant details were collected anonymously in that there were no names on the form (appendix 11). The form included ethnicity, age, gender, when they qualified as a nurse, the field in which they work and the region in which they work. Background/demographic questions are generally asked if they are relevant to the research study (Merriam and Tisdell 2016). Additional data was collected on the participant details as well as the demographic data.

One question asked any type of training undertaken in the MCA (e.g. mandatory e-learning) and how recently this was completed. The question on training was to establish if the participants had received any training in the MCA that might enhance their knowledge in the topic. Within the literature, some participants had denied receiving training in the MCA (Samsi *et al* 2011) and if this was the case a lack of knowledge may correlate with a lack of training.

Participants were also asked whether they had recently cared for someone with dementia. Although this may be discussed in the interview if the participant raised it, there was no guarantee that they would identify as a carer. As there are 700,000 friends and family caring for a person with dementia (Alzheimer's Research UK 2015), it was helpful to establish if the participants were representative of this and whether responses were influenced by the fact that they were or had been a carer of a person living with dementia. There may be a richness of data achieved from participants who have personal experience on which to draw for their responses to the vignettes and the interview questions. Data collection methods should be carefully constructed to generate rich data (Ogden and Cornwell 2010) and it was hoped that combining the vignettes, the interview questions and the opportunity to reflect on training and possible caring commitments would generate rich data in the case study.

There were also two questions asking the participant to self-rate their level of knowledge in the MCA and in the principle of best interests on a scale of 0 – 10 (poor – excellent). In the literature, staff identified that they wanted additional education and training on the legislation and self-identified reduced knowledge and confidence in applying the legislation in practice (Alonzi, Sheard and Bateman 2009; Wilson, Seymour and Perkins 2010; Samsi, Manthorpe and Rapaport 2011). These questions were to establish a baseline of how participants rated their own knowledge, to correlate with any relevant responses to the questions.

4.7.2 Vignettes

Vignettes provide sketches of fictional (or fictionalised) scenarios (Bloor and Wood 2011), where participants are asked to comment on how they feel they would have acted or how they feel a third party should act (Brewer 2011). They are described as short stories about a hypothetical person or persons, used in both qualitative and quantitative research, to glean information about participants' own set of beliefs (Gourlay *et al* 2014). Vignettes allow for context to be specific, so that participants can make observations about the topic in question rather than simply expressing general thoughts. They should contain precise references to the most important factors in the judgement-making processes of participants and provide a stimulus for discussion about real-life. (Alexander and Becker 1978). Vignettes provide realistic situations from which to extrapolate beliefs about specific circumstances. They allow for features of the context to be specified, so that the participant is invited to make statements about a set of social circumstances, rather than expressing their beliefs in a vacuum (Finch 1987).

Vignettes do not always require participants to have in-depth knowledge of the research topic (Hughes 2012). According to Jenkins *et al* (2010), the aim of a qualitative vignette should not be to arrive at an accurate prediction of an interviewee's behaviour but to achieve insight into the social components of the participant's interpretative framework and perceptual processes. It is also argued that vignettes allow researchers to simplify complex environments and to highlight variables related to the topic (Aldersey, Huynh and Whitley 2016).

Vignettes were successfully utilised in at least eight studies in the literature review (Cairns *et al* 2011; Carpenter *et al* 2014; Shepherd *et al* 2018; Rogers and Bright 2019) and informed the decision to utilise this approach in the proposed research study. HM Government (2014) recognised that it can be beneficial to use practical scenarios where the MCA has been applied successfully. Two vignettes were utilised within the study and were constructed to generate descriptive responses from the participants, as in what they would do, as well as some normative responses, in respect of what they thought should happen around initiation and continuation of treatment.

The vignettes were constructed according to a checklist for designing and strengthening a vignette shown in table 4.3 (Murphy *et al* 2021):

The vignette should be (recommended in the literature)	**Demonstrated by**
Based on research findings and context-specific	The construction of vignettes that describe reality and are valid can be done by reviewing the empirical literature or by consulting experts
Devised with expert consultation	Vignettes should be vetted by experts who can judge their suitability for the study
True to life	A vignette must simulate certain aspects of real-world scenarios, bearing some resemblance to situations encountered by the participants
Concise, readable and easy to understand	Carefully written and edited, clear and brief. Overly long vignettes risk the participant failing to respond
Piloted	It is important to pilot the vignette before data collection begins, usually on a small sample of 5 - 10 participants

Table 4.3: Checklist for designing and strengthening a vignette (Murphy et al 2021)

Initially, six vignettes were devised with reference to cases from the Court of Protection, such as the ruling that a mentally incapacitated adult could refuse a lifesaving amputation (Wye Valley NHS Trust *v* B 2015). All six vignettes referred to treatment decisions for a person with dementia where capacity to consent to treatment was not obvious. Cairns *et al* (2011) utilised vignettes devised from real-life cases, which influenced the decision to base the vignettes on actual cases but with details omitted or amended to anonymise them. In contrast to fictionalised vignettes, the use of 'real life' vignettes may reduce idealised answers (Sampson and Johannessen 2020). These idealised answers may derive from participants' perceptions of what is socially desirable, particularly when asked how they themselves would act in the scenario presented (Aldersey, Huynh and Whitley 2016).

The six vignettes were then presented to a group of 20 nurses who were asked to comment on the situations and identify any aspects that were unrealistic or unlikely to be experienced or to add detail that would make them more realistic and plausible. This approach is recommended by Randhawa *et al* (2015), as asking experts in the field tests face validity, content validity and feasibility. The rationale for the use of vignettes is that they can be particularly useful in researching sensitive issues, where they enable the exploration of participant's views without requiring personal disclosure (Bradbury-Jones, Taylor and Herber 2012; Kandemir, and Budd, 2018). The six vignettes developed were discussed in supervisory meetings and two were confirmed for the study to reduce the risk of participants becoming disengaged. If vignettes are too detailed or too complex, there is a risk that the participants will lose the thread or become disengaged with the process (Finch 1987). When a series of static vignettes are used, they risk a carry-over effect from one vignette to another, where participants draw from the context of the previous vignette (Hughes 2012). They were shared with a Best Interests Assessor and a Social Worker and amended further in response to comments, so that they were accurate depictions of what health and social care professionals may encounter in a clinical setting.

Evaluation of vignettes occurs through obtaining feedback from experienced researchers and through pilot study (St Marie *et al* 2021). The vignettes were amended after a pilot phase with five participants. The gender and names were swapped after five interviews to establish if there was any difference in responses from the age, gender, and perceived ethnicity of each person in the vignette. It is acknowledged by George *et al* (2020) that vignettes can reinforce stereotypes and reinforce negative connotations of the characters and the situations portrayed within the vignette. This illustrates that development of the vignettes was an iterative process, which is also recommended by Mulchan *et al* (2022).

Figure 4.2 shows the iterative development of the vignettes:

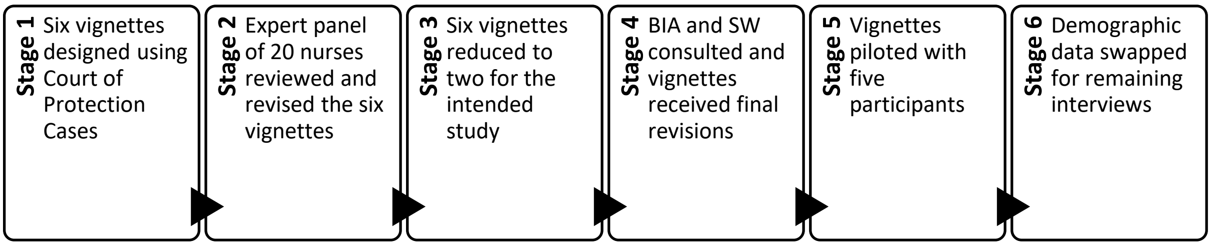


Figure 4.2 Iterative development of the vignettes

Vignette one was based on a person with dementia who required surgery to amputate their lower limb:

Alan is 83 years old and was diagnosed with vascular type dementia 8 years ago. He lives at home with his granddaughter and grandson-in-law and their 3 young children. His wife died over 20 years ago. Alan has multiple co-morbidities, including previous myocardial infarctions, hypertension, type 2 diabetes controlled with twice daily insulin, diabetic nephropathy, neuropathy and ischaemia.

Alan has an ischaemic right foot and he has been assessed as requiring a below-knee amputation. The risk to Alan if he does not have the amputation is infection, further vascular impairment and possible death. There are also risks with the surgery as well as potential complications of healing due to the diabetes, so with or without surgery, Alan has a significant risk of harm.

Alan expressed in the past that he would not wish to have an amputation. His granddaughter is very frank about this fact and she wants to respect Alan's wishes. Her dad however (Alan's son) wants Alan to have the amputation as he feels that Alan still has a role to play in the family and he does not want to lose his dad. He states that Alan would change his mind about the amputation now because he is happy and when he expressed the wish to avoid amputation he was not happy. He also says that Alan wanted the medical staff to resuscitate his wife, which proves that he values life.
Alan's dementia is advanced and he has been assessed as lacking the capacity to decide on the amputation at this time. He has not made an Advance Decision to Refuse Treatment, an Advance Care Plan or Lasting Power of Attorney for Health and Welfare. His granddaughter does have Lasting Power of Attorney for Property and Finance.

Data interpretation is a potential challenge when using vignettes. Researchers may not be able to distinguish what stimuli and assumptions trigger certain responses (Hughes 2012) Alexander and Becker (1978) discuss the order in which vignettes are presented, as this may influence the responses expressed. The order of the vignettes remained static, even though the details were swapped following the pilot study. Vignette two was based on a person with dementia with pneumonia who was being considered for antibiotic treatment.

Kashi is 63 years old and for the last 3 years she has lived in a nursing home. She is married to Vic and he visits her every day in the home. She has had Alzheimer's Disease for 8 years now (diagnosed early onset, aged 55) and it got to the point where Vic could no longer look after her at home as her care needs were too significant for him to manage.
Kashi is not able to communicate now. Her nutritional intake is minimal and is diminishing. She has recurrent respiratory tract infections, primarily due to aspiration of saliva and fluid intake. She only weighs 45kgs.
Kashi is incontinent, which is managed with pads and though she is at high risk of skin breakdown her pressure areas remain intact.
Despite her poor condition Kashi still enjoys her music, she smiles at Vic and appears to enjoy his company each day. She holds his hand as he sings along to music, where Kashi will swing her hand in time to Vic's voice. Vic feels that Kashi understands more than she is able to express. Their two sons also visit regularly, and they are a very close knit and supportive family.
Kashi has recently been admitted to hospital with pneumonia. The consideration is whether to initiate intravenous antibiotics to treat the pneumonia. No decision has been made but the clinical team are considering the viability and efficacy of the intervention.

Using participants as informants and gathering responses from a third-person perspective provides an immediate distancing effect that can be beneficial when exploring potentially sensitive topics and the approach may help minimise socially desirable reporting patterns

(Hughes 2012). The interview questions were devised so that responses would demonstrate the level of knowledge of the participants and the discussion could help to communicate practical considerations of decision making and ethical issues generated by the specific situation.

4.7.3 Semi-structured Interviews

Semi-structured interviews were formulated to complement the information in two vignettes, to generate significant information that might align to or refute the findings from the literature. Interviews were scheduled at a convenient time for the participants, to explore the factors that might influence their thoughts and feelings on best interests decisions. The dialogues from the semi-structured interviews endeavoured to establish the following and inform the research question:

- Do the participants demonstrate a level of knowledge of the legislation through their interpretation of the situation and their perceptions of what *might* or *should* happen?
- Are the participants self-aware in relation to the legislation and their limitations in knowledge and application?
- Do the participants identify ethical challenges within the process of best interests decision-making?
- What do participants consider as important when evaluating the potential outcome of a situation?
- How might the participants' individual experiences have informed their decision-making practice?
- How might the participants identify or recommend any initiatives to improve the process of best interests decision-making?

Interviews are acknowledged as one of the most important sources of case study (Yin 2018) and are the most common form of qualitative data collection (Harisson *et al* 2017). Qualitative researchers take pride in discovering and portraying the multiple views of the case and the interview is the main road to multiple realities (Stake 1995). Personal lived experience is not nomothetic but is perspectival and idiographic, which means that it is about what makes us unique and different and not necessarily what makes us the same. Idiographic research methods include case studies and unstructured interviews (McLeod 2019), which supports the use of interviews in case study research.

Semi-structured interviews have the same number and types of questions for all participants although the actual wording may be varied to make sure the participants understand the question (Parahoo 2014). Interviews are highly subjective and there is there is an inherent danger of bias in their use (Bell and Waters 2014). Interviews are also difficult to analyse as it takes a significant amount of time to summarise themes and does not take into account non-verbal responses such as intonation or body language (Vaughn, Shay Schumm and Sinagub 1996).

Another option for data collection was focus groups, which are a type of group interview where the primary aim is to promote interaction between group members rather than have an individual participant answer each question (Pope 2020). Focus groups are an insightful way of exploring people's views but they tend to produce less data than interviews with the same number of participants (Cohen, Manion and Morrison 2017). Weaknesses of focus groups (without effective management) include fear of expressing certain views or dominance of views by some individuals or the group not being representative of the target group (Bowling 2014). Table 4.4 compares the benefits and challenges of interviews and focus groups. Focus group interviews may not be suitable for sensitive or personal issues and behaviours that do not conform to the norm, if the researcher wants to seek views on several specific issues or validate findings (Parahoo 2014). One to one interviews were chosen in preference to focus groups because focus groups can present problems if participants are not balanced in respect of age, ethnicity and gender (Bell and Waters 2014). As it was not practical to arrange focus groups with such a balance, interviews were deemed to be the most appropriate option for data collection.

BENEFITS OF INTERVIEWS	BENEFITS OF FOCUS GROUPS
• They discover the individual's views on a topic • The interviewer can ask for clarity on points made • The interviewer can guide the process with some structured questions but also improvise with additional questions • The participant may be less self-conscious and more likely to contribute	• They confirm the group opinion • A consensus is formed (so links with an ethnographic approach) • They can work as peer support to clarify perspective and share views • Practicalities – they are time-saving, encourage participation and can be more anonymous (if online)
CHALLENGES WITH INTERVIEWS	CHALLENGES WITH FOCUS GROUPS
• The views gathered may not necessarily be honest views • The participant may say what they think is expected, rather than what they think • They can be considered as formal and potentially intimidating (no one likes 'interviews') • Practicalities – setting up, time consuming, analysis and themes of responses • Potential of 'interviewer bias' – manipulating the data by their understanding of the responses and their interpretation	• It is the 'group opinion' • Members may not contribute equally – some may lead the discussion so may be biased, rather than a consensus • Participants can get distracted and go off on a tangent, rather than stay on track • They may not be representative because you are 'preaching to the converted' as in you get participants who are already interested • Practicalities – writing up, transcribing • Less control over what data is produced

Table 4.5 Benefits and challenges of interviews and focus groups from: Gibbs (1997), eValued (2006)

A semi structured interview approach was adopted which gave the freedom to explore, probe and ask questions to promote a detailed picture of the participants' thoughts and feelings about the situations in the vignettes. The questions were devised to determine any evident level of knowledge of the BIS to provide some measurable data in what nurses understand about the concept of best interests. The intention was not to identify gaps in knowledge but to establish a level of explicit or tacit knowledge that nurses may then use to apply to their best interests considerations. Neglecting to state one aspect of the checklist would not necessarily mean that the nurse did not perceive or understand this aspect but may indicate their priorities in making best interests decisions.

The interview guide is also referred to as semi-structured interviews (Braun and Clarke 2013), although the study incorporated a guide (appendix 12) to determine the format of the interview and the semi-structured interview regime allowed flexibility in responses and order of how the questions were posed. Even in semi-structured interviews, there is some structure as the researcher poses questions and the participant answers the question but the use of reflexive or open questions allow the participant to determine the response (Braun and Clarke 2013). In line with the recommendations by King and Horrocks (2010), questions included experience/behaviour questions, opinion/value questions, feeling questions and knowledge questions to elicit information to answer the main research question. The questions are presented in appendix 13. The participant was given the opportunity to read both vignettes and then the questions were put to the participant, they were then given the opportunity to answer the question. The questions were piloted with five participants as were the vignettes. Each interview was recorded, and questions were asked in a specific order (according to the number sequence), the order was partially amended following the pilot phase to enable a more conversational style of interview. One question asked participants to identify and share areas of good practice from their own practice area to establish if they had experienced any incidents where the best interests decision-making process produced positive outcomes.

4.7.4 Researcher positionality

The interview is a social, interpersonal encounter and not just a data collection exercise (Cohen, Manion and Morrison 2017). The interview is not objective or subjective but intersubjective as the interview enables the participants to discuss their interpretations of the world and how they regard situations from their point of view (Cohen, Manion and Morrison 2017). The degree of structure and control, the process of interviewing and the content can vary from interview to interview. Researchers must be flexible in their approaches as interaction varies from situation to situation (Parahoo 2014). As the interviews progressed and the interviewer gained experience initiating the discussion, the sequence of the questions was amended to enhance the flow of the conversation.

Qualitative inquiry requires researchers to closely engage with both their study participants and the research process (Merriam and Tisdell, 2016). Researchers play an active role in interviewing, responding, and reacting to what interviewees say, encouraging conversation, and asking detailed questions to follow up the initial answers (Rubin and Rubin 1995). Because of this active role, researchers need to be sensitive to their own emotions as well as those of their interviewees. It was important to remain neutral and clear with questions, avoiding leading questions which may pre-empt the person into saying what they anticipate the researcher may want to hear. The axiological assumption where the researcher openly discusses the values that shape the narrative discussed by Cresswell and Poth (2018) whilst present, were kept at bay through use of the interview guide. This allowed flexibility of approach, regarding the phrasing of questions and the order in which they were asked (King and Horrocks 2010). The reflexive process adopted helped to consider personal characteristics, biases, and emotional responses to the participants responses Berger (2015). Bowling (2014) suggest that interviewers should proceed in a non-biased and non-leading way. However, Pope (2020) suggests that it is now accepted that the interview is a socially constructed concept, rather than naturally occurring and interview data are generated through interaction between the researcher and the participant, it is futile to think that the researcher does not influence what the interviewee says. As I had been employed at the University for 3 years before commencing data collection, I had previous interactions with some (not all) of the participants. I was aware that participants being known to me may have had some degree of influence on the participants and their responses. There was a potential advantage with having previously met the participants, as this allowed me to use common ground to develop a rapport and to utilise a conversational approach to asking the questions. It may be easier to build rapport if the interviewer already knows the participants (McGrath *et al* 2019). For the participants that I had not met previously, I adopted the same open, authentic and curious attitude to the interview, as recommended by DeJonckheere and Vaughn (2019).

My interest in dementia care and the legislation that supports decision-making was well known to students and when explaining the research project to potential participants, I was very frank about this being my area of interest. I may therefore have been viewed by some participants as having knowledge and being in a position of power in relation to the topic matter. Finlay (2012) suggests that participants knowing the researcher as an academic (and an 'expert'), may feel that they have to 'perform', showing off their competence and minimising their insecurities. Consequently, I had to be aware that my approach to questioning was to stimulate discussion and the participants' perspectives rather than questioning their knowledge or motives for responding in a particular way.

Another risk as a novice researcher is the interviewer being overly active in the conversations and filling in the blanks or driving the conversation in a certain direction, without being aware of doing so (McGrath *et al* 2019). I am aware that I tend to chat and fill silences, so I made a conscious effort not to do this in the interviews. In reality, I probably revealed less about my own views than I would do normally because I was so conscious of not taking over the discussion. I adopted an active listening approach and allowed the silence to drive the conversation forward (McGrath *et al* 2019). After each interview, I reflected on how I had performed as an interviewer and how the participant had performed as an interviewee and considered whether I needed to change my approach for the next participant. It is essential for the interviewer to begin to reflect on both the process and the content of the interview (DeJonckheere and Vaughn 2019).

Where I could, I tried to schedule one interview only per day so that I had time to reflect, process and revise my approach for the next interview. DeJonckheere and Vaughn (2019) discuss qualitative research interviews as being iterative in nature requiring changes to the guiding questions as the study progresses. I did change the order of the questions at times, depending on the flow of the conversation so that the interview felt more conversational, rather than rehearsed and artificial. I also gave feedback on the vignettes after the interview had been completed and I had thanked the participant for their time. I admitted that vignette related to amputation may result in a Court of Protection referral due to the disagreement between the clinical team and the family (as the vignette had derived from a true case) and that the pneumonia case would likely be an end-of-life care scenario, as evidence suggests a person in such a late stage of dementia would be unlikely to respond to antibiotics. I gave this feedback in a non-judgemental way, being careful not to make the participants feel that they had interpreted the situations incorrectly. I used points they had raised, such as "as you identified, it was a very complicated situation…." and I merely pointed out that the potential outcome was a court of protection referral or end of life care, as they were hypothetical situations and so there was no 'right' or 'wrong' response. I felt that my demeanour in the interviews resulted in the rich data characteristic of well-planned semi-structured interviews (Ogden and Cornwell 2010).

4.8 Data analysis

4.8.1 *Data transcription*

The interviews were transcribed from audio files, using orthographic transcription (Braun and Clark 2013). McGrath *et al* (2019) recommend transcribing data as soon as possible after the interview. Each interview was manually transcribed by the researcher, from 30 interviews there were 24 hours of data to transcribe. An example of one interview is presented in appendix 14. Transcribing data from qualitative interviews is time consuming and for novices, initial transcription may require as much as four to eight hours of transcription for each hour of recorded data (McGrath *et al* 2019). However, transcribing verbal data affords the researcher the opportunity to carefully listen to, pay close attention to, and think deeply about digitally recorded data situated within a particular interview context. Transcribing one's own data provides the opportunity to critique one's own work and improve interview technique. It also allows the researcher to analyse the emerging themes from findings and reflection on the process (Widodo 2014). The process yields vast amounts of material which must be iteratively scrutinized and waded through when analysing the data (McGrath *et al* 2019).

A common occurrence in small-scale research projects is that a degree of interpretation can be lost in interview transcripts based on words alone (Denscombe 2017). To counteract this, the responses were transcribed verbatim at the earliest opportunity and comparisons made between the responses for similarities and differences. A sample of transcripts were then peer reviewed within the supervision team to discuss the meaning of the responses to the interview questions. To ensure confidentiality, no original names were transcribed, and the interviews were coded to participants as they were transcribed (Beauchamp and Childress 2019).

4.8.2 Approach to data analysis

Data analysis is a complex process where the researcher moves from seeing the big picture and the particulars and it is best done in conjunction with data collection (Merriam and Tisdell 2016). The analysis of case study evidence is one of the least developed aspects of doing case studies, it is easy to become stalled at the analytic stage and the novice researcher is at a disadvantage compared to experienced researchers (Yin 2018). Cresswell and Poth (2018) suggest that data analysis is choreographed, that the processes of collection, analysis and report writing are interrelated and go on simultaneously in a research project. They go on to describe the data analysis process as a spiral, with the researcher circling around and around, using strategies to generate specific outcomes with the data. This spiral commences with data collection and involves managing and organising the data, memoing emergent ideas, classifying codes, developing interpretations, and representing the data, which reflects the phases of thematic analysis. Thematic analysis is one of the most used methods to analyse qualitative data but is not recognised as a high-quality qualitative method (Trainor and Bundon 2021). Thematic analysis provides a flexible approach that does not require detailed technical or theoretical knowledge and offers an accessible form of analysis (Nowell *et al* 2017). It is an approach to data analysis can be helpful to novice researchers if considered as an analytic strategy in the research design, as recommended by Yin's (2018). The data was analysed using the six phases of thematic analysis recommended by Braun and Clarke (2006).

1. Familiarisation with the data
2. Coding
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes

6. Writing up

Six phases of thematic analysis (Braun & Clarke 2006)

The most current terminology for Braun and Clarke's approach is *reflexive thematic analysis*, an approach that was identified as good practice in the 2013 text but has since become the preferred terminology (Braun and Clarke 2019).

4.8.3 Familiarisation with the data

Making sense of the data is far from straightforward, so repeated reviewing and sorting of the data are integral to the process of analysis (Crowe *et al* 2011). With case study research, in addition to a large amount of data, the range of data sources may present disparate, incompatible and contradictory (Merriam and Tisdell 2016). Therefore familiarisation should be an active process, where the researcher reads the words analytically and critically, thinking about what the data mean Braun and Clarke (2013). To become immersed in the data involves the repeated reading of the data in an active way searching for meanings and patterns (Robson and McCartan 2016; Nowell *et al* 2017). 'Playing with the data' may provide insight that can initiate an analytic path, identifying potential relationships (Yin 2018).

The organising of the data can be done by hand (Merriam and Tisdell 2016), or a computer-assisted tool may be utilised to help code and categorise the data. Computer programs can be helpful but they are not able to process or judge the value of the data inputted (Nowell *et al* 2017). Therefore it is important to study the outputs to determine if any meaningful patterns are emerging (Yin 2018).

The researcher should start reading and re-reading transcripts and notice things of interest that might be overall impressions, an overall idea, or more concrete issues (Braun and Clarke 2013). Things of interest might also be meaningful segments (units of data) that are responsive to the research question, which can be as small as a word a participant uses to describe a feeling or phenomenon. One unit of data should be compared with the next, to identify recurring regularities in the data (Merriam and Tisdell 2016).

4.8.4 Coding

Qualitative data analysis is inductive and comparative (Merriam and Tisdell 2016). Yin (2018) considers the analytic strategy for case study and discusses an inductive approach, working the data from the 'ground up'. The strategy that he suggests is common to but not exclusive to grounded theory and involves assigning codes to the data, each code representing a concept of interest.

Coding can be used as a constructionist method, which examines the way in which events, realities, meanings, and experiences are the effects of a range of discourses operating within society (Robson and McCartan 2016). There are different ways to code and the method will be determined by the researcher's perspective and research questions (Maguire and Delahunt 2017). The coding phase involves the initial production of codes from the data, which allows the researcher to simplify and focus on specific characteristics of the data. It is a theorizing activity that requires the researchers to keep revisiting the data (Nowell *et al* 2017).

A consistent approach is needed, and there are several approaches that can be used, but it is important to code in a disciplined way and not to fit it into a pre-existing coding frame or the researcher's analytic preconceptions (Nowell *et al* 2017). First, the researcher should read the transcript and jot down expansive notes, comments and observations of anything that might be useful in the margins, which is called open coding (Merriam and Tisdell 2016). Each interview needs identifying notations to access them in the analysis and write-up (Merriam and Tisdell 2016). With reflexive thematic analysis, Braun and Clarke (2022) do not advocate line-by-line coding, as only data relevant to the research question needs to be coded.

Examples of what can be coded are specific acts or behaviours, events, activities, practices, states, meanings, participation, relationships, conditions, consequences (Robson and McCartan 2016). It can also be single words, letters numbers, phrases or combinations of these (Merriam and Tisdell 2016).

Initial codes may begin to form main themes, and others may form subthemes. Researchers may also find codes that do not seem to belong anywhere (Nowell *et al* 2017). Braun and Clarke (2013) discuss data-derived codes and researcher-derived codes. Data-driven codes are generally semantic and use the language of the participants, whilst researcher derived codes are latent and imply meaning from the data. In practice, codes can and do have both elements but they should be as concise as possible and each code should be distinct in some way (Braun and Clarke 2013).

4.8.5 Searching for themes

Part of the flexibility of thematic analysis is that it allows researcher judgment to determine themes in a number of ways (Nowell *et al* 2017). Assigning codes to pieces of data is how to begin constructing categories or themes (Merriam and Tisdell 2016). Braun and Clarke (2013) explain that the codes are the individual bricks and tiles of the house, where the walls and roof are the themes. They also suggest that searching for patterns is like sculpture, where the researcher actively makes choices about shaping and crafting raw data.

In reflexive thematic analysis, a theme is a pattern of shared meaning organised around a central concept (Braun and Clarke 2022). Techniques for identifying themes are repetitions, indigenous categories, metaphors, transitions, similarities and differences, missing data, and theory-related material (Robson and McCartan 2016). The patterns and regularities from each set of notes become the categories or themes into which subsequent items are sorted

(Merriam and Tisdell 2016). Frequency is important but elements that are the most meaningful is more important (Braun and Clarke 2013).

With an inductive approach, the themes identified are strongly linked to the data themselves and may bear little relation to the specific questions that were asked of the participants (Nowell *et al* 2017). A common pitfall is to use the main interview questions as the themes. Typically, this reflects the fact that the data have been summarised and organised, rather than analysed (Clarke & Braun, 2013). A theme has a central organising concept that says something about the content that is meaningful (Braun and Clarke 2013). It is not necessary to capture everything in the dataset, more to tell a particular story about the data that addresses the research question (Braun and Clarke 2022).

4.8.6 Reviewing themes

This phase is particularly recursive, according to Braun and Clarke (2022), where the researcher moves backwards and forwards between the data to check the direction of analysis is not moving too far from the data or travelling in the wrong direction. The researcher should check if the themes adequately capture what is in the data (Robson and McCartan 2016). The coded data extracts for each theme are reviewed to establish if they form a coherent pattern (Nowell *et al* 2017). If the themes meet the basic criterion of having an identifiable concept and is therefore a viable theme, considerations for review include identifying boundaries, identifying evidence, avoiding divergence, and communicating the importance of that theme (Braun and Clarke 2022). The themes should be coherent but also distinct from each other and the researcher should consider if the themes make sense, if the data supports the themes, if there is too much in one theme, if themes overlap or if the themes are sub-themes (Maguire and Delahunt 2017).

Each theme needs the space to be explored and developed fully, with the richness captured in the account written up (Braun and Clarke 2022). However, Robson and McCartan (2016) say that the researcher could go on forever if they are not careful. One of the most difficult decisions to make is where to stop the process of development (Nowell *et al* 2017). So, the researcher should have an intuitive feeling about what the different themes are, how they fit together and the overall story they tell about the data (Robson and McCartan 2016). The role of the researcher is to speak for the themes and tell the story made from the dataset, to tell the reader why they matter (Braun and Clarke 2022).

4.8.7 Defining and naming themes

Devising categories or themes is largely an intuitive process but it is systematic and informed by the researcher's knowledge and the meanings made by the participants (Merriam and Tisdell 2016). Braun and Clarke (2006) suggested that theme names need to be punchy and immediately give the reader a sense of what the theme is about. (Merriam and Tisdell 2016) suggest that the names of the themes can come from at least three sources: the researcher who comes up with the terms concepts and categories that reflect what they see in the data, the participants exact words or sources outside the study, such as the literature or a mixture of all three.

Braun and Clarke (2022) recommend avoiding one-word themes or anything too obscure as they rarely capture the meaning evident in a theme. They suggest that a good theme will be informative, concise and catchy, a short phrase, a heading or a sub heading that captures the essence of the theme. Merriam and Tisdell (2016) advise that the number of themes be manageable, as the fewer the themes, the greater the ease to communicate the findings. They suggest a criteria for devising themes: that they answer the research question and be exhaustive, mutually exclusive, sensitive, and conceptually congruent.

It is important to let some things go even when at the point of confirming the themes (Braun and Clarke 2022) and if the themes are too numerous or concerned with different aspects, then Robson and McCartan (2016) recommend putting them into two or more groupings. Braun and Clarke (2022) also warn that the dataset can contain tensions with contradictory meanings so it is important to resolve any contradictions by renaming themes. The themes reached may still contradict other themes but should not contradict themselves.

4.8.8 Writing up

Conclusions are important to tell the reader why the analysis matters, for instance conclusions relating to the data, conclusions relating to the discipline, the methodology, practice or wider societal context (Braun and Clarke 2022). Case studies can be written up in many different ways (Robson and McCartan 2016). The researcher should explain their rationale for using thematic analysis as well as explaining how analysis was carried out and how thematic analysis was applied rather than the generic phases (Braun and Clarke 2022). In their case study guide Rashid *et al* (2019) suggest that themes generation and coding is the most recognised data analysis method in qualitative empirical material. They recommend that the conclusion should be written in a way that gives the reader a comprehensive view about the exploration of the focal issue of the case study.

The researcher should start the analysis section with a brief overview of the themes using narrative, a list, table or map (Braun and Clarke 2022). Then the final analysis should create an overall story about what the different themes reveal about the topic and the researcher should build a valid argument for choosing the themes by referring back to the literature (Nowell *et al* 2017). Writing the analysis is like writing a story, engaging the reader and convincing them of the validity of the analytic terms and the argument (Braun and Clarke 2022). Short quotes may be included to aid in the understanding of specific points of interpretation and demonstrate the prevalence of the themes. More extensive passages of quotation may be included to give readers a flavour of the original texts (Nowell *et al* 2017). Include the most vivid extracts across a wide range of data items with a wide range for each theme and contextualise extracts where necessary, explain to the reader what is important and interesting about what they are saying (Braun and Clarke 2022).

4.9 Ethics

NHS Research and Development and ethics was not required because recruitment was from a University student base. To counter the risk of coercion, the participants were informed about the research and that there was no obligation to participate. The open invitation enabled interested participants to volunteer, and to support this, communication was provided (appendix 15), stating the purpose of the research and the process that would be followed. The participant was provided with participant information when attending for the interview (appendix 16).

Ethical approval was granted by Keele University Faculty Research Ethics Committee (appendix 17). The six key principles of ethical research (Economic and Social Research Council (ESRC) 2015) was followed, which supports high standards of ethical research demanded by the University. It was considered that there would be no severe or significant interference with the participants' wellbeing, the participants were not considered vulnerable and no access to confidential records was required. A consent form was completed by each participant (appendix 18). All potential participants were deemed to have capacity to consent due to the nature of their role; none were classed as vulnerable adults. Confidentiality was maintained by ensuring that the transcripts of interview responses were anonymous, stored securely during the study and they will be deleted/shredded within the appropriate timeframe when the study is complete. Information and individual results will not be divulged to anyone outside the research supervision team. The participants assured anonymity and confidentiality prior to participation. The only personal data to be collected was demographic data, which was reviewed to demonstrate that responses are representative of the workforce involved. The consent form for the interviews did include name and signature and these consent forms were stored separately and securely. All participants were interviewed at the HEI at a time of their choice. All data in respect of the study was protected and stored in accordance with General Data Protection Regulation and Keele University Code of Good Research Practice (Keele University 2019).

The other ethical consideration to consider was that participants might feel that they were compromising themselves by admitting their own ethical values. This was addressed by emphasising the fact that the study was purely investigative. Some participants also may not feel comfortable with expressing their opinion or they may give answers that they believe are socially acceptable as they do not want to appear different from other members of the group (Vaughn, Shay Schumm and Sinagub 1996). To counteract these problems, honest responses were encouraged, giving the assurance of confidentiality and the ability to withdraw from the study at any time. Participants were also offered a de-brief at the end of each interview where information was shared about the possible action in each vignette. For instance, vignette one may be referred to the Court of Protection if no consensus could be reached on whether amputation was in the patient's best interests. In vignette two, pneumonia is a potential consequence of advanced dementia and may not respond to antibiotics, so the decision not to initiate antibiotics may be the most appropriate in the circumstances. Sharing this information as a 'de-brief' for the participants resulted in many of them intending to read more about the topic to enhance their knowledge.

4.10 Summary

Cresswell and Poth (2018) use a framework to guide understanding of how philosophical assumptions and interpretive frameworks are influential to the research process. The five phases that they present consider the following questions: what perspectives the researcher brings to the research, how the researcher's beliefs guide their actions, how the researcher's philosophical and theoretical frameworks inform their choice of approach, in what ways said approach influences the methods and what contributes to the decisions related to rigor, inferences and use of findings.

The following table explains the philosophical framework in respect of the study design:

Paradigm	Qualitative	Qualitative research explores a problem, to develop a complex and detailed understanding of an issue by talking directly to people and allowing them to tell their stories, unencumbered by the literature or what the researcher expects to find.
	Interpretative	The interpretivist paradigm tries to understand what the subject is thinking or the meaning they are making of the context, to understand the viewpoint of the subject being observed, rather than the viewpoint of the observer.
Ontology	Relativist	There is no shared reality, only a series of different individual constructions. The social world is different to the natural world because human beings have agency and therefore have choice about what they do, rejecting the idea that fixed 'laws' govern the social world.
Epistemology	Subjectivist	The knower and the participant co-create understandings. Social reality is impossible to abstract from social settings and reality is interpreted through a 'sense making' process.
Axiology	Value-based	Qualitative researchers make their values known. The researcher openly discusses the values that shape the narrative and they include their own interpretation in conjunction with those of the participants.

Methodology	Case Study	A case study presents a unique opportunity to focus on social interactions and the developing meanings that participants in the system attach to each other.
Method/ Data Collection	Interviews	A semi structured interview approach gives the freedom to explore, probe and ask questions to promote a detailed picture of participants' thoughts and feelings about situations.
	Vignettes	Vignettes provide a stimulus for discussion about real-life. The use of vignettes allows for features of the context to be specified, so that the participant is invited to make statements about a set of social circumstances.
Data analysis approach	Thematic Analysis	Thematic analysis provides a flexible approach that does not require detailed technical or theoretical knowledge and offers an accessible form of analysis.

Table 4.1 philosophical framework of the proposed study

The study is applied research, using vignettes and interviews as part of a case study approach from an interpretivist/social constructivist perspective in a topic identified from the researcher's experience as a nurse with an interest in decision-making legislation and advanced dementia. The ontology, epistemology and methodology align in respect of the paradigm of interpretivism; the understanding that reality is relative to the individual and the situation, that knowledge is subjective and that a case study methodology provides the opportunity to explore a complex situation in context. Case study research is a valid approach as it aligns to qualitative research methodology, providing the opportunity to ask about a contemporary set of events, over which the researcher has little or no control (Yin 2018). The set of events is:

- the design of this case study is a single case study
- the context of the study is best interests decision-making as part of the Mental Capacity Act (2005)
- each case consists of nurses' perceptions, thoughts and experience of Best Interests decision-making in relation to two vignettes

The first part of this chapter justified the case study approach to answer the research question and the inductive, interpretivist research approach. Using qualitative tools; vignettes and semi-structured interviews enabled the question to be explored. Best interests decision-making by nurses on behalf of patients with advanced dementia is influenced by factors such as the physical condition of the person, including co-morbidities, the risks associated with the treatment, their overall quality of life and the feasibility of proposed treatments. Mental capacity and best interests decision-making is complicated and cannot be fully understood without consideration of the factors that influence the decisions. Therefore, the phenomenon being examined in this study is likely to be influenced by factors that are inter-related and needs to be explored with a comprehensive approach. A qualitative case study was chosen for the study to explore the phenomenon in its real-life context, i.e. the factors that nurses consider when making best interests decisions on behalf of a person with advanced dementia. Case study researchers can eclectically combine elements from different approaches that best serve and support their design (Yazan 2015) and design aspects from Stake (1995), Merriam and Tisdell (2016) and Yin (2018) all informed the design of the study. This qualitative case study draws on demographic data, survey questions, vignettes and interviews as sources of evidence to generate meaning within the responses and similarities and differences between responses. The interviews and the vignettes used as a complementary technique to enhance data collection (Barter and Renold 1999). It was anticipated that this approach would enable data to be collected that would lead to an in-depth understanding of decision-making from the perspectives of nurses answering the study's 'what' and 'how' questions.

Chapter Five
Results and data analysis

Introduction

Chapter four outlined the research design and the planned process of data collection. The aim of this chapter is to present how data was collected and the responses from the participants. Four key areas were identified from the analysis of the responses; firstly, that participants overall accepted the criticism presented about the MCA and best interests, secondly, that there was evidence of both explicit and tacit knowledge of the legislation through the discussion that participants initiated. Participants also referred to clinical experience to support their responses and fourthly, person-centredness influenced responses about what should happen to the characters in the vignettes. From the codes identified from the responses, six initial sub-themes were created, which were subsequently reduced to three overall themes.

Initially, the demographic data will be presented and analysed in respect of the self-assessment of knowledge of MCA and best interests. Participants' responses to the criticisms will then be explored and presented before the semi-structured interview responses are identified within the themes.

5.1 Process of analysis

Recruitment of 30 nurses facilitated 24 hours of interview data to be collected, the aim being to generate data that revealed answers appropriate to case study research. According to Braun and Clarke (2019), qualitative research is about meaning and meaning-making, viewing the meanings as context-bound, positioned and situated. The case study approach is beneficial when what is needed is an in-depth appreciation of an issue in its natural real-life context (Crowe *et al* 2011). Using hypothetical scenarios that project dilemmas, choices, and behaviours onto fictionalised protagonists, the vignette technique has been used to engage participants in talking about 'sensitive' issues without fear of self-incrimination or negative social judgement (Jenkins and Noone 2019). Vignettes are useful to triangulate with other techniques, especially semi-structured interviews (Aujla 2020). Semi-structured interviews allow the researcher to collect open-ended data, to explore participant thoughts, feelings and beliefs about a particular topic and to delve deeply into personal and sometimes sensitive issues (DeJonckheere and Vaughn 2019). There is a great deal of versatility in semi-structured interviews and questions can yield considerable streams of data, so it is important to take time to absorb the data through a progression of analytical steps (Galletta 2013). Thematic analysis is widely used as an analytic approach across methods and paradigms by case study researchers because of its power to yield insightful interpretations that are contextually grounded (Mills *et al* 2010). There are different ways to approach reflexive thematic analysis (Braun and Clarke 2022). For this study, the six phase process of analysis presented by Braun and Clarke (2006; 2013, 2019, 2022) was utilised; familiarisation, coding, generating, developing, refining themes and writing up. Braun and Clarke's (2022) reflexive thematic analysis provides guidelines for the process but recognises that the researcher is the situated, insight-bringing, integral component of the analysis.

There were several approaches of examining the data that were utilised to compare, contrast, identify patterns and commonalities in responses to facilitate the construction of codes and themes as presented in table 5.1:

Data processing approach	Details
Initial transcription	Manual transcription from audio file - involves repeated listening
'Notes on quotes'	Manual notation on the transcriptions for each meaningful response
Best Interests Standards mapping	Inferred meaning to demonstrate tacit knowledge or explicit statements demonstrating explicit knowledge
MCA mapping	Inferred meaning to demonstrate tacit knowledge or explicit statements demonstrating explicit knowledge
Data extracts question by question	Response to each question collated for each participant, similarities or nuances in responses identified and code generated for common ideas

Table 5.1 – Methods of data examination

5.1.1 Familiarisation of the data

Thematic analysis is valuable as a sensemaking approach, to reduce and manage large volumes of data without losing context and for getting close to the data, for organising, summarising and interpretation (Mills *et al* 2010). The participant's angle and vision of the interview are present in the data as central ingredients in data for the analysis, so even though the participant is no longer before the researcher, becoming steeped in the data returns to the depth of engagement between the researcher and the participant (Galletta 2013).

Self-transcription of the data facilitated this first phase of familiarisation of the data, where the audio was played multiple times for accurate transcription and each interview was anonymised by numbering. Braun and Clarke (2013) confirm that in qualitative research, it is not essential to have all the data collected to start the analysis, which applied in the study as analysis commenced immediately on transcription of each interview. Each transcript was read and re-read and notes made in the margins for pertinent statements, quotes, words, or potential inferences for statements (Merriam and Tisdell 2016). Responses to the interviews were analysed using the framework method (Gale *et al* 2013) to identify emerging patterns, insights, or concepts. Any explicit references to the legislation were identified by highlighting words such as 'power of attorney', 'advance decision', 'advance statement' or any terminology that could be attributed to the legislation.

Each interview transcript was mapped against the Best Interests Standards, as presented in appendix 19 to establish if the responses demonstrated explicit knowledge of the standards or if they could be interpreted as tacit knowledge. An example being, for BIS 3: ‘Consider the individual’s views, whether expressed verbally or in writing, including their feelings, religious beliefs and past habits’, participant 1 responded thus:

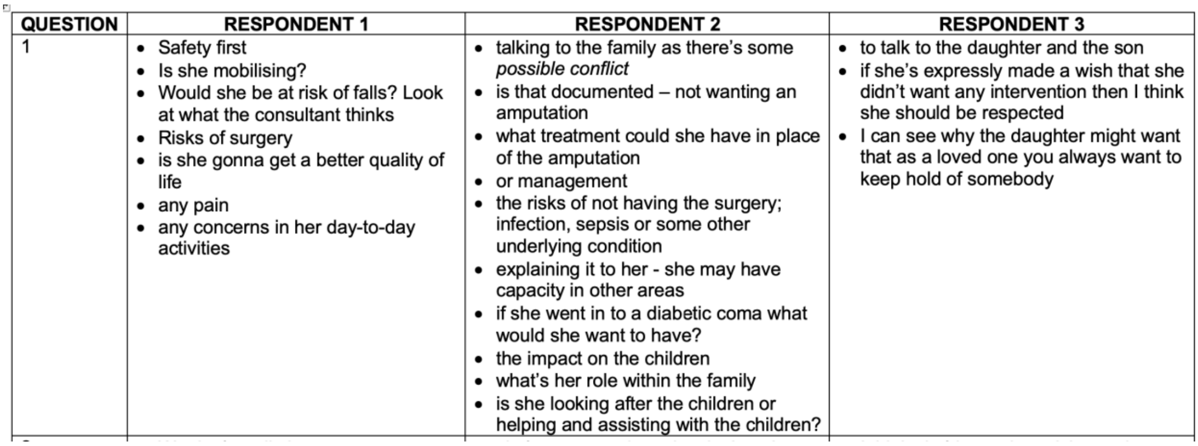
> Her daughter says she’s happy, what do they mean by that? **Q2a**
>
> …there’s nothing written down… **Q2b**
>
> she’s got to have said it for some reason, it’s not something you discuss randomly..
> When she had capacity if she could make that statement, so I’d say it’s still something that she was always knew would happen…**Q2d**
>
> …take in to account the grandson and the daughter’s concerns and also what Kashi said previously… **Q3a**

The responses were inputted into the table for each Best Interests Standard and the data retained for analysis and comparison to subsequent interview transcripts. This process was repeated for the principles of the MCA (2005), as presented in appendix 20.

PARTICIPANT/ VIGNETTE	**Participant 2 – Vignette 1**	**Vignette 2**
Presumption of capacity	Suggests that whilst the patient lacks capacity at the time she might have it in other areas. Also says would want to check capacity. Mentions this several times.	Asks whether the patient has capacity.

These responses deemed to indicate tacit or explicit knowledge of the MCA principles and the BIS were recorded on a table to collate the number of participants who demonstrated knowledge of the legislation, which is presented in appendix 21.

After each subsequent interview was transcribed, each set of responses to each question was compared to the previous set of responses to try to identify any patterns or commonalities in the responses. The following is an example of the responses to question one for participant 1 – 3:



QUESTION	RESPONDENT 1	RESPONDENT 2	RESPONDENT 3
1	• Safety first • Is she mobilising? • Would she be at risk of falls? Look at what the consultant thinks • Risks of surgery • is she gonna get a better quality of life • any pain • any concerns in her day-to-day activities	• talking to the family as there's some *possible conflict* • is that documented – not wanting an amputation • what treatment could she have in place of the amputation • or management • the risks of not having the surgery; infection, sepsis or some other underlying condition • explaining it to her - she may have capacity in other areas • if she went in to a diabetic coma what would she want to have? • the impact on the children • what's her role within the family • is she looking after the children or helping and assisting with the children?	• to talk to the daughter and the son • if she's expressly made a wish that she didn't want any intervention then I think she should be respected • I can see why the daughter might want that as a loved one you always want to keep hold of somebody

Braun and Clarke's (2013) recommendation of noticing things of interest that might be overall impressions, an overall idea or more concrete issues was observed and a separate document commenced where 'thoughts about what the data was saying' were recorded. These thoughts were simply recorded until data analysis was completed and then closely examined for relevance to the dataset. It is recognised by Braun and Clarke (2013) that the researcher's initial thoughts about responses may be influenced by their own beliefs and values, so it was important to retain these predilections until the analysis was distinct enough not to be influenced by the researcher.

5.1.2 Coding

The basic analytic strategy used in thematic analysis is coding, a process of closely inspecting text to look for recurrent themes, topics, or relationships, and marking similar passages with a code or label to categorise them for later retrieval and theory-building (Mills *et al* 2010). Transcripts can be coded, using pre-established codes, or going through the data separately looking for new ones (Stake 1995). Open coding, axial coding and selective coding all featured in the analysis process. During transcription, the interviews were anonymised by numbering and open coding was utilised, where data is attentively read line by line and coded subjectively but in a systematic way (Kara 2019). Open coding began with identifying categories and subcategories (Mills *et al* 2010), this was undertaken manually as it was a practical option that suited the researcher. Codes were identified from the explicit statements that each participant had expressed. With each subsequent transcription, new codes were added but the overall number reduced as the responses were similar and codes were identified as being present in more than one transcript. This approach is recommended by Braun and Clarke (2022); coding relevant statements with an existing code, tweak it or add a new code. Stake (1995) discusses going through passages line by line, identifying issues or topics.

Coding is a subjective process; a process of interpretation or meaning-making and different coders will notice and make sense of data in different ways (Braun and Clarke 2022). Axial coding is the second level of coding, where collected data can be sifted, refined, and categorised with the goal of creating distinct thematic categories in preparation for selective coding (Williams and Moser 2019). Participant responses to each question were printed and collated so that it was possible to see all responses to one question and then highlight text within each transcript to start to form categories and potential themes.

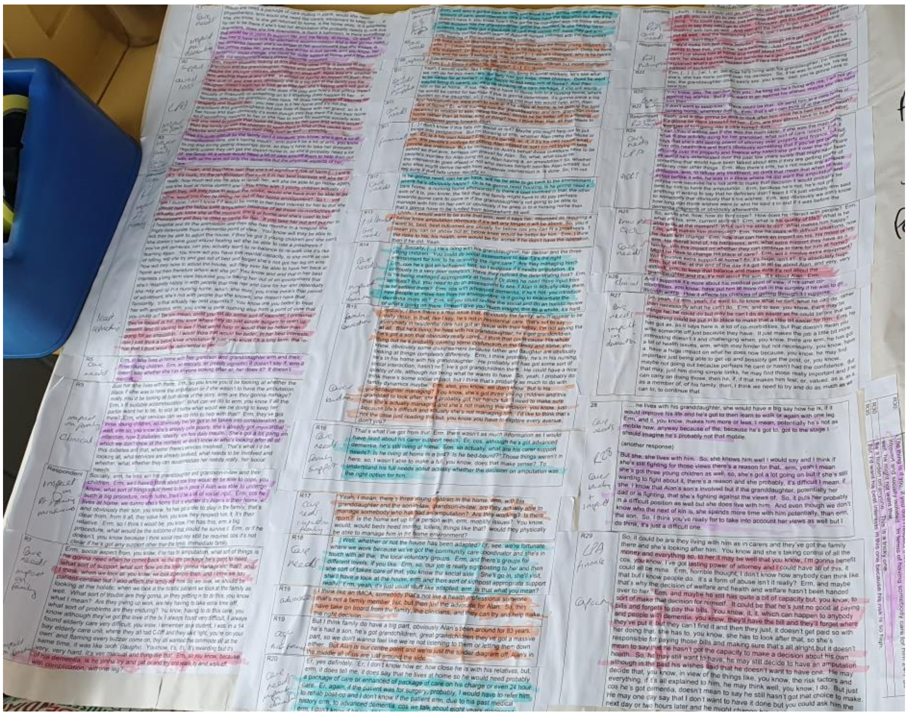
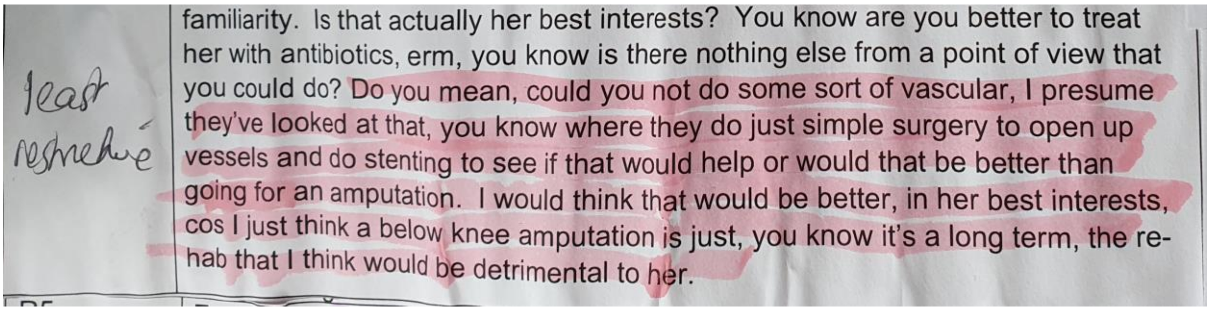


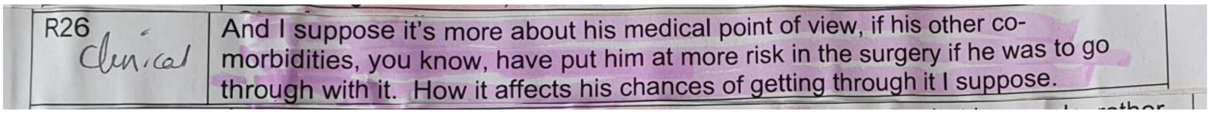
Figure 5.1 compiled questions with coding ideas

Coding is about starting to capture repetition of meaning and codes can shift throughout the coding process to better evoke meanings in the data (Braun and Clarke 2022). Braun and Clarke (2022) discuss semantic and latent coding and confirm that coding can use a mixture of both. Semantic codes relate to the language that participants use and latent codes that focus on more implicit meaning, abstracted from the obvious content of the data. This process consisted of reading through the statements made by participants and naming the statement. The following example shows how the principle of the least restrictive approach was identified, which is both a principle of MCA and a standard within the principle of best interests (fig 5.2) and how the clinical picture was considered (fig 5.3):



least restrictive	familiarity. Is that actually her best interests? You know are you better to treat her with antibiotics, erm, you know is there nothing else from a point of view that you could do? Do you mean, could you not do some sort of vascular, I presume they've looked at that, you know where they do just simple surgery to open up vessels and do stenting to see if that would help or would that be better than going for an amputation. I would think that would be better, in her best interests, cos I just think a below knee amputation is just, you know it's a long term, the rehab that I think would be detrimental to her.

Figure 5.2 Participant #4 – question 3c



R26 Clinical	And I suppose it's more about his medical point of view, if his other co-morbidities, you know, have put him at more risk in the surgery if he was to go through with it. How it affects his chances of getting through it I suppose.

Figure 5.3 Participant #26 – question 3a

The following table presents an example of the statements made by participants and the codes attributed to those statements:

Example data extracts	Code and number
"as health care practitioners, sometimes the drive is to do all we can until nothing can be done" (P11) "I think it's sometimes with nurses or clinicians I feel that the, they've got that duty to care and so they have to do something, they have to react, they have to." (P28)	Strive to Survive/Preserve Life (N = 11)

"but without it or with it, oh it's a difficult one" (P21) "So, there, it's a very complex situation really that isn't, this isn't just about Alan" (P25)	Complex situation (N = 26)
"they'd look at how many times she's been having infections and pneumonias. She's now got an aspiration, how advanced the dementia is, er Alzheimer's, sorry" (P14) "you wouldn't want her becoming dehydrated, you wouldn't want her to be in pain, you wouldn't want her to be breathless, you wouldn't want her, erm, drowning on her own saliva, all that would be treated" (P18)	Clinical 'default' (N = 20)
"she's got a lot of co-morbidities, which you know, you look at things like diabetic neuropathy, she's got ischaemia, her wound healing will be poor, actually it's a massive operation to do on someone so the risks are quite high and she could end up having a stroke, she could have an MI on the table." (P4) "there's lots of different risks there isn't there? So, potentially, he's got the risk of harm if he doesn't have treatment" (P9)	Safety and Risks of Intervention/Non-Intervention (N = 30)

Table 5.2 – Examples of semantic and latent codes

Braun and Clarke (2013) also discuss selective coding, where the researcher identifies a collection of instances that they are interested in. There was an element of selective coding in the analysis as specific statements were recognised through the transcriptions, specifically terminology relating to the legislation that would be indicative of explicit knowledge. Once the researcher has gone through the dataset thoroughly a couple of times and refined and finalised the code labels and checked for consistency and thoroughness, it is probably the right time to stop (Braun and Clarke 2022). There were 110 codes identified, a sample of which is presented in appendix 22. Codes were around a broad range of concepts, such as terminology of the legislation, professional expertise, and person-centred concepts.

5.1.3 Searching for themes

Themes do not passively emerge from data (Braun and Clarke 2019). Searching for themes requires the researcher to actively search for patterns of meaning that are underpinned by a central organising concept (Clarke and Braun 2017). The search for meaning in case study research often is a search for patterns, or for consistency within certain conditions, known as 'correspondence' (Stake 1995). To identify patterns in the data, the codes and the collated data for each code were reviewed to identify similarities and overlaps, as recommended by Braun and Clarke (2013). The following table presents Braun and Clarke's recommendations for searching for themes:

GOOD QUESTIONS TO ASK YOURSELF IN DEVELOPING THEMES

- Is this a theme? Is it just a code or a sub-theme?
- Is there a *central organising concept* that unifies the data extracts?
- What is the quality of this theme? Does the central organising concept tell me something meaningful about a pattern in the data, in relation to my research question?
- Can I identify the boundaries of this theme? What does it include and exclude?
- Are there enough (meaningful) data to support this theme? Is the theme 'too thin'?
- Is there too much going on in the theme, so that it lacks coherence? Are the data too diverse and wide-ranging? Would using sub-themes resolve this problem? Or should it be split into two or more themes, each with its own central organising concept?
- How does this (potential) theme relate to other (potential) themes? Is the relationship between (potential) themes hierarchical or linear?
- What's the overall story of my analysis? How does this theme contribute to that overall story?
- Is the central organising concept reflected in the title I have given to the theme?

Braun and Clarke (2013) p. 226

Table 5.3 – Braun and Clarke's questions for developing themes

It is important to consider patterned meaning, which means the same ideas should be evident in different participant responses. If one participant expresses the same idea several times but they are alone in this feature, then it is likely not to be the basis for a theme (Braun and Clarke 2022).

It is important to identify a number of themes that capture the most salient patterns in the data relevant to answering the research question (Braun and Clarke 2013). The number of codes combined into potential themes will vary (Braun and Clarke 2022). An example of the themes considered at this stage were:

- Accepting criticism
- Demonstrating legal knowledge/legal literacy
- Demonstrating tacit knowledge
- Demonstrating explicit knowledge
- Is it explicit knowledge or tacit knowledge?
- Defaulting to clinical knowledge
- Implications of treatment and no treatment
- Ethical empathy
- Who is this person with dementia?
- Considering the family
- Person-centredness

At this point it was a matter of making sense of the various codes and finding a term, statement or quote that described a collection of codes. Some codes fit in a few themes, for example, DNAR (Do Not Attempt Resuscitation) was a code that was used when participants specifically stated the term. It could be attributed to explicit knowledge, tacit knowledge or clinical knowledge depending on the context of the original statement. This is one reason for a cyclical process in thematic analysis, as the researcher can return to the codes to consider if the theme attributed to it is the most appropriate. At times it is necessary to work backwards and re-visit the coding, re-code or even discard some coding. This is an important part of the process and represents the researcher's commitment in producing a quality analysis (Braun and Clarke 2022). When a list of themes was available that appeared to encompass all of the codes, then the next phase of reviewing themes was initiated.

5.1.4 Reviewing themes

This is the quality control aspect of analysis, checking whether the candidate themes fit with the coded data. It is about telling a story that is faithful to the data (Braun and Clarke 2013). Moving through the phases is not a linear exercise but a diffuse exercise (Castleberry and Nolan 2018). A good theme will be informative, concise and catchy and it can be a short phrase, a heading or sub-heading that captures the essence of the theme and engages the reader (Braun and Clarke 2022). Moving backwards and forward from the codes to the considered themes, the following initial themes were adopted (with examples of associated codes aligned to the theme):

Themes	**Examples of codes**
Receptive to Criticism	Not enough training in pre-reg education Not enough time to consider properly Not been involved in decisions
Tacit Versus Explicit Knowledge	Regain capacity Participation Recognises family bonds/impact on family
Minimal Legal Terminology (sub-theme)	States Best Interests Recognises that best interests are the patients and not the family's Question the motives of LPA for P & F
Experiential Relevance (sub-theme)	Personal history (considering the answer) Experience-related response Empathy with the spouse/child/grandchild
The Clinical Comfort Zone	DNAR Futile/harsh Whole clinical picture Invasiveness of treatment
Ethical Empathy	Motivation of family perspective Family enjoyment/Connection Carer burden

Table 5.4 – Initial themes with examples of associated codes

Receptive to criticism was a stand-alone theme that was created to answer the research question and in direct response to the criticisms directed towards healthcare professionals, as the participants were not opposed to the notion of knowledge being poor. The theme around knowledge was too unwieldy to be a stand-alone theme and the existence of explicit or tacit knowledge was a central focus of the responses that informed the codes. The decision was made to split this theme into experiential knowledge and legal knowledge and how the responses were suggestive of tacit or explicit knowledge. The focus on minimal legal terminology was an attempt to name the theme in an interesting way. Minimal legal terminology as a sub-theme was meant to evoke the sense of knowledge being tacit even though there were not significant statements using terminology related to the legislation.

The codes suggested that participants framed responses around the clinical outcomes of each vignette, even when the questions related to aspects of care outside of the clinical interventions. The participants relied on clinical knowledge to support their responses and many of the codes were clinical in nature, so the clinical comfort zone was another theme created. Ethical empathy was the final attempt to be creative with naming the theme that acknowledged that participants expressed thoughts about complexity, conflict, challenging situations in relation to the vignettes and the characters within them.

To know when there has been enough reviewing, this phase should end with a set of distinctive, coherent themes, and a sense of how they fit together and tell the story about the data, it is not possible to find the *perfect* 'fit' (Braun and Clarke 2013). Following supervision discussions and further consideration of the themes proposed, the final themes were organised as follows:

Theme		**Context**	**Example codes attributed to theme**
1	Receptive to criticism	The participants accepted the criticisms and agreed in full or partially	Direct question posed to the participants – direct response in agreement or defence of knowledge
2	Tacit versus explicit knowledge	The participants demonstrated knowledge explicitly through use of terminology or tacitly through using experience or aligning discussions with the legislation Sub-themes of: • Minimal legal terminology • Knowledge through narrative • Experiential relevance	Explicit knowledge (correct) Legal Terminology (ADRT, BI, DOLS) Professional Decision Questions resuscitation wish Consider impact on patient's dementia
3	The clinical comfort zone	The participants defaulted to clinical aspects of care to consider the vignette	Whole clinical picture Invasiveness of treatment Focus on the condition (dementia)

			Treatment is the right way Different levels of sickness
4	Ethical appreciation	The participants were conflicted with the ethically challenging situation posed with the vignette and the correct course of action	Carer burden Ethical considerations Duty of Care Care environment Comfort

Table 5.5 – Confirmed themes with context and examples of associated codes

5.1.5 Defining and naming themes

Researchers at the interpretivist end of the continuum may argue that the very process of analysis itself, which is breaking texts into parts to reduce, sort, and label them, fractures the coherence and contextuality of narratives that constitute the data (Mills *et al* 2010). It was important to retain the context of themes when defining and naming them for write-up. The final analysis is the product of deep and prolonged data immersion, thoughtfulness and reflection, something that is active and generative (Braun and Clarke 2019). Following feedback from the viva, the analysis process was revisited, codes reconsidered and themes were further revised and reorganised thus:

Theme		**Context**	**Example codes attributed to theme**
1	Acknowledging criticism	Most of the participants accepted the criticisms partially or in full	Direct question posed to the participants – direct response in agreement or defence of knowledge
2	Demonstrating Knowledge	Sub-themes of: • Explicit knowledge – with use of legal terminology or factual statements • Tacit knowledge – with reference to understanding of the situation or drawing on experience to support thoughts The participants demonstrated knowledge explicitly through use of terminology or tacitly through	Legal Terminology (ADRT, BI, DOLS) Professional Decision Clinical rationale Questions resuscitation wish Consider impact on patient's dementia

		aligning discussions with the legislation	
3	The clinical comfort zone	The participants defaulted to considering clinical aspects of care to consider the vignette	Whole clinical picture Invasiveness of treatment Focus on the condition (dementia) Treatment is the right way Different levels of sickness
4	Person-centredness	The participants were conflicted with the ethically challenging situation posed with the vignette and the correct course of action so considered the person at the centre of the decision, their biographical history and quality of life. They also used personal experience to reflect on the vignettes.	Value-based QOL Family enjoyment/Connection Need to know the patient Personhood

Table 5.6 – Final themes with context and examples of associated codes

Criticisms were retained as it was a core concept of the study but acknowledged rather than accepted as some participants did recognise criticisms but defended their own practice. Knowledge was revised to encompass the explicit and tacit knowledge demonstrated by reference to the legal terminology, clinical and personal experience that was either factually correct and explicitly communicated, or factually correct and tacitly inferred within the context of the discussion. Having tacit knowledge and explicit knowledge as sub-themes made it possible to consider how responses contributed to demonstrating knowledge via different means. The clinical comfort zone was retained as it explained the default response of referring to clinical knowledge no matter the question posed and ethical appreciation was revised and reframed. Codes and responses aligned better to person-centred considerations that participants identified in respect of quality of life of the characters in the vignettes.

5.1.6 Writing up

An inductive approach is typical of thematic analysis where the researcher builds a complex exploratory, descriptive, or explanatory case analysis grounded in the particulars of the case (Mills *et al* 2010). The researcher should speak for the themes to tell the story they have made from the dataset and the analytic task is to tell a particular story about the data that addresses the research question, not to represent everything in the dataset (Braun and Clarke 2022). The research question focuses on the factors considered when determining best interests for patients with advanced dementia, with sub-questions about the procedural and substantive considerations, demonstrating knowledge of the Best Interests Standards and the available support mechanisms for best interests considerations.

A write-up can be organised any way that contributes to the reader's understanding of the case (Stake 1995). Yin (2018) proposes six approaches to organising the write-up of a case study. The linear-analytic structure of identifying the problem, reviewing the literature, methods used, data collection and analysis and findings, conclusions and implications is the standard approach discussed by Yin (2018) and adopted for this study.

5.2 Demographic data

Description of participants along with their working and involvement level in the case under study should be reported clearly with at least a short overview to give the reader an idea about the participants involved (Rashid *et al* 2019). The demographic data was collected at the beginning of each interview, this was reviewed at the start of the analysis process, followed by the responses to the interview questions. This study recruited thirty participants, each of whom participated in a semi-structured one-to-one. The interviews lasted from 30 minutes to 1 hour. The difference in time was a result of the semi-structured aspect of the interview and how participants engaged with the questions posed. The participants were recruited as volunteers from the student body of a University in the West Midlands, from a variety of post-registration courses lasting 6 months to 3 years (e.g. independent prescribing, Specialist Practice, Advanced Clinical Practice).

Table 5.7 details the demographic data about the participants. There were a range of participants in age, gender and ethnicity with a varied level of post-registration experience. According to the Nursing and Midwifery Council NMC, (2019), around eleven percent of registered nurses in the UK identify as male, a similar percentage of registrants are from outside the European Economic Area (EEA). The largest group of registrants are aged 31 – 50 years (around 50%), so the demographic of the participant group were representative of the register. More of the participants were studying at level 7 than level 6 and more were (or have previously been) caring for a friend of relative living with dementia. All had undertaken some form of education and training on MCA, from mandatory training as face-to-face or e-learning, to a half day training event within the last five years.

Age	Male	Female
Aged 20 – 29	1	3
Aged 30 – 39	1	5
Aged 40 – 49	2	12
Aged 50 – 59	0	6
Total	4	26
Ethnicity		
White British	2	22
White European	1	0
Mixed White and Black Caribbean	0	1
Black African	1	1
Black Caribbean	0	1
Asian	0	1
Professional Discipline		
RN Mental Health	1	0
RN Adult	3	26
Years Qualified		
< 5 years	1	3
5 – 9 years	2	7
10 – 15 years	1	6

16 – 20 years	0	2
> 20 years	0	8
Place of Work		
Community	1	18
Hospital	2	4
GP Practice	0	4
Health in Justice	1	0
Area of Work		
Birmingham	0	1
Dudley	0	3
Sandwell	0	3
Shropshire	0	2
Staffordshire	2	0
Telford	0	1
Walsall	0	7
Wolverhampton	2	9
Level of Study		
Level 6	0	11
Level 7	4	15
Cared for a PLWD		
Yes	2	17
No	2	9

Table 5.7: Demographics of Research Participants (n = 30)

Code	Nurse field	Years Qualified	Ethnicity	Gender	Age by decade
P1	RN Adult	4	White British	Female	20s
P2	RN Adult	13	White British	Female	30s
P3	RN Adult	30	White British	Female	50s
P4	RN Adult	31	White British	Female	50s
P5	RN Adult	17	White British	Female	50s
P6	RN Adult	23	White British	Female	40s
P7	RN Adult	15	White British	Male	40s
P8	RN Adult	21	White British	Female	40s
P9	RN Adult	13	White British	Female	40s
P10	RN Adult	11	Black African	Female	40s
P11	RN MH	4	Black African	Male	40s
P12	RN Adult	14	White British	Female	40s
P13	RN Adult	13	White British	Female	40s
P14	RN Adult	8	White British	Female	30s
P15	RN Adult	29	White British	Female	40s
P16	RN Adult	5	White British	Male	20s
P17	RN Adult	18	Mixed White/Black Caribbean	Female	40s
P18	RN Adult	25	White British	Female	40s
P19	RN Adult	8	White British	Female	20s
P20	RN Adult	8	White European	Male	30s

P21	RN Adult	9	White British	Female	50s
P22	RN Adult	5	Asian - Indian	Female	50s
P23	RN Adult	9	White British	Female	40s
P24	RN Adult	9	White British	Female	30s
P25	RN Adult	22	White British	Female	40s
P26	RN Adult	9	White British	Female	30s
P27	RN Adult	24	White British	Female	40s
P28	RN Adult	3	White British	Female	20s
P29	RN Adult	14	White British	Female	50s
P30	RN Adult	2	Black Caribbean	Female	30s

Table 5.8 Participant characteristics

Participants were asked to score their knowledge of the MCA and BIS from 0 to 10 (0 = poor, 10 = excellent). This is a subjective measurement but widely used as a scaling method (Taherdoost 2019). Table 5.9 shows how participants responded to this question on the demographic data form.

Mental Capacity	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
				2		15	4	8	1		
Best Interests	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
	1	1		1	2	10	4	7	3		1

Table 5.9: Self-Assessment of MCA and best interests Knowledge

The majority of participants scored themselves 5, 6 or 7 for both MCA and best interests (N = 27 or 90% for MCA and N = 21 or 70% for best interests). Only two participants scored very low (0) or very high (10) for best interests. The responses for best interests were less clustered than the responses for MCA, although most responses for both were between 3 and 8. Table 5.10 further details the scores in relation to age and table 5.11 in relation to length of post-qualifying experience.

AGE		Median	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
20 – 29	MCA	6						1	2	1			

	BI	5.5						2	2				
30 – 39	MCA	6				1		2		3			
	BI	6.5	1						2	3			
40 – 49	MCA	5						8	1	4	1		
	BI	5				1	1	6		3	2		1
50 – 59	MCA	5				1		4	1				
	BI	5		1			1	2		1	1		
Median MCA				5		Median BI						5.5	

Table 5.10: Self-Assessment of MCA and best interests Knowledge in Relation to Age

Table 5.10 shows how 16% of the participants (aged 30 – 39) scored themselves 5 plus in both MCA and best interests. The lower scores were for best interests rather than MCA and the lowest scores were with those in their 30s and 50s, although only one response per age group. The highest scores were also from participants in their 40s and 50s, although only one participant scored 10 for best interests and two scored 8 for best interests.

Qualified		Median	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
<5 years	MCA	5						3	1				
	BI	5.5					1	1	1	1			
5 – 9 years	MCA	6				2		2	1	4			
	BI	6	1					3	2	2	1		
10 – 15 years	MCA	6						4		2	1		
	BI	7						2	1	3			1
15 – 20 years	MCA	6							1	1			
	BI	5						1			1		

>20 years	MCA	5						6	1	1			
	BI	5		1		1	1	3		1	1		
Median MCA		5				Median Best Interests				5.5			

Table 5.11: Self-Assessment of MCA and best interests Knowledge in Relation to Length of Post-Qualifying Experience.

Table 5.11 shows how participants scored themselves in knowledge of MCA and best interests by length of service/qualification. Twenty-four and twenty-one (80% and 70%) scored themselves mid-range (5 – 7) for both MCA and best interests respectively. The median was 5 for MCA and 5.5 for best interests. With the shortest time qualified participants (<5 years) four participants (13%) scored themselves 5 plus in both MCA and best interests except for one response. The lower scores, for best interests were from those with 5 – 9 years' experience or over 10 years' experience where two participants scored less than 5 who were qualified for 5 – 9 years. Three participants scored less than 5 who were qualified for over 20 years. The highest score was from a participant with 10 years plus experience, whilst four scores of 8 were from participants with 5 – 9 years or over 20 years' experience.

Overall, this data does not confirm anything other than participants seem to score themselves in the mid-range (which would be expected (Moors 2008)). However, the lowest scores tended to come from those in their 30s or 50s, the highest scores also in the older age groups. The lowest scores were in those with lengthier years in experience, as were the higher grades. This could suggest that the older participants (seemingly those with the lengthier experience) had greater insight into their strengths or limitations or that the younger participants' knowledge was more current, reflecting their recency of pre-registration education. This may suggest that MCA is covered more comprehensively in pre-registration curriculums.

Appendix 23 presents the themes that were developed from the analysis of the data.

5.3 - Theme 1: Acknowledging criticism

The criticisms of the MCA and best interests were considerable within the literature and therefore a key feature of the interview. In the write-up, considering the participants' responses to the criticisms was a logical place to start. A significant proportion of the participants (n=13 or 43%) agreed with the statement that knowledge and understanding of the MCA and best interests by healthcare professionals is poor. The reasons for this were either not articulated or participants suggested that training was either of a poor standard or not frequent enough, seven (23%) participants expressed the standard and availability of training as a reason for knowledge being poor. Some simply admitted that they do not know enough about it (MCA/best interests), or that they did not work in a role where it was necessary to know about it. In their self-assessment of knowledge, the majority scored in the middle range for both MCA and best interests, there was no correlation between scoring and opinion on whether knowledge was poor or not.

Only six (20%) participants disputed the assertion that knowledge is poor. They defended their statements by offering assurance about their own practice; that they behave in an ethical way, in a person-centred way and therefore their knowledge is evident through their ethical behaviour. Some also commented that other limitations create challenges that might suggest a lack of knowledge. These six participants did not support their knowledge by using the terminology but they expressed that they did not think that knowledge is necessarily poor.

> *'I think that erm, I always try to look at things from an ethical perspective and try and weigh up the benefits and burdens….' (P25)*

> *'…we do look at it… as clinicians, as professionals we always try and look at what's in the best interests of that person, irrespective, although we're not mental health trained…' (P29)*

There were eleven participants (37%) who did not convey an agreement or rebuttal of the notion of poor knowledge, but they acknowledged the difficult and challenging concept of the MCA and best interests. Words used to depict the complexity were:

> *"big area", "grey area", "minefield", "many facets", "it changes", "it's varied", "bigger than you think*"

Even though the eleven participants did agree or rebut the notion of lack of knowledge, some blamed the quality and availability of training as reason for the assertion. Others referred to the training offered either in pre-registration training or during pre-registration training generally, as though this is when training should be received. Two participants expressed that different professionals may have different opinions on the MCA and best interests, which complicates the process whilst another suggested that other clinicians also previously had poor knowledge. There were three participants (10%) that expressed that they think that assessment is another person's role, rather than theirs; that they either pass on that responsibility to someone else or that another professional automatically takes on the responsibility. The reason for this will be explored in the following chapter.

Two participants suggested that people are afraid of the legislation or are nervous about it. There was some insight into the legislation from another two participants who explained how it was used incorrectly in their experience, through being advised to do a 'test' on every patient, with a recognition that this contravenes the 'presumption of capacity' and another participant suggested that there is often a presumption of incapacity associated with specific diagnoses, that some do not take the time to communicate with patients to support their decision-making.

When discussing the criticisms of the MCA and best interests, one participant identified a lack of resources as being a reason for the lack of application of the legislation:

> *"I don't know whether it's cos' our knowledge is poor; I think a lot is time and resources. Erm, yeah, I wouldn't say it's so much as not having the knowledge, it's yeah, it's being able to, to get to these patients and, you know, erm, have the discussions and the meetings and, you know, discussing best interests, having advance care plans, you know, they've been rolled out for a long time but still, so many people, because people haven't got time to actually fill them out or discuss erm, so, yeah, I, I think I'd probably disagree with that it's about, about knowledge." (P27)*

However, another three participants (20%) identified resources affecting the implementation of the legislation in incidental information, where they referred to specific cases where increased demand on services had had a direct impact on the ability to fully consider the MCA:

> *"I think we're all so concerned with time and getting things done quickly and getting people in and out and getting, you know, 'if I have to, I haven't got time, we're gonna breach'." (P13)*
>
> *"..we might be aware of the legislation and what have you but the resources are so stretched and you make decisions there and then because you might not be looking at that one person but you're looking at a group or you're looking at a family and sometimes there is, it is it's just a matter of resources sometimes. It's not that you don't know, so then start get frustrated and their families get frustrated and maybe the best isn't being done but it's not for a lack of people not wanting to, it's just for the things not being there". (P18)*

So, from the thirty participants, none defended their knowledge with any level of conviction, only six (20%) suggested that their practice reflected their knowledge (or others' knowledge in general). More participants agreed with the lack of knowledge and some offered reasons for this, others simply accepted it and with those who were non-committal about knowledge or the lack of knowledge, they explained the criticism in association with the complexity of the legislation within practice settings.

5.4 Theme 2 – Demonstrating Knowledge

The theme of *Demonstrating Knowledge* was developed through reviewing codes that infer a level of knowledge through the context of the response to the interview questions, where participants used terminology pertinent to the legislation and/or clarified their perceptions through the context of their response.

Table 5.12 shows the number of participants that demonstrated either explicit knowledge by stating facts relating to the MCA principles or BIS or tacit knowledge through discussing information that related to MCA principles or BIS.

Best Interests Standards	
Past wishes and values	30 (100%)
Least restrictive option	16 (53%)
No assumptions	8 (27%)
Consider all circumstances including family obligations	24 (80%)
Consider if the person will regain capacity	1 (3%)
Encourage participation	13 (43%)
If the decision is about life sustaining treatment, not to hasten death	1 (3%)
Consider what decision would be made if the person could make it now	5 (17%)

Consider others’ views	20 (67%)
Considered one or more of the 4 Arms of decision-making	14 (47%)
MCA Principles (best interests and least restrictive as above)	
Presume capacity	13 (43%)
Support	11 (37%)
Unwise	2 (7%)

Table 5.12 - Number of participants to identify MCA principles or BIS

5.4.1 Sub-theme - Explicit Knowledge

Explicit knowledge is knowledge that can be articulated in formal language, easily transmitted, and implies factual statements about matters that can be encoded by language in written words and/or machine (Olomolaiye and Egbu 2005). Reviewing the data specifically for terms used within the legislation, such as *advance statements, advance decisions, ADRT, Power of Attorney*, suggested that the participants utilised language associated with the legislation. There were three participants that queried if the patient required a DOLS (Deprivation of Liberty Safeguard), which might be required for the patient with pneumonia who was in a hospital/nursing home but their rationale for querying DOLS was not clear; they also articulated other terminology relating to the legislation. On deeper analysis that focused specifically on terminology, there was only one participant that did not use some language or terminology reflected in the full legislation or the COP (DCA 2007). This was inferred as explicit knowledge of the legislation.

An example of explicit knowledge referring to an unwise decision:

> *‘….. everybody’s got capacity unless they make an unwise decision but people can make an unwise decision and still have capacity but I think people forget that and then put it down and say that ‘well they’ve not got capacity’….’ (P2)*

The participants that demonstrated explicit knowledge, were those who made factually correct statements in relation to the legislation, of which there were fourteen (47%). Some of the facts expressed were around the process of capacity assessment and best interests considerations, who is able to make a decision on behalf of another, the legality of expressed statements and the principles of the MCA. There were also six (20%) that correctly identified that the amputation case might benefit from referral to the Court of Protection (or the organisation's legal team), which is a demonstration of explicit knowledge of process. Cross referencing these participants showed that nineteen (63%) in total expressed factually correct responses, demonstrating explicit knowledge of certain processes.

There were inaccuracies in some of the responses, for example, that the next of kin would be the decision-maker or that the LPA in property and finance intimated some decision-making responsibility for health and welfare. There were eight participants (27%) that were keen on identifying the next of kin of the patients discussed in the vignettes, as though they would have some influence in the process. The term next of kin is an umbrella term, creating the potential for public and professional misunderstandings. The term signifies no formal rights or liabilities, the next of kin cannot make treatment decisions about another, nor receive information about another's health care or treatment without the consent of that individual (James and Cornock 2008).

Some of the incorrect responses were in response to the power of attorney for property and finance being applied to health and welfare:

> *"Erm, so power of attorney, you know, granddaughter's got power of attorney, so she should really have the say in erm, you know, how he's cared for and also given the fact that he's living with her. So, she's should really have the overall say." (P22)*

There were also several responses where power of attorney for property and finance was misunderstood, including that a lawyer has to be involved in its formulation, that it gives responsibility for the last will and testament and that the attorney can 'sell everything from underneath a person'. Other incorrect responses were pertaining to MCA and best interests to the mental health arena:

> *"Erm, I think where it does come to mental health it is a big conflict, especially for us in health, when there's not always that training there for what to do in specific situations, like anything." (P19)*

There were twelve participants who expressed information that was factually incorrect, although they had utilised the terminology of the legislation, they responded in ways that were factually inaccurate; this increases to sixteen if querying next of kin is cross-referenced. Inaccurate information relayed in the responses could undermine the inference of explicit knowledge through the interviews. However, the inaccuracies were generally compensated for through other statements made by the participants, some of whom also stated factually correct information within their other responses. Explicit knowledge was inferred through participants' references to the legal terminology but the limitation with this was that some incidences were factually dubious, which demonstrates that explicit knowledge can be inaccurate (Esteki 2014).

5.4.2 Sub-theme - Tacit Knowledge

Tacit knowledge is the kind of knowledge that is difficult to demonstrate and is not known explicitly; individuals are not always aware of their knowledge or how to communicate it externally. A qualitative study conducted by Kothari *et al* (2012) explains through reference to the literature, that tacit knowledge incorporates practical and experiential knowledge, which is often preferred by nurses over traditional, formal sources. Knowledge about work practice, how one does one's job is also tacit, and can be conveyed by narrative (Linde 2001). An example of tacit knowledge referring to the four arms of decision-making (retain the information):

> *'But, has he got an understanding of, of, of the complications, of the benefits, the risk factors? Erm, he hasn't got, cos he hasn't got capacity do we know that he is able to obtain the information to make that decision? It's hard to say what he would want.' (P14)*

As the data was analysed and emerging codes were identified, the BIS checklist was considered as a potential coding term, to establish explicit or tacit knowledge. The factors within the checklist identified in table 5.13 were considered and when developing the thesis, grouped together in respect of similarity or cohesiveness, additional codes were also considered in the writing up phase.

Code (best interests checklist or additional)		**No: of responses**
2	Consult all those close to the individual	20 (67%)
3	Consider the individual's views, whether expressed verbally or in writing, including their feelings, religious beliefs and past habits	30 (100%)
4	Consider all circumstances, including emotional bonds and family obligations	24 (80%)
+	Evidence of wishes requested	23 (77%)
+	Check validity of advance statement	8 (27%)
+	Respect expressed wishes	19 (63%)

+	Decision is a professional decision	10 (33%)
+	Clinical rationale for decision needed	4 (13%)

Table 5.13 participants where responses aligned to the best interests checklist

There were a significant number of participants that, when discussing the vignettes, identified or queried the importance of exploring the past wishes or life-values of the person when making best interests deliberations. When cross-referencing responses, of the thirty participants that considered this aspect of the checklist, twenty-four (80%) also considered all circumstances, twenty-three (77%) also requested evidence to support the expressed wishes of the patient and eight (27%) wanted to check the validity of any advance statements, whilst nineteen (63%) directly stated that they wanted to respect the expressed wishes.

Past wishes:

> *"…but… you see cos she wanted her husband resuscitated (ssmmmm huhhh) but that's hard …. isn't it? cos that's a different circumstance, you don't know what circumstance that was in….." (P2)*

Evidence to support past wishes:

> *"…he'd expressed some previous wishes. Erm, however, then we then go on to say that this wish may have been done whilst he was unhappy. So, was there any under depression about when he made that decision about not wanting amputation?" (P16)*

Check the validity of any advance statement:

> *"So, it's I think you sort of, it's got to be looked at when was the decision made? How, what stage of dementia had he got when the decision was made, or even if he had dementia at that time?" (P29)*

Respect any expressed wishes:

> *"I would want them to erm, take the wishes I'd made when I had mental capacity because, you know, with her erm vascular dementia she's had for 8 years, the problem is that her daughter's saying she might have changed it but we will never know because you can't, any question you ask her, I don't know whether she's got a lot of short or long term loss, you're living in that moment so you can't really gauge her wishes, you have to go by what wishes she made the first time. That's what I think." (P4)*

There were eighteen participants (60%) in total that considered all circumstances when discussing the vignettes (all circumstances including family obligations):

> *"So, even though she's got dementia, she's still deriving satisfaction there. And the family is close, and the family are very supportive of her, so, I think, from that information I would think she would want to erm, have the intervention of er, antibiotics." (P11)*
>
> *"I imagine what they feel Alan is able to do with his family. Er, what, what things does he do with them, what, er, what help does he need, does he play with his great grandchildren, do they manage to get him out? Is he just stuck at home? Those sorts of things; see whether not that he, whether that should be or shouldn't have it done but whether if he, he could make that decision, to be able to carry on doing those things that he enjoys." (P26)*

There were twenty (67%) participants who consulted those close to the individual, ten (33%) were confident that the decision would be a professional's responsibility and four (13%) specifically requested the rationale of the clinician that would make the decision to treat or not to treat.

> *"I would wanna know how the family felt about it. Cos the family are obviously still active, her husband's going and seeing her every day. The sons see her regularly, they're very*

close. I'd would, I'd wanna ask family, what would your mom want? Cos, we don't know. There's no comment about what would mom want in this scenario is there? Has she got any advance care plans in place? Is there anything, again this was eight years ago, so has anything been done so maybe that might be the thing, the two things I'd wanna know what the family think and is there anything been formally in, put in place for such decisions?" (P12)

"So, from him not having capacity the clinicians would have to make one on the best interests of him." (P7)

Code (best interests checklist or additional)		**No: of responses**
1	Encourage the individual's participation	13 (43%)
5	Avoid making assumptions	8 (27%)
6	Consider whether capacity will be regained in the future and whether this discussion could be delayed until then	1 (3%)
7	Consider the potential decision the individual might have made if they still had capacity	5 (17%)
8	Consider whether the least restrictive option has been taken in making the decision	17 (57%)
9	If the decision is about life-sustaining treatment, ascertain that no one involved in the decision-making process has a desire to end the life of the individual and that no assumptions have been made about their quality of life	1 (3%)
+	Presume Capacity	13 (43%)

+	Support	11 (37%)
+	Unwise Decision	2 (7%)
+	4 ‘arms’ of decision-making	14 (47%)
+	Query or accept the assessment of capacity	16 (53%)

Table 5.14 participants where responses aligned to the MCA principles

With the principles of the MCA as additional coding criteria, thirteen (43%) participants made comments that suggested that they presumed that the patient had capacity, an additional seven (23%) either queried if a capacity assessment had been completed or accepted that the vignette intimated that the patient had been appropriately assessed as lacking capacity. Of the thirteen (43%) that presumed capacity, seven (of a total thirteen) were cross-referenced as encouraging participation in the process or stated the need to support the patient to be involved in the decision-making process (seven of a total eleven):

<u>Presume capacity/Query capacity assessment</u>

> *“At this time there’s no mention that, yes, he has lack, he is lacking capacity to decide on an amputation at this time, but there’s nothing in place really stating that he lacks that capacity. So, he has not been asked as a person, he himself has not been approached to see if he really wants an amputation or not.” (P10)*

<u>Participation</u>

> *“…has somebody actually sat down and explained to him? Because if they ex, if they do explain to him, they’re probably gonna have to repeat it each time they explained to him, they’re going to have to repeat it aren’t they at that point, I imagine.” (P12)*

<u>Support</u>

> *“…but he’s unable to communicate then over cos if he’s verbally can’t communicate erm and whether the use erm they use er either like pen and a paper cos erm whether he can*

> *whether he can er still write or whether he can communicate through a board or a erm tablet, picture cards, things like that…" (P2)*

There were five (17%) participants who considered what decision the patient might make if they were able to on the day but only one considered if capacity would be regained. However, two participants referred to the challenges of assessing capacity, especially when capacity is fluctuating. This highlights the consideration of capacity resuming when it is not a permanent and sustained loss. Only two participants considered that patients may make what are deemed as unwise decisions and this was in general, rather than in relation to one of the vignettes. However, seventeen (57%) participants did consider if the treatments suggested were the least restrictive approaches and suggested other treatments that might be considered as less restrictive than what was considered within the vignettes. As one person stated:

> *"…what treatment could she have in place of the amputation, I suppose, or the management of it if she didn't have the amputation because what with the risks that she's got of the harm of not having the surgery, of infection and things like that…" (P2)*

Although BIS state that no assumptions should be made, including where treatment involves life sustaining interventions, participants did make statements about the patients' quality of life, though generally from a perspective of preserving life rather than life-ending. Participants either made assumptions about the patient's quality of life, acknowledging that they were making assumptions or stated that they should not assume anything about a patient:

> *"We don't know her quality of life, …. And I think that would give you more to make your decision on. ……. If she's completely sort of end stage or probably only has months to live why are we putting her through more pain and things…" (P4)*

> *"I think in situations like this, it, we are, we do, we have to make assumptions around how the person might feel, because if they're not able to express themselves er, in a way that we might understand, that's what you, you do." (P11)*

The four arms of decision-making capacity, referred to in table 2.2 (section 2.1) namely, understand, retain, use and communicate was used to establish if the participants reflected the terminology in their responses. There were fourteen (47%) participants that discussed at least one of the 4 arms of decision-making:

> *"…did he understand the potential of that this could be the decision that was gonna be made? Erm did Alan risk, understand the risks of surgery at that point?" (P6)*
>
> *"So, it's not er, er, a one-day wonder, you have to keep coming back to make sure that that patient understands what there's, what you are asking them to do, can they retain that information?" (P10)*

Whilst the responses indicate a level of knowledge, both tacit and explicit, it is not possible to evidence presence of or lack of knowledge in all elements of the legislation. Participants demonstrated explicit knowledge by stating factual information or by using the terminology of the legislation and they demonstrated explicit knowledge by inferring an understanding of the legislation in an appropriate context.

5.5 Theme 3 – The clinical comfort zone

When responding to the questions on the vignettes, the participants answers were more fluent when they were discussing clinical aspects of care. Some participants defaulted to discussing clinical aspects when the questions were posed around non-clinical aspects, such as individuals' feelings about the situation, legal aspects to consider, and potential conflict to identify. As clinical care is a fundamental aspect of nursing care, it is acceptable that the participants demonstrated a level of fluency when discussing the clinical aspects of the vignettes. However, BIS specify that more needs to be considered than simply the clinical outcomes of a case. It is evident in theme 2 that the participants did consider other issues as well as clinical, such as the views of others, but a default to the clinical context of the cases was a common theme in the interview responses. Each vignette was a case, where a clinical decision was required on initiation of treatment, so it was expected that participants would rationalise their considered responses to each case from a clinical perspective.

In the case of the amputation (vignette 1), sixteen (53%) participants made the decision to amputate, twelve (40%) made the decision not to amputate and two did not commit either way. In the case of the aspiration pneumonia (vignette 2), twenty-seven (90%) participants chose to initiate treatment, whilst three (10%) chose not to initiate treatment; sixteen (53%) participants chose to treat in both cases and only two (7%) participants chose not to treat in both cases. There were seventeen (57%) participants that felt that clinical treatment was a priority, an additional three (10%) who felt that treatment was the right way to go in either one of the cases, so twenty (67%) in total felt that treatment in either or both cases was important. As illustrated by:

> *"The key priority is making sure that Kashi gets the treatment that she would have wanted and erm, what is best for her now in the situation she's in" (P4)*
>
> *"I'm thinking, if he's erm, if he has the amputation, he's probably, well, if he doesn't have the amputation, give, you know, he's gonna lose his leg anyway. So, his foot is the priority in all of this." (P22)*

There were twenty-six (87%) participants that considered a complete clinical picture when rationalising their response to the questions, such as the multi-morbidities that the patient lived with (in the amputation case) and the number of admissions that the patient with pneumonia might experience if their condition is not addressed. As this quote suggests:

> *"…to look in relation to how she's, how many times she's had pneumonia, in whatever timeframe, see what antibiotics have worked and how effectively they have worked, and then assess her general health to how everything, to how she is erm, and maybe speak with the microbiologist with regards to different types of antibiotic and what they suggest with regards to where we go, where we carry on from here. Like I say, MDT meetings, getting the GP, maybe respiratory consultant, people together in order to get a plan in place for what to do next if the antibiotics are not working what plans do we have in place.." (P24)*

The clinical default was identified in nineteen (63%) of the participants, where they chose to relate to clinical aspects of the case as opposed to what was asked in the question (e.g. the legal aspects). It was not always inappropriate, and the participants may have referred to the question in another way, but it did demonstrate that they were more confident with their clinical knowledge when responding to the question than non-clinical knowledge. As this quote suggests:

> *"Erm, […] and it's a risk, also the legal aspect is to the, his er age and everything else does he meet the anaesthetic criteria? That would be a legal impact because they could come and say 'sorry, you don't meet the ASA criteria, that you could end up dying during the operation cos it's such a risky operation'. So, that would be another legal matter in there because that, that actually may sway things…" (P7)*

The participants demonstrated their clinical knowledge in respect of each vignette when they balanced the risks and benefits of intervention versus non-intervention. All thirty participants considered potential risks of treatment and non-treatment of the patient, sixteen (53%) also focused on the impact of the condition of dementia on the patient and whether this would influence the decision to treat, including if the patient would be resistive to care. The following quotes gives an example of risk versus benefit:

> *"Erm, I think from, what would be useful is his multiple co-morbidities, so his history, erm, the risk of harm and the pros and cons of both amputation and no amputation. …. Erm, the risk of surgery and all the potential complications and the healing process due to some of his co-morbidities. Such as the diabetes." (P14)*
>
> *"…he's also got multiple comorbidities, erm and there is risks if he has any surgery that he might not pull through it." (P23)*

Other considerations that participants considered as part of the clinical aspects of care were the standard of care offered in the care settings in which the patients resided, for instance at home for the patient in vignette 1 and the nursing home for the patient in vignette 2 (n=18 or 60%). Patients' mobility prior to and/or post intervention was also a consideration for six participants and the number of admissions experienced as part of the overall care was considered by three participants. This links in to considering the whole clinical picture; participants evaluated a number of factors that might impact on the patient's clinical stability, risk and benefit of intervention.

There were two participants that spoke about the different levels of sickness (primarily pneumonia), where patients may recover from one type but not the more serious; basically, considering how significantly poorly the patient was and whether initiating treatment was futile. Parallel to this, participants considered whether treatments were viable (n=13 or 43%), the invasiveness of any potential treatment or whether it would be futile to treat (n=13 or 43%). The following quotes demonstrate this:

> *"But if, if it's just a pneumonia; she's coughing and you know, you, you can see, there, there are different levels of sickness. You know that someone is really, really unwell*

> *and anything we can do now, there's no guarantee that is gonna bring them back. Or we just let them be comfortable and slide to sleep." (P10)*
>
> *"She's obviously not well if she's going in and out of hospital getting infections but maybe for her, she wouldn't potentially, wouldn't want to be treated and would just want to be left without having the infection/treatment, infection/treatment, infection/treatment." (P28)*

There were sixteen (53%) participants that considered whether the patient(s) were at the end of their life or required palliative care interventions/had reached their ceiling of care. Of those sixteen participants that recognised the potential palliative condition of either patient, five (17%) still considered initiating interventions that are advised against in end-stage dementia (PEG/NG) and fifteen (50%) decided to treat the aspiration pneumonia with antibiotics even though it is not deemed as useful in end-stage dementia. The rationale for this was linked to the fact that IV antibiotics are not wholly invasive and theme 4: ethical appreciation. The following quotes give examples of this:

> *"If she's completely sort of end stage or probably only has months to live why are we putting her through more pain and thing, and I think that would be a better indication that would give you more information to say what's the best interests" (P4)*
>
> *"But in the SALT assessment, it's really important even before starting the medication for the simple fact of, er if we do the swallowing assessment of a patient, erm, I can, er, figure it out if the patient needs a naso-gastric tube or not." (P20)*

In respect of invasiveness and treatment futility, eighteen (60%) participants in total mentioned a Do Not Attempt Resuscitation (DNAR) order, querying whether the patient(s) either had or required one, recognising that it would be appropriate to organise in either or both vignettes and establishing the difference between actively intervening to sustain life and initiating cardiopulmonary resuscitation (CPR). The following quote suggests this:

> *"It doesn't say that she's got a DNR. Erm, so, is it down to her family to decide or is it medics? Well, it's both isn't it really? But, erm, I think there are challenges because, clearly, she's so, in such a poor state physically, one episode of pneumonia and that really could be the end for her couldn't it? Is it fair to keep her going for another, to sit and wait for another infection cos she's at high risk of one isn't she?" (P15)*

Also linked to the clinical comfort zone was the tendency to involve other members of the multidisciplinary team (MDT) in the care of the patient and, where necessary to refer the decision to another, acknowledging either the limitations of their role or suggesting that the 'decision-maker' would be a more senior member of the MDT. This is acceptable in respect of the process of best interests meetings, as a decision-maker does tend to be nominated and it is often the senior clinician involved in the case. However, it may indicate that the participants do not view themselves as potential decision-makers and this may be a reflection on knowledge and practice within the guidance/legislation. Others' views is an important aspect of the best interests checklist, the fact that 24 participants considered the input of specialists is encouraging in respect of the legislation. It reflects the theme of the clinical comfort zone because it is, again, a default position to involve others when decisions are complex and require input from others to reach a consensus. The following quotes support this:

> *"Erm, well it for me, I would be thinking it's an MDT erm situation, where you would discuss the patient and their condition with everybody involved in the patient's care." (P6)*

> *"Potentially, erm, they might see end of life as being more appropriate in her situation. Erm, cos unfortunately, it's often not wonderfully understood, I don't think. Erm, from a medical perspective, not that I am, but from a medical perspective, that's quite a big negative." (P18)*

Interestingly, ten (33%) participants stated that patients "strive to survive" or that professionals have a desire to preserve life, which could explain why treatments are initiated when they may not be the most appropriate way forward for the patient concerned. As two participants commented:

> *"I think we all strive to survive whatever the cost, don't we?" (P13)*
>
> *"…my practice is to preserve life, so I would well be like, well, you know what I'm leading to saying 'have the amputation', because it's in the best interest but I dunno if that's the A & E in me because if somebody says 'no I'm not having it…' and then they pass out we have the right to invoke the emergency rule, which is to save life…" (P7)*

There were several inaccuracies in respect of clinical care that suggests a lack of knowledge in clinical care of a person with dementia, rather than a lack of knowledge in MCA and best interests. There were twelve participants (40%) that suggested insertion of a feeding tube to counteract the swallowing difficulties of the person in vignette 2 with aspiration pneumonia. Either the insertion of a percutaneous endoscopic gastrostomy (PEG) or naso-gastric (NG) tube was suggested, when in fact it is advised against in people with advanced dementia as the risks outweigh any potential benefits of the intervention (Chang and Walter 2010). The desire to treat the person with pneumonia was potentially also contentious as antibiotic therapy at end-stage is generally not effective, so participants may not have correctly identified that the person is entering the end-stage and may be dying.

5.6 Theme 4 – Person-centredness

Theme 4 evolved from collating the statements made by the participants about the challenging aspects of each vignette from a person-centred perspective. They considered quality of life issues in relation to whether it was suitable to align these to the best interests process. The participants also acknowledged 'soft' detail, such as the emotions evident from all parties involved, the impact of the decision on all those involved, relationships and the motivations to sustain them. This theme combined moral and ethical considerations, professional considerations and the domains that influence if life is worthwhile; it is a culmination of the person-centred considerations that the participants expressed when responding to the questions.

Participants either mentioned quality of life directly or spoke about quality of life in respect of value-based experience of the person with dementia to justify the course of action they were considering. There were twenty-seven (90%) participants that mentioned quality of life directly and sixteen (53%) that mentioned value-based quality of life aspects, so, when cross-referenced, twenty-eight (93%) in total explored quality of life issues in respect of whether treatment was or was not indicated. If participants decided that intervention was not appropriate, they used quality of life to justify non-intervention. Similarly, if intervention was an option, then quality of life was given as a reason to intervene/treat. The following quotes give examples of this:

> *"You know, erm, that she still has things that she enjoys about life. That she recognises, or appears to recognise, you know, something about her husband. That she smiles, she enjoys his company, holding hands and you know, sink into the music and what have you… there's, still a little bit of happiness there, there's still life there and, and it might not be my idea of a, of a great life but it, it, that's what she's got*

> *and perhaps, you know, she was a more resilient person before it happened and this, you know, she seems, she seems quite happy..” (P13 – chose treatment)*
>
> *“She’s just so fragile. She’s not taking anything in, so nutritional intake is minimal. So, I would think that is fluids and food. She’s got this recurrent chest infection, this respiratory infection. She’s aspirating on fluids. Her weight’s lost, she is incontinent, she is at high risk of breakdown. If you take the person out of it, it’s not very good picture overall is it? As a health condition. And putting in the IV antibiotics in, might be causing more harm […] than […] well, nature.” (P12 – chose not to treat)*

Participants recognised the emotive situation and the complexity involved. *‘It’s hard’, ‘It’s difficult’*, were comments that were made by fifteen (50%) participants, when identifying the emotive aspects of the situation. One participant responded by expressing how they felt the family member who wanted to respect the patient’s wishes would feel:

> *“Well I think he’s making a very hard decision er but he’s doing er what she wanted so he’s respecting her wishes erm and I think he’s got, it’s quite difficult for him because obviously when not everybody in the family is on board that can make it even more difficult to be the one that continues to make the decision that the person wanted in the first place. So, I think that’s quite difficult for him.” (P3)*

The conflict in vignette 1 was a particular cause for concern, with five (17%) participants identifying it as the most challenging vignette because of the conflict involved. There were four (13%) further participants who expressed that both vignettes were complex and challenging, though not uncommon. In total, nineteen (63%) participants expressed that the situations were challenging enough without the conflict being introduced, an additional five (17%) acknowledged how complex the vignettes were.

Connections between family members, relationships within the care environment and motivations for decisions were common considerations with the participants. There were fifteen (50%) participants that queried the motivation of the family member for supporting a course of treatment, from who is most affected by death, to the unfortunate consideration of financial control, to what the significant other's desire for the patient might be and potentially projecting their wishes on to the patient. Advocates were suggested in some circumstances (ten participants 33%), either through professionals or independent advocates to support the decision-making process. The person at the centre of the vignette was the primary consideration for these participants in these instances.

Family connections and family support were important to nineteen (63%) participants, with carer burden and the care environment being issues that were also raised. Communication was also an issue, to encourage unity in the decision-making process; if family members were communicated to in a sensitive way, they may well concur with the course of treatment suggested by the clinicians and a best interests consensus more easily reached. The following quotes are examples of each aspect:

Motivation

> *"…even though they live there it's not their home so if something happens to her or she has to move for instance socially wise, will she need to provide that home as payment for her care and where would then the family go with the children to uplift them to kind of like cause erm disturbs and disturbance into their daily lives as well.." (P2)*

Family connection

> *"But then I suppose it does, you have to question how long he's been living with the granddaughter and what she actually does for him erm, in order to make that decision." (P24)*
>
> *"..the patient doesn't remember their death, the family do." (P28)*

Communication

> *"Well you'd hope, I think, that with discussions the family might see that it's potentially the best option to not keep treating." (P26)*

In respect of the complexity of both vignettes, twenty-three (77%) participants observed the lack of or importance of advance planning in dementia, to avoid future conflict in decision-making and to avoid the emotional turmoil that accompanies surrogate decision-making in any form. This was one of the person-centred ethical considerations that was identified by participants, alongside 'duty of care' that was identified by six (20%) participants. They used duty of care as a rationale for treating the patient in both scenarios, one participant suggesting it as a reason for respecting the wishes:

> *"I think, yeah, I think it's sometimes with nurses or clinicians, I feel that the, they've got that duty to care and so they have to do something, they have to react, they have to." (P28)*

In respect of duty of care, participants also suggested that it is not appropriate to use the diagnosis as a reason not to treat, which reflects the person-centred ethical considerations discussed.

> *"Again, you know, it's listening to the doctors rationale, making sure that their rationale is patient focused and not, sort of, yes, clinically focused if it's about the patient, but not, erm, just looking at, at the patient and saying 'well, she's got*

> *advanced dementia and she's not eating and drinking as much, so, we're not gonna give her antibiotics'." (P25)*

There were general questions posed to each participant, including a question about whether they felt that it was easier to make a decision for a patient if they were not directly invested in the situation, if they had no prior knowledge of that person. There were nineteen (63%) participants who specifically stated that they would prefer to have first-hand knowledge of the patient so that they could represent their wishes or support the family through the process. Only four (13%) participants thought that it was beneficial to have no knowledge of the patient or the situation because it promotes objectivity, although one of these participants made another comment that it is important to know the patient. There were seven (23%) who saw the value in not being personally invested but also saw the benefit of first-hand knowledge, particularly as it would give you the opportunity to observe how the patient may have changed over the course of their involvement.

There were also several comments about personhood, how the patient were 'in themselves', and how they responded emotionally or intuitively to their surroundings and relationships. These responses demonstrated that the participants were receptive to non-clinical aspects of care, the aspects of care that inform what a person's values might be, that can inform decisions. This links back to tacit knowledge and supports the idea that tacit knowledge is difficult to quantify but is enduring throughout the responses.

> *"Erm, and, and I would imagine that even though she may, she has been assessed and she's lacking capacity erm I don't, you know we don't know what erm exactly how… I would imagine that she would be able to be feeling the tension and feeling the pull of the two different people knowing very well that, you know, she's not going to be pleasing both of them erm in this situation." (P5)*

Another consideration in respect of person-centredness was related to the age of the characters in the vignettes and whether the participants made any value-based assumptions in relation to their ages and conditions. In fact, twenty-nine (97%) participants did refer to the ages of the patients, but not entirely in a judgemental way. Some did make assumptions about the older patient:

> *"I wouldn't want to be treated. I would want to erm, I would just want to be left alone; I'm 83, I've got loads of co-morbidities, erm, I've got advanced dementia and I knew I didn't want any intervention so erm I I'd want my wishes to be respected." (P3)*

Only one participant did not mention the age of the characters in the vignettes, an interview question asked for their perspective of the ages and whether they considered age when responding to the vignettes. There were three (10%) participants who felt that there would be a bias towards younger patients and that healthcare professionals would take more intensive action for younger patients, even though they expressed that this might not be the most ethical approach. There were twelve (40%) participants who expressed that they did not think age was a factor at all when considering treatment options for the patients in the vignettes, as it would be discriminatory or unethical, although all of them did mention age in their responses to the questions (some as a reason to initiate treatment):

> *"For me I would say it, the family would probably, you know have a lot to say because on the face of it she may just look, just like a nursing home patient but she's still relatively young, erm she's had Alzheimer's Disease for 8 years but she was 55 and I think she's still got some quality, her family still recognise that she's enjoying them being around even though she's not in her own home." (P6)*

Of the participants who did consider the age of the patient in each vignette when responding to questions about the treatment options, five used age as rationale when considering treatment options and twelve considered the physical state of the patient alongside the age to establish if age was a factor in treatment outcome:

> *"You know, he's 83, he's got advanced dementia he's got a load, quite a lot of comorbidities and I'd think they'd look at clinically as a whole, his not, he's not great, is he?" (P14)*
>
> *"But, definitely, even with 83 years old I think that he could have a further ten years of er, life or, or so, erm, even with his comorbidities. Cos, I cannot, I can't tell that he has an MI in the past but er, taking that away and I know that he is got some renal, er concerns, I would say that there is no heart failure, there is no renal failure, there's nothing, there's no concern. So, there's nothing to say straight away that the patient wouldn't last after the surgery." (P20)*

Finally, in this theme, participants focused on measures to enhance comfort and ensure that the treatment pathway was patient-focused, also recognising that as conditions change, the person's wishes may well change, adding to the complexity of the situation:

> *"I think clinically you know is to continue obviously to provide best care so do the dressings and keep her comfortable and free of pain, erm, erm and all that kind of thing, erm but to respect the fact that she doesn't want to have, she doesn't want an amputation so the best that we can do, given the circumstances." (P3)*

When considering their responses to the questions, some participants referred to either personal or professional experience to give context to their responses. There were 19 (63%) participants who had or were caring for a person living with dementia, but only seven (23%) recalled personal or professional experience when responding to the questions. The responses were around perspectives on how the patients in the vignettes felt or how the participants had dealt with similar situations themselves.

> *"I used to work in a nursing home ……. I do remember, one used to sit in the office with the staff, cos she didn't like the other ……. there was still things that she enjoyed, and you could never really tell, you could never really tell how she was feeling but if you sat there and held her hand she'd sit and hold your hand. …. I don't know how, I don't know how far it goes when you feel that you're actually, that your no longer just locked inside yourself but there's nothing, there's nothing else there." (P13)*
>
> *"I've just had two that have been too poorly and gradually died because of their, not just the ischaemia, but they've got an ischaemic limb and there's nothing they could do with them." (P26)*

Drawing on experience supported the participants' responses to questions, demonstrating how they reflected on experience to consider their judgements on the vignettes, putting the person at the centre of the decision.

In respect of this theme, participants demonstrated insight into the additional aspects of care delivery, outside of the clinical picture that they discussed easily and fluently. Although they may not have used the legal terminology as confidently, they were able to rationalise their considerations from a clinical viewpoint but also show how they would approach the situation in a person-centred way, acknowledging the emotions of all involved and piecing together clinical and moral reasoning to reach a consensus.

5.7 Incidental information

During or at the end of the interview, some participants expressed some incidental information that related to experiences they had about the MCA and best interests. Some of the experiences shared were associated with the 'least restrictive' aspect of the BIS. Although the individual participants did not relate the experience directly to the 'least restrictive' aspect, the detail of each incident featured practice that was potentially restrictive of the person’s freedom and the participants struggled with the impact of the incident; demonstrating the challenges that they have faced in practice involving MCA and best interests. For instance, one participant described an incident where a patient required a urinary catheter insertion, deemed in their best interests but the actual procedure was traumatic for the patient, as well as being disturbing for the staff undertaking the procedure. The participant did not explore whether this incident contravened the ‘least restrictive’ aspect of the BIS but acknowledged how difficult the incident was for all involved.

> *‘Obviously, erm, in her, it was in her best interests for me to re-catheterise her, she couldn’t make that decision herself, she couldn’t retain the information that, that I was telling her or understand what I was telling her, she couldn’t make a decision for herself, it was clear that she didn’t have the mental capacity to say yes, for me to re-catheterise her and so I tried to do it, to re-catheterise her in her best interests because otherwise she would have been in pain, there would have been severe complications because she couldn’t pass urine…….it was very, very difficult erm, and very upsetting erm but that had to be done at that, for that patient at that time, otherwise there would have been severe complications on her health………. That stayed with me for a long time because I was thinking ‘did I do what was right in the best interests of that patient?’ ….. other avenues were pursued as a result of that, as well, to see if there was anything else we could do for this lady, ……. so, then it wouldn’t be as, you know, difficult erm, sort of, erm, intrusive, for her’. (P25)*

Two participants recounted situations where a patient was refusing medication and, in their best interests, it was decided to administer via an injection. Neither participant explored or expressed any consideration about the ‘least restrictive’ option but did express how difficult the situation was at the time. One discussed how at a later date; the patient was taken off the medication. This demonstrated that the 'least restrictive' option may not have been explored at the time and as it transpired, was not the least restrictive option; a less restrictive option was finally taken for the individual involved. The participant was frustrated about this situation, expressing that the final treatment approach was requested previously but was not implemented until the patient moved care settings. The participant was aware that the least restrictive option was not taken in this instance although did not refer to it directly when discussing the situation.

> *I've also had the situation; we had a patient that had got dementia and they had to have a daily insulin injection and they refused insulin ……. it was a very grey area because I felt like sometimes I was giving it and I thought like 'well have I got consent?' ……. We did a capacity assessment and we assessed that he hadn't got capacity but then nothing was done with it and you know that really upset me cos I thought he still doesn't want it, ….. we didn't really know much about mental capacity or the mental capacity act or anything. I think that hindered our ability to protect that patient just from having the insulin injection because the GP wanted to get his blood sugars lower….. when he went to another care home they took him off insulin the next day and yet we were begging the GP and the diabetes team to do that, and they wouldn't do it.' (P1)*

In the other case, the participant refused to restrain the patient to administer the injection as they were uncomfortable with the potential use of restraint:

> *'… no way am I forcing anybody to have anything they don't want.' (P21)*

The MCA does, in fact, recognise the potential use of physical restraint if it is imperative to prevent harm and is proportionate to the situation. There are examples in the MCA COP (DCA 2007) where restraint was used for the shortest period in order to meet the needs of the patient, for example to obtain blood samples or administer medication. Although the participant did not allude to the least restrictive option or the potential use of restraint in order to initiate required treatment, they were reluctant to impose treatment on a patient, regardless of their capacity to consent.

Other issues identified through incidental data were identified within the themes identified from analysis of responses to the interview questions; the need for appropriate communication, resources affecting practice and the challenges faced including fluctuating capacity.

5.8 Ideas for good practice

Following the question about the criticisms of the MCA and best interests, participants were asked to identify if there were any examples of good practice that they had observed or been involved in that would be worthy of sharing to enhance others' practice. None of the participants actually expressed educational interventions that they felt had been beneficial to them, other than one participant but they were not able to go into detail about the session content and the impact that it had. Some participants suggested more than one approach to improve practice, two were unable to suggest anything they had experienced to enhance practice and three thought that MCA and best interests were not part of their role or that decisions were left to the consultant or that they were not involved as a nurse.

There were nine participants (30%) who thought that additional education and training would be beneficial, but not online or e-learning and three felt that the use of case reviews or reflective exercise would enhance the learning experience. Tools or templates to simplify the process and promotion of these templates were recommended by two participants.

The most common suggestion was collaborating with others to enhance knowledge, with sixteen participants discussing exposure to specific cases in practice as a reliable way of enhancing knowledge. There were nine who valued multi-disciplinary meetings as a way to enhance knowledge, six favoured involving or shadowing specialists who have an enhanced understanding of the legislation and two thought that their own experience in practice enhances knowledge and practice. There were seven participants who suggested that knowing the patient, understanding the condition (dementia) or promoting advance planning in some form would help enhance outcomes.

5.9 Summary

Analysis of the responses has shown that 24 participants were aware of their limitations of knowledge in respect of the legislation but whilst knowledge was not defended, practice was defended as being person-centred and ethically considered in respect of the best interests of the patient concerned. Participants indicated that resources (often time and staffing) had an impact on how they were able to fully engage with the best interests decision-making process. Four identified that a lack of resources had a detrimental effect on best interests processes.

Participants demonstrated explicit knowledge through their reference to the legal terminology relating to MCA and best interests and through the context in which this legal terminology was used. Participants tended to default to the clinical aspects of care when questioned about each vignette, although they did acknowledge the complexity of each situation and they appreciated the ethical dilemma that each vignette posed.

Participants did not have many suggestions for education and good practice for the MCA and best interests but did comment that the availability of education and training needed improvement and that a focus on e-learning did not offer the best opportunity for learning or understanding of the legislation. Tacit knowledge was evident from the responses in that participants demonstrated appropriate considerations of the legislation and COP. Chapter 6 will explore the responses in more detail, aligning to the literature identified in chapter 3.

Chapter Six
Discussion

Introduction

The analysis of the responses in chapter five revealed that participants were aware of their limitations of knowledge in respect of the legislation but defended their own practice as being person-centred and ethically sound in respect of best interests decisions. Participants indicated that in their experience, a lack of resources often had a detrimental effect on best interests processes. The participants demonstrated explicit knowledge through direct reference to the legal terminology relating to MCA and best interests and through the context in which this legal terminology was used. However, participants tended to default to the clinical aspects of care when questioned about each vignette, although they did acknowledge the complexity of each situation and they appreciated the ethical dilemma that each vignette posed. The aim of this chapter is to review the study, through synthesising the findings with the literature. The research questions will be reintroduced, to establish their relevance in line with the data collected. Methodology will be considered in line with the strengths and limitations of the research design and the implications for both practice and academia will be presented. The chapter will conclude by summarising the key factors of the study, identifying the original contribution to knowledge.

The MCA (2005) is the legislation that gave nurses a framework to use when caring for people with impaired capacity who cannot consent to their care, but Taylor (2015b) proposes that it has not yet fulfilled its aims. This study focused on the fourth principle of the MCA, the BIS, rather than the legislation in its entirety. The criticisms identified relate widely to the use of the legislation in context but more specifically, the BIS that are a significant principle of the legislation. It is impossible to consider one without the other but it is important to clarify that it is the BIS relating to decision-making in patients with advanced dementia which is the focus of the study. One of the factors to take into consideration when making a best interests decision is whether the patient will regain capacity, therefore there is a need to understand the MCA in its entirety to appreciate the meaning of capacity and how to judge if a person has capacity to consent. When incapacity is suspected then established, then the BIS are invoked, demonstrating the interconnectedness of the two aspects of the legislation

The over-arching question of the study was:

- What factors do nurses consider when determining best interests for patients with advanced dementia?

Three sub-questions were utilised to explore the concept of best interests:

- How is knowledge of the Best Interests Standards demonstrated?
- What procedural and substantive considerations do nurses identify when making best interests decisions?
- What support mechanisms are helpful for nurses in relation to undertaking best interests considerations?

The analysis of the responses from 30 participants found that nurses consider their clinical knowledge, their experiential knowledge, their ethical knowledge, and their legal knowledge in respect of best interests determinations for patients with advanced dementia. Their knowledge relating to the Best Interests Standards was both explicit with direct references to the legislation and tacit through explaining their perspectives on vignettes so that inferences could be made that align to the BIS. Procedural decisions consisted of consulting with the multi-disciplinary team and family members to determine best interest options for the characters within the vignettes. Substantive decisions consisted of exploring the pathology, morbidity, clinical treatment options and social situation of the characters in the vignettes. Inferences were made about tacit knowledge from how the participants considered the rights of the person, the concerns of the family, and the potential outcomes of active treatment or conservative management of the characters in the vignettes.

Participants did not rate their explicit knowledge of the legislation very highly, the average was around 5/10 and although most participants referred to the language of the legislation when discussing the vignettes, there were no extensive references to legislation. For example, of the 13 points related to the legislation (appendix 21) only nine participants referred to 6 or more. Most of the participants referred to less than six in their entire responses. Although the participants shared some perspectives on the quality and type of training they had received, there were few valuable suggestions for support mechanisms other than shadowing experts or being involved in multi-disciplinary meetings.

There was a significant amount of data from the interviews, all of which gave a lot of information about the perspectives of nurses in best interests decisions. A visual representation of this data is available in figure 6.1 as a word cloud. A word cloud does not suffice as a method of analysis on its own but can often be a good starting point to get the researcher thinking (Thomas 2021). The patient featured as a central word in the word cloud, which reflected the patient-centred responses that the participants conveyed. Family also features, as did clinical, care and treatment. This reflects the priorities that participants identified when discussing their thoughts on the vignettes. They focused on the family connections in each vignette and the impact of clinical care and treatment options in each case. A word cloud provides a graphical representation of knowledge that allows a viewer to form a quick, intuitive sense of a text and is an easy way to share high-level data without information overload. They show immediately what common themes and phrases appear in the text yet preserve the anonymity of the participants (De Paolo and Wilkinson 2014).

Figure 6.1 word cloud of responses to questions

Returning to the research questions, each will be presented with the discussion points raised through analysis of the data.

6.1 What factors do nurses consider when determining best interests for patients with advanced dementia?

It is helpful here to refer to the BIS Checklist to consider the factors that participants considered and whether there are links to the checklist from the responses to the vignettes.

1	Encourage the individual's participation
2	Consult all those close to the individual
3	Consider the individual's views, whether expressed verbally or in writing, including their feelings, religious beliefs and past habits

4	Consider all circumstances, including emotional bonds and family obligations
5	Avoid making assumptions
6	Consider whether capacity will be regained in the future and whether this discussion could be delayed until then
7	Consider the potential decision the individual might have made if they still had capacity
8	Consider whether the least restrictive option has been taken in making the decision
9	If the decision is about life-sustaining treatment, ascertain that no one involved in the decision-making process has a desire to end the life of the individual and that no assumptions have been made about their quality of life

Table 6.1 Nine principles to guide best interest decisions (Regan and Sheehy 2016)

The most evident aspects of the checklist from the responses to the interview questions in order of response were:

1	If the decision is about life-sustaining treatment, ascertain that no one involved in the decision-making process has a desire to end the life of the individual and that no assumptions have been made about their quality of life	1 (3%)
2	Consider whether capacity will be regained in the future and whether this discussion could be delayed until then	1 (3%)
3	Avoid making assumptions	8 (27%)
4	Consider the potential decision the individual might have made if they still had capacity	5 (17%)
5	Encourage the individual's participation	13 (43%)
6	Consider whether the least restrictive option has been taken in making the decision	16 (53%)
7	Consult all those close to the individual	20 (67%)
8	Consider all circumstances, including emotional bonds and family obligations	24 (80%)
9	Consider the individual's views, whether expressed verbally or in writing, including their feelings, religious beliefs and past habits	30 (100%)

Table 6.2 responses to the checklist by number

Although only one participant specifically referenced life-sustaining treatment and not wanting to hasten death, another fifteen participants (53% in total) discussed the possibility of palliative or end of life care for the individuals in the vignettes (mainly with pneumonia). This demonstrates that the participants did think about the prognosis of the individual and how they should be managed. This also links with the BIS that stipulates no assumptions should be made about quality of life. What was evident is that participants seemed to accept that capacity was lost, so very few considered if capacity might be regained. Even those that questioned the original capacity assessment and whether the person had been adequately supported did not elaborate by stating that the individual may regain capacity. It was not clear if this was due to the diagnosis of dementia or a lack of knowledge of that standard in the checklist. However, both vignettes were written so that immediate treatment was really warranted, so this may negate the fact that a postponement was not considered.

Almost half of the participants (n = 13 or 43%) did consider involving the individual in the decision, which does help to negate the lack of consideration of regaining capacity. Also, over half of participants did think about the least restrictive option of treatment for each of the vignettes. For instance, whether an alternative to surgery was available or oral antibiotics for the individual with pneumonia. This demonstrates that participants did refrain from forcing treatment on a person. If this is linked to the study conducted by Howarth *et al* (2014) where the concept and practice of forced care may indicate a lack of insight into the legislation that governs care interventions, then it indicates the presence of insight, rather than a lack of it. However, the HOLSC (2014) also suggested that the least restrictive option is not routinely or adequately considered (p. 8), so it is not accurate to suggest that the findings dispute this.

The COP states:

> *'.. anyone working out someone's best interests must not make unjustified assumptions about what their best interests might be simply on the basis of the person's age, appearance, condition or any aspect of their behaviour…. 'Appearance' is a broad term and refers to all aspects of physical appearance, including skin colour, mode of dress and any visible medical problems, disfiguring scars or other disabilities. A person's 'condition' also covers a range of factors including physical disabilities, learning difficulties or disabilities, age-related illness or temporary conditions (such as drunkenness or*

> *unconsciousness). 'Behaviour' refers to behaviour that might seem unusual to others, such as talking too loudly or laughing inappropriately* (p73).

There were eight direct references to not making assumptions about the individual within the vignette, for instance, 11 (37%) participants did remark that the diagnosis (of dementia) was not a valid reason to not treat the person with pneumonia. There were also other comments relating to age where participants suggested that advancing age of the person in the first vignette was no reason to not consider the amputation. However, considerations of age were not included in 'no assumptions' unless the participant directly mentioned age in their other responses, rather than in the question directly posed about the age of the individuals within the vignettes. There were four (13%) responses that suggested the participant was making an assumption about the person in the vignette: one participant suggested that the individual in vignette two was a 'burden on society' from a cost perspective and this participant, along with three others thought that the person in vignette two should not live with such a poor quality of life. However, each of these participants thought that the person would receive treatment for their condition. Although their comments may be considered contentious, they did not influence whether they thought the person would receive treatment or not. In this vignette, twenty-seven (90%) participants chose to initiate treatment or to trial treatment and re-consider if there was no response to treatment. This is in line with the suggestion from Martin (2015), that a trial of treatment might be an appropriate option where the benefits and risks are uncertain.

The most prolific of the BIS demonstrated in the findings were the consultation with others, considering all circumstances and considering the views of the individual. All participants considered the views of the individual, including past wishes, 80% (n = 24) considered all the circumstances of the vignette when deliberating their response and decision and 67% (n = 20) consulted others in respect of the situation. Wade and Kitzinger (2019) suggested that most people will be influenced by their family and social attitudes and values. With the pneumonia case, most of the participants focused on the quality-of-life issues experienced by the person with dementia. The aspect of enjoying experiences seemed to promote the consideration that treatment should be initiated to prolong life. These are examples of the circumstances that were considered by the participants: family circumstances and care environment, how the person's quality of life could be judged, what interests and previous role they had that might influence how they would feel about their current situation.

Although participants discussed some of the BIS within their responses, one of the themes of the results was the 'clinical comfort zone' that was apparent in many of the responses. The clinical comfort zone was where participants identified the clinical aspects of the patient when asked about the vignette. For instance, they identified poor nutrition, risk of surgery (or other risks), and they demonstrated considering why the overall clinical picture suggested a poor prognosis for the patient. The clinical comfort zone (default position) is not a criticism but a reflection on how the participants addressed the questions relating to the vignettes. Over half of the participants (n = 19 or 63%) discussed the clinical picture when asked a question that did not request reference to the clinical status of the patient. They used the clinical picture to support the point that they made about the question. This is unsurprising, as clinical care is the remit of the participants recruited and to refer to clinical aspects of care to defend a position is not unethical but may lead to the paternalism that is suggested in the criticisms. Unfortunately, the HOLSC (2014) identify that in best interests decisions, the wishes, thoughts and feelings of the patient are not routinely prioritised and clinical judgements predominate (p. 8). If clinicians default to the clinical picture in practice, then the risk of clinical judgements predominating is intensified and this may be a reason that the criticisms remain.

In respect of the literature, factors considered in respect of decision making were discussed in a range of studies, including Dunn *et al* (2010) who found that support workers draw on their own decisions that they make in their own lives when making substitute decisions for others. This was reflected in the study as some participants drew on experience to reflect on the vignettes and what they thought might happen to the character in the vignette. Livingston *et al's* (2010) findings showed that family carers were focused on establishing previous wishes of the person, which is one of the Best Interests Standards and was also a focus for the participants in the study. The complexity of the legislation and how that complexity impacts on decision-making featured in several studies. Cairns *et al's* (2011) study asked a range of practitioners to consult on a range of DOLS decisions in vignettes and the consensus was that the legislation is complex and that the legislation makes decisions difficult. This was echoed by the Delphi study completed by Clerk *et al* (2018) where the complexity of the legislation was a consensus. Carter *et al* (2018) focused on family carers but found that they required support from healthcare professionals as they were anxious about making best interests decisions, which indicates the complex nature of making decisions on behalf of a person. Participants in this study also recognised the complexity of the legislation and of people's situations that lead to use of the legislation. In Boyle's (2013) study of couples where one person was living with dementia, there was a general tendency of female carers to preserve the autonomy of the person with dementia, whereas male carers were more restrictive of their partner's rights. There was no such demarcation in this current study with gender and participants were primarily focused on seeking out and preserving the wishes of the person with dementia.

Howarth *et al* (2014) devised a study to examine forced care in care homes and found that forced care is carried out regularly in the care home sector and therefore not supportive of person-centred care, which is an infringement of the rights of the person with dementia. Similarly, Poole *et al* (2014) found that preserving the rights of the individual with dementia was superseded by risk management. This demonstrates that perspectives from these two studies focused on risk to the person with dementia, in preference to preservation of rights. This was partly evident in the study with the clinical outcomes being a focus of participants' perspectives. Although the participants discussed establishing any previous wishes and the expressed wishes of the characters in the vignettes, the clinical risks posed by treatment or no treatment presented a dilemma for the participants and responses reflected this. Clarke *et al* (2015) focused on artificial nutrition and established that risks and burdens of treatment, ethical values and treatments goals were priorities for their participants. Similar results were demonstrated by Scott *et al* (2018) where healthcare professionals considered co-morbidities, social support and quality of life. This reflects the priorities for the participants in this study as they focused on the same aspects concerning the characters in the vignettes who lacked decision-making capacity.

To answer the question of what factors do nurses consider when determining best interests for patients with advanced dementia, it is apparent that the individual's circumstances are a significant factor and that the BIS do feature in those considerations. Participants did discuss the views of the individual with dementia and how their 'personhood' should feature in any decisions made. The participants considered the involvement of others in the decisions, particularly those that knew the individual with dementia best. They also considered all the circumstances, such as care environments, how the family might be impacted by the decision and the burden of caring for a person with advanced dementia.

6.1.1 How is knowledge of the Best Interests Standards demonstrated?

A significant proportion of the participants (n=13 or 43%) agreed that knowledge and understanding of the MCA and best interests by healthcare professionals is poor. Some admitted that they do not know enough about MCA and best interests, or that they did not work in a role where it was necessary to know about it. Hislop, Bosua and Helms (2018) suggested that explicit and tacit knowledge are two pure and separate forms of knowledge, where explicit knowledge is regarded as objective and can be codified in a tangible form, whereas tacit knowledge is personal, held by people, and may shape how they think and act and is almost impossible to codify. Chergui, Zidat and Marir (2020) suggest that all knowledge has a tacit origin and therefore explicit knowledge depends on and is rooted in tacit knowledge. Kothari *et al* (2012) discuss the concept of knowledge transfer, a commitment to develop the science in public health knowledge exchange and uptake. They discuss how knowledge gained through years of experience augments research findings to make them relevant and applicable to the local setting and make the distinction between explicit knowledge (codified, written) and tacit knowledge ('know-how'). Tacit knowledge is multi-dimensional, context-specific, and practice-related and aids in the interpretation of explicit knowledge; clinical practitioners draw on tacit knowledge to address health problems.

In analysis of the data, explicit knowledge was measured by direct or indirect use of the terminology in the legislation, or by stating what might happen in each vignette as factually correct or factually incorrect. It is important to consider how tacit knowledge was assessed from the participants responses, considering the assertion that it is difficult to articulate. Arling and Chun (2011) discuss tacit and explicit knowledge in relation to their case study on knowledge management and support the notion that knowledge is relational and context specific and that it is created through conversion of tacit and explicit knowledge. Conversion of tacit to explicit knowledge occurs through externalisation, an example being articulation of best practice or lessons learned. In the case of this study, tacit knowledge was considered through associating the participants' responses with the characteristics of the BIS, to establish if 'know-how' could be mapped to the legislation guidance. This aligns to the approach that Arling and Chun (2011) endorse about articulating best practice. To establish tacit knowledge, there was a need to infer meaning from the participants' responses. Tavory (2020) suggests that semi-structured interviews contain open context in which it is possible to cautiously infer about other situations. To infer knowledge about the interpretation of the situation in the vignettes the researcher considered responses aligned to the BIS. For example, for considering all circumstances, if the family were considered or if the participant considered who would look after the person or what the care was like in the nursing home, these responses inferred that the participant was considering a range of circumstances in line with the BIS. Another example of inference was not bringing about the person's death, if the responses considered if the character needed palliative or end of life care, this was inferred as aligning to the BIS. This was how tacit knowledge was inferred from the responses.

Only one participant did not utilise the terminology associated with the legislation, which may indicate a level of explicit knowledge but it is important to explore the context in which the terminology was utilised. Participants questioned the existence of Lasting Power of Attorney (LPA) in the right context and whether either patient in the vignettes had an Advance Decision to Refuse Treatment or and Advance Care Plan. These terms were utilised in the appropriate context, which demonstrates a level of explicit knowledge of the terminology. Some participants also mentioned some of the principles of the MCA, again in context, so there was evidence of knowledge. However, there were ways that the terminology was used incorrectly or not in context, such as nominating an LPA when a patient does not have capacity, and at times the use of DOLS was mentioned but the context was not entirely clear. When responding to questions, very few of the participants linked their response directly to the legislation. Some discussed assessment of capacity and who may have made the decision that the patient lacked capacity but overall the responses were not underpinned with a direct reference to the legislation or the terminology within the legislation.

Explicit knowledge was considered through the responses and if they were discordant with the legislation or with what should happen in legal terms with each of the vignettes. In the first vignette, a likely outcome would be that the case would be referred to the Court of Protection because of the conflict evident. Only one participant correctly identified that the case would warrant a Court of Protection referral, so most of the participants did not consider this. Also, several participants were interested in the next of kin of the characters within the vignettes, as though to assume that the next of kin has a legal role in decision-making, which is factually incorrect. The explicit knowledge that was identified was factually correct information, such as best interests decisions being clinical decisions where there is no LPA, that best interests decisions are the best interests of the patient and not others or that no apparent ADRT meant that previous wishes could not be substantiated and would not be legally binding. There was also explicit knowledge demonstrated on the principles of the MCA, though the focus of the study was best interests decisions.

There were three (10%) participants that expressed that they think that assessment is another's role, rather than theirs; that they either pass on that responsibility to someone else or that another professional automatically takes on the responsibility and this could suggest a lack of confidence in taking the lead in decision-making or not recognising one's potential role in the process. This was identified in the literature, with Manthorpe *et al* (2014) identifying that professional hierarchies were an issue, some managers assumed only doctors could assess capacity and best interests. Brown and Marchant (2013) also found that some practitioners passed responsibility to a medical professional, thinking that it was the correct procedure. The Code of Practice (DCA 2007) states that many different people may be required to make decisions or act on behalf of someone who lacks capacity and therefore work out what would be in their best interests. Nurses may be the decision maker where the decision involves the provision of medical treatment or where nursing care is provided (p. 69 – 70). Although this is stated in the Code of Practice, the participants would pass the decision-making responsibility to a medic or another health professional.

The reasons for passing on responsibility was not explored in the interviews but within the HOLSC (2014) report, a Best Interests Assessor identified a strong reluctance by some nurses and social workers to undertake and assessment due to a fear that their decision might be tested by the legal profession in a court of law (p. 35). This could be a reason why the three participants might pass the decision on to a more experienced clinician. It could also be due to professional identity and nurses viewing themselves as professionally inferior to other health professionals (particularly medics). Self-concept and professional identity is influenced by the idea of being subordinated to the medical profession (ten Hoeve, Jansen and Roodbol 2013). Establishing a professional identity in nursing likely has everything to do with self-confidence and the ability to collaboratively work with others to impact patient outcomes (Goodyear 2021). Due to an inaccurate image which projects them as caring and trusted, nurses have been overlooked as autonomous healthcare providers lacking in influence and autonomy (Godsey, Houghton and Hayes 2019), and generally as a profession nurses do not think highly of themselves (Fletcher 2007).

The participants confidently engaged with discussion in the interviews around the role of the multi-disciplinary team in managing the patient in the vignettes but passed the final decision to the senior clinician involved and this would likely be the medic. It could be that for the three participants who explicitly stated it was another professional's responsibility, that this has been their experience and therefore influenced their opinions. It is also important to note that the NMC (2018) stipulate that a registrant should recognise and work within the limits of their competence, asking for help from a suitably qualified and experienced professional to carry out any action or procedure that is beyond the limits of their competence (p. 15). This could be a reason for referring the decisions regarding best interests to another clinician.

Most of the knowledge evident in the responses was tacit knowledge, where the responses were aligned to the BIS checklist, some of which is discussed in 6.1. All but one participant utilised the terminology aligned to the legislation, which is how explicit knowledge was identified. However, there was not extensive references to the legal terminology, therefore tacit knowledge was most evident in the responses. The participants were aware of the need to involve family in the decision-making process, they suggested options of treatment that were less restrictive than those suggested in the vignette, they referred to advance statements (or the lack of) that might have helped to make the decision. Their considerations incorporated the beliefs and values of the person in the vignette that might influence their decision if they were able to make it.

From the literature, the studies that support that knowledge of the MCA is satisfactory do not differentiate between tacit and explicit knowledge. Murrell and McCalla (2016) suggested that the principles of the MCA bear legal weight and that consolidation of the knowledge and understanding of the principles make the tacit knowledge more explicit and benefit the implementation of the legislation. They do not support this assertion with any evidence but their discussion of responses highlight this point in that they ascertain practitioner knowledge from the context of their response. Walji *et al's* (2014) study contained self-reported data that reflected appropriate knowledge, so it would be unrealistic to suggest that knowledge was either explicit or tacit in this study. They did report that some responses about the legislation were erroneous, which suggests that knowledge was incorrect or misrepresented, which is reflected in this study where thirteen participants responded with incorrect knowledge.

Manthorpe *et al* (2009) and Manthorpe, Samsi and Rapaport (2013) asked participants to estimate their level of confidence about their knowledge and most scored themselves mid-range, none at the top of the range. The study also tested explicit knowledge via summarising their grasp of four main elements of capacity and most demonstrated a thorough understanding, although they were adult safeguarding leads and so would be expected to have substantial knowledge on the topic.

Manthorpe *et al* (2011) asked participants to define what capacity meant, so tested explicit knowledge and found that there was a mixed level of awareness about the legislation. This was early in the implementation of the legislation, when not all participants had received training. The 2014 study was with specialist nurses in dementia care and as it was over a period, knowledge of specific aspects of the legislation were improved by Time 2. The interviews asked about awareness of the legislation, rather than testing specific knowledge (no example of questions were presented). Participants also self-rated their knowledge and confidence about the legislation and most scored 3 or less out of 5 in Time 1 but most scored 3 or more out of 5 in Time 2, which showed an increase in knowledge and confidence (Manthorpe *et al* 2014, Manthorpe and Samsi 2016).

Three further studies did not test explicit knowledge but declared that knowledge was variable. Harris and Cohen Finberg (2011) studied beliefs and attitudes about the MCA and best interests in the decision-making of health and social care professionals and found that understanding varied, with some participants demonstrating clarity about the legislation but almost half demonstrating a lack of clarity with the MCA. The researchers established this through the context of the participants' responses and presented quotes to demonstrate the lack of clarity with the concepts such as best interests. Manthorpe and Samsi (2015) conducted a study over two time periods and asked about knowledge of the (then) new offences. They did not indicate how knowledge was tested (whether explicit or tacit) but asked about experience and conveyed evidence of knowledge to the experience that participants discussed. They found that knowledge was variable in the participants. Knowledge was not measured in the study by Samsi *et al* (2011) where Admiral Nurses were interviewed and described not feeling confident about their understanding of the legislation but felt they should be more confident. The study suggested that some reasons for a lack of confidence was a lack of experience with using the legislation.

Rowley *et al* (2013) tested explicit knowledge through a ten-part questionnaire testing knowledge of staff in one trust and found that implementation of the legislation was not up to standard. Shepherd *et al* (2018) also tested explicit knowledge as they asked participants to select the legally authorised decision-maker in a scenario and provide supporting reasons for their response. This study reported a high variability in MCA knowledge and practice, with a lack of knowledge about the locus of authority and the legal basis for decision making.

The study found similar results to the various studies from the literature review; knowledge was demonstrated either explicitly where it was tested through direct questioning or tacitly where responses were taken in context to imply knowledge. Where knowledge was tested, it was variable. There were some aspects of sufficient knowledge demonstrated and some inadequate knowledge and when participants self-rated knowledge, it was rated below average in general.

6.1.2 What procedural and substantive considerations do nurses identify when making best interests decisions?

Procedural decisions were considered in line with the legislation and whether participants explicitly or tacitly responded in such a way that the processes relating to the legislation could be established. There was a significant focus on advance care planning by the participants, with nineteen (63%) mentioning the lack of or importance of advance planning in dementia, to avoid future conflict in decision-making and to avoid the emotional turmoil that accompanies surrogate decision-making in any form. In the first vignette, which focused on a decision around a limb amputation where the patient had allegedly said they did not want an amputation no participant identified this specifically as an advance statement that would require exploring as part of the BIS checklist. There were five participants that would explore the validity of the statement made around refusing amputation, but they did not utilise the term 'advance statement' when referring to the topic. Participants were focused on preserving life, rather than hastening death and in some respect, they wanted to avoid the person with pneumonia dying what they saw as prematurely. This may have something to do with the ethical principle of non-maleficence or beneficence, where professional duty of care morally obliges health care professionals to do good and do no harm. Professional duty of care was certainly at the forefront of responses and participants were keen to articulate their professional obligations with each patient. Martin (2015) acknowledged that the MCA is focused on preserving life (although it does promote allowing a natural death).

Substantive decisions are decisions that shape the process or outcome and within the study, many of the participants acknowledged that the vignettes were difficult to decide upon and struggled to confidently rationalise their potential decision. There was a lot of deliberation and moral questioning, which reflects the argument that emotions are decisive and most people find emotional decisions nigh on impossible (Swaab 2014). The participants struggled with the vignette where there was conflict and recognised the ethical challenges associated with family conflict around healthcare decisions. As there was no apparent conflict in the vignette depicting the patient with pneumonia, the participants were less hesitant to respond and defended their decisions with greater confidence, recognising that a harmonious family unit made the situation easier to consider.

From the literature, Evans, Warner and Jackson (2007) found that doctors, nurses and paramedics did not know how to assess capacity, although this study was very early in the implementation of the legislation. Luke *et al* (2008) found that doctors and nurses in the study were indifferent to the role of IMCAs whose role is fundamental in the legislation. The lack of understanding of and appropriate referral to IMCAs was also a component of the HOLSC (2014) report. Wilson, Seymour and Perkins (2010) found that it was unclear to participants when it was necessary to record best interests decisions and when it was not necessary. McDonald's (2010) study with social workers found that they feel forced to take a legalistic view of the legislation, rather than an actuarial view where they could weigh up risks and decide using their judgement. Phair and Manthorpe (2012) found that the legislation was not embedded in practice, so procedurally the legislation was not followed. Williams *et al* (2012) was also critical of the procedural elements of best interests determinations. In comparison to other groups, people with dementia were disadvantaged when it came to capacity assessments and best interests determinations. Brown and Marchant (2013) reviewed complex cases in respect of best interests and found that practitioners passed on the responsibility of the decision on to another professional, thinking it was the correct procedure. Heslop *et al* (2014) reviewed the deaths of people with a learning disability and revealed that decisions were made on prejudice, a lack of information about the person or a lack of holistic assessment, which would be in breach of the legislation. Rogers and Bright (2019) investigated the approaches of different groups of assessors to the MCA assessments as part of DOLS and found some good practice but also that assessors did not refer to the two-stage test of capacity and judging a person's ability to weigh up information was subjective and value-based. Carpenter *et al* (2014) was one study that had positive findings in respect of procedural decisions, suggesting that they were made with a high level of confidence and no statistically significant variables between professions.

This study reflected some of the findings from the studies in the literature review, where there were some examples of good practice but overall procedural standards were variable and there was no clear indication that the aspects of the legislation were fully implemented. When counting each aspect of the legislation, as shown in appendix 21, the maximum number identified by participants was nine and 26 of the participants identified seven or less. This suggests that knowledge of procedural aspects is relatively low.

When discussing the criticisms of the MCA and best interests, one participant identified a lack of time and resources as being a reason for the lack of application of the legislation. Others identified where increased demand on services had had a direct impact on the ability to fully consider the MCA. The HOLSC (2014) suggested that clinical judgements or resource-led decision-making can predominate, which was the only indication in the literature that resources had any bearing on the failure to apply the legislation in practice, so more research on this is worthwhile. Only a small number of participants identified resources as a reason for the alleged lack of knowledge and understanding of the legislation. Therefore, it may be an incidental finding.

6.1.3 What support mechanisms are helpful for nurses in relation to undertaking best interests considerations?

This was the most challenging of the sub-questions to complete as the responses from participants were vague, as though they were unable to specify their own learning needs or how improvements could be made to education and development opportunities. The literature supports face-to-face sessions, rather than e-learning, which seems to predominate the available training for the participants in the study. Surr *et al* (2017) reviewed education and training in dementia care and found that e-learning is not favoured by many practitioners, but experiential learning is much more favoured and successful.

In the study, none of the participants identified any beneficial educational interventions. There were nine participants who thought that additional education and training would be beneficial, but not online or e-learning and three felt that the use of case reviews or reflective exercise would enhance the learning experience. Tools or templates to simplify the process and promotion of these templates were recommended by two participants. The most common suggestion was collaborating with others to enhance knowledge, with sixteen participants discussing exposure to specific cases in practice as a reliable way of enhancing knowledge. There were nine who valued multi-disciplinary meetings to enhance knowledge, six favoured involving or shadowing specialists who have an enhanced understanding of the legislation.

Within the literature Alonzi, Sheard and Bateman (2009) found that nursing staff were not confident of how to proceed in virtually every aspect of the MCA and that training was insufficient to prepare them. Wilson, Seymour and Perkins' (2010) study found that a number of staff felt they had had insufficient training or did not feel their learning was optimized by the training delivery method. Manthorpe and Samsi (2011) looked at training, roles and activity and found there appeared to be a perception of training as events to be attended rather than an ongoing process where, through new information, staff members actively learn and apply new understanding. The various studies completed by Willner *et al* (2011a, 2011b, 2012, 2013) included NHS and social care staff in their studies and found that knowledge improved following training, although limitations did remain. Gough and Kerlin (2012) found gaps in knowledge of care home staff and suggested that training needed review. Manthorpe, Samsi and Rapaport (2012a) directly questioned participants on whether they had received training and what was helpful with the training and whether it helped with practice. There were no significant statements about what participants responded as beneficial from training but a finding was that there was a significant need for ongoing training. Cliff and McGraw (2016) acknowledged the complexity of the legislation and suggested that practitioners needed support to manage the challenges, encouraging interprofessional working sharing knowledge and skills. Marshall and Sprung (2016) found that community nurses were not confident with the legislation, regardless of how long they had been qualified and their participants identified the need for additional training even though they had all received some training. Chapman (2020) suggested that training needs to extend beyond theoretical knowledge and direct staff in to how to apply their knowledge to positively influence practice. Phair and Manthorpe (2012) study, participants understood the general points of the MCA but were less familiar with the details and in fact more than half of the participants were not confident in how to establish a person's best interests. Training was described as "bolt-on" to consent training, theoretical and short in duration with no skills or competences taught. Participants proposed ways to improve knowledge in the Trust in line with other initiatives, such as hand-washing posters to promote awareness and encourage best practice. In respect of this study, the participants also appeared to understand the general points of the legislation, demonstrated through tacit knowledge and some examples of explicit knowledge. However, they did not offer many tangible examples of how to promote understanding and best practice, despite being critical of the training they had received.

6.2 Knowledge and participants' perceptions of advanced dementia

The study was about considerations of best interests decisions for people with advanced dementia. It would be remiss to avoid considering the thoughts and knowledge of advanced dementia that were identified in the responses, including any implications for practice. The study aims were to identify potential implications for practice for implementation in practice of best interests decisions and the MCA (2005) as the main legislation. However, it is also worth considering any implications for practice around best interests decisions for people with advanced dementia. People with advanced dementia cannot (in most circumstances) speak for themselves, so practitioners are needed that can listen to what they might have said in the past and try to preserve their rights by respecting their wishes. This is an important aspect of the BIS and needs to be translated into dementia care.

Stigma around dementia was discussed in chapter one and the lack of recognition of personhood is a risk associated with dementia. There was the realisation that decisions are tough for those 'left behind' as they can never be sure it is what the person would want. There were physical aspects of advanced dementia that were missed, and this may have impacted on the decisions made if the participants had that knowledge. Some did question whether the patients were at the end of their life, particularly with the case of pneumonia and expressed that end-of-life care planning would be initiated if that were the case. However, few recognised explicitly that dementia is a terminal condition and that pneumonia for instance is potentially inevitable at the end stage of the condition, an indication perhaps that the patient has reached the end of their life. A patient may have repeated infections and several antibiotic treatments and still have a deteriorating health condition (Midtbust *et al* 2018).

A significant proportion of the participants focused on Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) and acknowledged that it would not be appropriate to undertake CPR on a patient with advanced disease. However, they did not apply the same logic to other interventions that they seemed to think of as less invasive and so they were happy to initiate, such as intravenous antibiotics. One participant expressed that knowledge of dementia is generally poor, so there is the consideration that a poor understanding of a condition may influence the potential outcomes of decisions for patients with advanced dementia.

The participants overwhelmingly considered past wishes when discussing the vignettes as all participants referred to establishing past wishes for one or both of the vignettes. This demonstrated tacit knowledge of the best interests principle. When considering all circumstances or what decision the person with dementia may make now (if they were able to) 24 participants (80%) referred to this aspect of best interests considerations, which again demonstrated tacit knowledge of the principle. There was little evidence to suggest that participants would exclude the person with dementia from the decision-making process, although only 13 (43%) explicitly stated that they would encourage the participation of the person in the vignette. However, each vignette did suggest that capacity was impaired, which may explain why past wishes was considered more robustly than active participation in the decision. Larsson and Österholm's (2014) suggest that the literature says more about the exclusion of people with dementia from care decisions than it does about their active involvement. In respect of this study, it could be suggested that encouraging participation as a BIS should be emphasised as being just as important as ascertaining past wishes if people's rights are to be preserved.

6.3 Study limitations

As the focus of the study was on the legislation that governs England and Wales, the findings are limited to practice in England and Wales. However, learning from international research is apparent and informs practice even though the study may not have been conducted in the country that adopts the associated learning.

In respect of the data collection tools used, it is worth considering that it may be limiting the scope of the research by providing limited detail in the vignettes, i.e. written information to process and nothing visual or tangible on which to make a decision. In the first vignette, carer burden was evident and the person with dementia had expressed a desire not to have surgery. However, there was a statement from the adult child that the person was happy and had a role to play within the family. The second vignette was a person who was clearly unwell but had elements in their life that they appeared to enjoy. It would be interesting to perhaps remove the 'positive' elements in the vignettes and see if participants afforded the same positive responses in respect of what they thought should or would happen.

A potential limitation was with sampling in the study, as it was students at the researcher's university. This meant that there was no NHS ethics process, just solely university ethics to engage in. This presented a limitation to the study as the participants were individuals who were engaged in cognitive debate through being on an academic course. All participants approached were on a course, not just a single CPD module so were studying at level 6 or 7 and would therefore have a level of academic knowledge even if not around MCA, BI or dementia. This needed to be considered in the analysis and interpretation of the data. Although the explicit knowledge of MCA and BI were not extensively demonstrated by the participants, they may have had an advantage in being able to apply logic to their debate because of being 'academically prepared'. Responses may have been different if a group of nurses were recruited who were not on an academic course, so this could be a consideration for future study. However, to counter this limitation, registered nurses are expected to remain up to date with their knowledge and to undertake 40 hours of continuing professional development over three years (NMC 2018). This could suggest that all registered nurses are 'academically prepared' due to the nature of their professional body requirements, so it may not be a serious limitation.

If the study were to be repeated, one recommendation would be to establish a system to assess explicit and tacit knowledge prior to data collection to enable the researcher to identify when explicit knowledge is evident or tacit knowledge is suggested. For this study it could be achieved by identifying key themes, or model answers that might be expected for each question, like model answers devised for recruitment in job interviews. In this study, this process was conducted retrospectively during data analysis when responses were mapped to the MCA and BIS. This process was subjective in nature, as meaning was inferred when analysing each interview transcript. With an analysis guide to specifically identify a pre-determined response, agreed with a group of peers, the subjectivity might be removed and the analysis process more straightforward and reliable. There would be some flexibility with this approach as additional responses that did not fit with the suggested answers could still be utilised as evidence of knowledge if appropriate. The potential value of this approach became evident after data analysis, so it was not practical to introduce such a system in this study.

6.4 Generalisability, validity and reliability

It is essential to establish the quality and integrity of a research study if it is to have any worth. Case study research is criticised for its lack of representativeness and rigor (Zainal 2007), but it can provide insights into the relationships in health care and in this way it generates information that might not be achievable using other approaches (Baker 2011). Certain activities, problems or responses will come up again and again, so certain generalisations can be drawn (Stake 1995). Yin (2018) states that the goal of case study research is to expand and generalise theories and not to extrapolate probabilities. Dawes Farquhar (2012) suggests that case study researchers would assert that case study research can make its own contribution in its own right. The contribution of this study is proposed later in the chapter.

There is also some debate over whether vignette responses are representative of or generalisable to behaviour of the participants, which is an issue for qualitative research generally. Bloor and Wood (2011) state that vignettes should not be thought of as matches for real-life experiences and responses as reportage of behaviour in real-life situations, instead they are a useful guide to group norms and beliefs.

Qualitative research is criticised for lacking scientific rigour with poor justification of the methods adopted (Noble and Smith 2015) and case study research is also criticised for lacking scientific rigour (Crowe *et al* 2011). There are ongoing debates about whether terms traditionally used for quantitative research are appropriate for qualitative research, so alternative frameworks for establishing rigour have been proposed of truth value, consistency, neutrality and applicability (Noble and Smith 2015). Thomas (2021) agrees that the notions of reliability and validity have been imported from other kinds of research and that their meaning in case study is less clear. He suggests that with a single case study, expectations about reliability drop away because there can be no assumptions that if repeated by different people at different times the results would be similar. Yin (2018) however refers to the terms of construct validity, internal and external validity and reliability in case study research and provides examples of how they can be demonstrated. Table 6.3 presents how Yin recommends validity is demonstrated and how it was achieved in the study.

Test	**Yin's (2018) Tactic**	**Demonstrates in this study by:**
Construct validity	• Use multiple sources of evidence • Have key informants review draft case study report	• Used questionnaire, vignettes and interviews to generate data • Review reports with key informants – supervision team discussed transcripts and data analysis report
Internal validity	• Do pattern matching • Do explanation building • Address rival explanations • Use logic models	• Data analysis – compared responses for similarities • Cross checking responses with literature
External validity	• Use theory in single-case studies	• Defined scope of the study • Compared the findings with the literature
Reliability	• Use case study protocol • Develop case study database • Maintain a chain of evidence	• Recorded data electronically • Organised and document collected data • Used peer review (through supervision team) of transcripts

Table 6.3: How validity and reliability were demonstrated

Construct validity is challenging in case study research, as the researcher may fail to develop a comprehensive set of measures for the concept being studied (Yin 2018). It is demonstrated by the justification of the data collection method and the results from what is measured (Braun and Clarke 2013). Validity in qualitative research means "appropriateness" of the tools, processes, and data, whether the research question is valid for the desired outcome, and that the results and conclusions are valid for the sample and context (Leung 2015). The tools and processes used were rationalised and developed from the literature, therefore were appropriate for the study.

Using the criteria proposed by Noble and Smith (2015), table 6.4 presents how truth value, consistency/neutrality and applicability were achieved in the study.

Test	**Noble and Smith's (2015) Tactic**	**Demonstrated in this study by:**
Truth value	• Recognise that multiple realities exist • Clearly and accurately presents • Participants' perspectives	• Reflection on own perspective • Peer review of transcripts • Audio recorded interviews to allow return to data

		- Use of verbatim extracts to make judgements about the themes
Consistency/ Neutrality	- The researcher's decisions are clear and transparent - Acknowledging the methods undertaken and findings are intrinsically linked to the researchers' philosophical position	- Clear description of the research process - Emerging themes discussed with supervisory team to reach a consensus
Applicability	- Consideration is given to whether findings can be applied to other contexts, settings or groups	- Detail of the context of the study and alignment of the responses to existing literature facilitates evaluation of the findings and comparison to other groups/settings

Table 6.4: How truth value, consistency and applicability were demonstrated

In respect of the methods used in the study, Stokes and Schmidt (2012) suggest that vignettes are a valid research method in respect that the factors within them, the allocation of the vignettes to participants and the resemblance of responses to how a person would behave in real-life enhance their robustness with internal and external validity. Lapatin *et al* (2012) recommend varying the characters in vignettes, which was also supported by Finch (1987). Detail about the characters in the vignettes was switched following a pilot study (age, gender, perceived ethnicity and name) to attempt to ascertain if demographic detail initiated specific responses. Consistency gave confidence that the responses were unaffected by biases. McGrath *et al* (2019) suggest that the qualitative interview is a rigorous data collection tool that requires an iterative and reflective working process to best service its purpose. They provide 12 tips for conducting interviews that can add to the rigour of the approach, which include steps taken in this study and include constructing an interview guide and testing the questions, adjusting the interview guide, and transcribing the interviews and analysing the data in good time. The methods of vignettes and semi-structured interviews were constructed in accordance with the literature to guide their use, which adds to the reliability of the study.

Something that was not considered prior to the study was the importance of language in the responses and whether it was a requisite for the participant to use the legal terminology to assess explicit knowledge. Use of the terminology could have been weighed up as substantive or explicit knowledge of the legislation whereas analysis relied on tacit knowledge, which was much more subjective. However, this was considered in the analysis and became part of the analysis process, so was useful in assessing tacit or explicit knowledge but not implying a lack of knowledge just because the terminology was not utilised.

Member checking is a valuable means of guarding against researcher bias and happens when material is returned to participants but there can be problems if the interpretation is challenged (Robson and McCartan 2016). This approach was not embraced, as the questions posed were to elicit responses that were spontaneous and so that the participants did not have the opportunity to consider their answers and align them to formal sources of information. Member checking had the potential to dilute this spontaneity should the participant want to consider and then change their response. Instead, peer review was undertaken with the supervision team, where transcripts were debated, and points of consideration were identified to inform the analysis of responses. These debriefing sessions can also reduce the risk of researcher bias (Robson and McCartan 2016) as they encourage reflection on the interpretation and build consensus on the meaning of the responses.

6.5 Contribution to knowledge

This research study identifies the considerations that nurses make when working out the best interests of people with advanced dementia in line with the legislation of the Mental Capacity Act (2005). Understanding what influences nurses' decision-making can help to determine educational incentives that might improve knowledge, understanding and application of the legislation for nurses and other health and social care professionals who have been at the root of criticism for failing to adhere to the legislation. The unique and significant contribution to knowledge from this study is how the findings can influence education and training of nurses, health care policy and future research. Exploring the perspectives of nurses on best interests decisions for patients with advanced dementia will inform these processes. There are a range of studies that have explored the legislation, its implementation and the impact, and nurses have featured as participants alongside other healthcare professionals. The report from the HOLSC (2014) criticises healthcare professionals and their understanding and application of the legislation in practice. Nurses are one of the healthcare professionals that the criticisms are aimed at.

Nurses are expected to be decision-makers in best interests processes, this is stated in the Code of Practice (DCA 2007 p. 69 – 70). Twenty-seven of the participants in the study accepted the role nurses play in best interests decision-making. Thirteen participants agreed that the knowledge of healthcare professionals is poor. This demonstrates that more needs to be done to increase knowledge and as nurses are part of the decision-making team, they would benefit from initiatives to increase knowledge and enhance future practice.

A small number of studies have focused on nurses specifically and their knowledge of the full legislation but not on best interests decisions or on patients with advanced dementia. There appears to be no studies about advanced dementia and decision-making processes by nurses and factors that feature when considering best interests. Vignettes have been used in other studies about mental capacity and best interests and have been to be useful. Vignettes were utilised in this study to encourage the participants to discuss situations in an honest way and not to have to reflect on their own experiences. The originality emerges from using vignettes to encourage nurses to give opinions of how they might act in a certain situation, such responses may not have been evident with a different research design.

Existing studies have focused on direct observations of procedural knowledge and factual knowledge of the legislation from a multi-disciplinary perspective. There is no clear picture what practitioners involved with best interests meetings worry about, the ethical dilemmas and the difficult decisions that prove challenging. Existing studies explore explicit knowledge but do not go as far as considering what thought and feelings the individual professionals have in respect of the decision processes and the decisions that are being made.

There also appears to be no studies around best interests processes for people living with advanced dementia. Dementia does feature in existing research, in respect of capacity and the ability to be involved in decisions for both health and welfare and property and finance. However, dementia, and more specifically, advanced dementia is not a focus of any study where the condition and awareness of how it impacts on the person may then impact on how decisions are considered and made by others. In line with this, elements of dementia care, such as the preservation of personhood is a factor that practitioners should consider in Best Interests determination, as part of the 'consider all circumstances' instruction within the checklist. It is a contribution to the knowledge base if it can be suggested that there are aspects of dementia care and awareness of dementia as a condition that may directly influence practice and process of a particular piece of legislation. The learning may well have a role to play in improving outcomes in practice by identifying ways in which to improve practice, outcomes and indeed knowledge of the concepts that surround the legislation.

6.6 Reflection

de Vries and Timmins (2016) assert that reflection should be a touchstone for effectiveness in care, be critical in nature and focus on consistency of care delivery with values, standards, and regulations. Middleton (2017) argues that the effectiveness of reflection can be questioned, especially reflection that focuses on feelings, or introspective reflection. She suggests that critical reflection is required in practice, in professional, ethical and legal matters so that healthcare professionals are empowered and have the capacity for change and to improve health outcomes. Critical reflection requires consideration of practices, processes and identities, looking beyond the circumstances to the external factors, policies and people that might influence choices made and actions taken (Sutherland 2013).

Through reflexivity, critical reflection becomes part of a process of examination of the relationship between self and knowledge creation, opening-up personal and epistemological influences (Smith 2011). Reflexivity has two elements: prospective and retrospective reflexivity, or the effect on the research by the researcher and the effect on the researcher from the research (Attia and Edge 2017). Reflexivity is important to consider beliefs, goals, values and explanations of nursing (Reed and Shearer 2011). The personal values, professional and life experiences that influence one's views of nursing support the ontological and epistemological views and help develop a philosophical inquiry (Reed and Shearer 2011).

6.6.1 What brought me to the study

I have had a developing interest in both dementia care and in mental capacity and best interests processes since the inception of the legislation in 2007. My interest in decision-making in general and in the intricacies of the MCA precede my evolving interest and involvement in dementia care. I sought to develop my knowledge in dementia and its related topics so that I could commit to delivering education to others from a position of in-depth knowledge and understanding. I completed a post graduate course in Medical Ethics and Law (MEL) in 2013 as I wanted to better understand the legal and ethical implications of nursing in particular; moreover, nursing adults who are impaired from an autonomous decision-making viewpoint. At the same time, I developed knowledge and understanding of dementia care, my study of personhood has broadened into person-centredness and the needs of patients to be supported in respect of decision-making when their capacity to make decisions is compromised. I think that people living with dementia deserve the same considerations as any other person who has intact cognition or impaired cognition but needs support to process information.

Having worked in nursing during the implementation of the MCA (2005) and its BIS, I maintained an interest in the legislation and how well it was applied in practice. I wondered if a decision can be made that is truly in the best interests of the patient; accepting that the best interests of others is likely to be an influencing factor when considering health care decisions. I think several factors have the potential to influence what one considers the best interests of another, and this belief is compounded by statements that I have heard over the years. These statements are echoed in literature about dementia, where the cognitive decline is likened to the living death suggested by Peel (2014). I have heard statements such as 'death would be a release' in various forms from various people when referring to patients and their own relatives. These statements are generally in response to the challenges that carers face when caring for a person with advanced dementia, when there is either behaviours that challenge or when burden is significant. In these cases, the best interests that were at the forefront were the best interests of the carers, more so than the patient. Although a peaceful death was considered as potentially the best for the patient too.

I am a nurse, so I am interested in what decisions are made by nurses, how these decisions are made, what nurses think about dementia and how this then impacts on their opinion of best interests. By exploring perspectives I could add to the body of knowledge on best interests decision-making in dementia and perhaps develop some recommendations to benefit practice.

6.6.2 Reflecting on the literature

There was very little written about what I wanted to research, but there was lots written about capacity, best interests and decision-making (in dementia). However, everything written was from a wider perspective, not specifically about nurses' perspectives on the best interests of a person with advanced dementia. I found it difficult to discount literature because I felt anything remotely relating to my topic could inform my research and I became fearful that leaving anything out would weaken my research. In the end, I had to stop myself being overwhelmed by the literature. I had to accept that as a novice researcher I would undoubtedly include literature that more experienced researchers would confidently discount and I reassured myself that I would learn from the process. Following feedback from my viva, I removed literature that did not add anything to the narrative I was seeking to inform and yet I was still anxious to remove some studies as I did not want to weaken the argument for my study to be conducted. I suspect that developing and adhering to inclusion and exclusion criteria becomes easier as more research is undertaken. The literature helped me to decide the type of study I wanted to conduct and how I could collect and interpret my data. It helped me to consider what had already been discovered about my topic of interest and how I could explore additional viewpoints to provide another facet for others to consider.

6.6.3 Methodology

Case study seemed to 'fit' with the proposal; more so than other approaches such as ethnography as it supported a level of distance where I could review the situation in more depth. The development of the methodology following the literature review was a significant learning process. I have an appreciation of different methodologies and with more experience (and confidence) I can see where further research might be possible. My insight has developed during reflection on the process. For instance, if I was going to re-live the experience, I would consider formally testing knowledge with direct questions about the vignettes and then discuss the vignettes to gather perspectives or assess tacit knowledge. The value of developing pre-determined ways to assess of tacit knowledge was also evident after data analysis. I could have developed a set of criteria with my supervision team as to what indicated tacit knowledge, for example suggestions of insight into the legislation. This occurred to me when reflecting on the process and writing the thesis. Perhaps future research might incorporate these options.

6.6.4 As I progressed through the research

As I have progressed with my research, I have been informed through informal sources that practice around mental capacity and best interests in general remains at best, inconsistent, at worst deficient and in complete contrast to the legislation. Though these sources are informal (such as Twitter), they are posted by respected professionals, some with a body of publications, and they catalogue incidents where practice is left wanting and incapacitated adults are disenfranchised as a result. I would like to improve this by disseminating the learning from the study and suggesting a novel approach to education that might enhance knowledge of the legislation.

Since I started this research, NICE guidance has been published and the Deprivation of Liberty Safeguards have been replaced with Liberty Protection Safeguards, a new COP for the MCA though delayed, is anticipated imminently. I wondered at the time if it was worthwhile continuing with my study or whether I needed to revise my original question. However, due to the criticisms on social media, it is questionable if many nurses/clinicians are aware of the original guidelines, much less the proposed changes. I felt it was justifiable to continue because the criticisms focus on the existing guidelines and any potential knowledge could inform practice surrounding the existing and the updated guidance.

When completing this study, I was very conscious of not wanting to add to the criticism of healthcare professionals (and more specifically, nurses) who already work incredibly hard in a very pressurised system. The nurses and healthcare professionals I have worked with during my career have all shown such professionalism and sincerity in caring for their patients that I felt disappointed that practice is shown to be impaired in respect of the legislation. This was particularly difficult because when I discussed aspects of capacity and best interests with nurses, I felt that there was a lot of knowledge embedded in their responses, so much so, that I wanted to explore further and establish if the criticisms were indeed warranted. What is undeniable is that there are gaps in knowledge relating to MCA, best interests and additionally in relation to dementia. These gaps are known by the participants, yet they were not able to define how they would like to address the gaps.

6.6.5 Thoughts on the data

My past experience initiated an interest in how best interests decisions are considered and if factors such as apparent quality of life bear any weight. This, partnered with the criticisms (such as those from the HOLSC 2014 report) were a constant point of reference when transcribing the data, mapping the responses, and interpreting the findings. I wanted to find out if the propositions of poor knowledge and understanding were justified or could be disputed. I was worried that I would interpret the data with bias, in that I wanted to identify knowledge, so I would apply any tenuous comment to evidence of knowledge. I was conscious to engage with the data and consider if I could identify knowledge through what was expressed whilst accepting that my analysis might not necessarily be what the participant meant by their response. Analysing sample transcripts with my supervisors helped to process the information in a less subjective way, as consensus was developed around the meaning and implications of the responses. Also, using Thematic Analysis and adhering to the guidance in how to use the method to analyse made the experience more robust and limited the risk of being biased and reading more into the responses than was meant by the participants.

When analysing the results, I was surprised that no participants had any tangible examples of good practice, or ideas where they felt they would enhance learning. Some discussed experience working with other professionals as valuable but I expected them to have stronger ideas about their own learning, considering they had identified limitations in their knowledge. What I was not surprised with was the level of tacit knowledge that became evident as this is what had sparked my interest in the topic to start with. Being conscious of the criticisms, when I spoke to professionals, I found that they did have insight into the legislation and this was evident in the discussions, although few utilised the legal terminology to support their points. Clinical knowledge and logical decision-making was evident in their responses; this is where the clinical comfort zone came in – participants were clinically confident to discuss the treatment aspects of each case as they could draw on their extensive knowledge and experience. However, they did not align the clinical factors to the legislative factors, which is where the criticism arises.

During this research, I have learned that real experiences shared between individuals is an excellent way to strengthen knowledge about legislation and its impact on practice. Participants sharing their own experiences of dealing with capacity and best interests issues helped them to consolidate their own knowledge and demonstrate that they considered the BIS within the checklist when relating to a hypothetical situation. They did have gaps in their knowledge about capacity issues, best interests processes and patients with advanced dementia. However, they also had significant knowledge and experience to draw on to consider their practice in relation to the vignettes. I was reassured that they would question their practice if unsure, except a small number did remind me that sometimes resources (such as time and staffing) hinder best practice. This is an unfortunate but real illustration of today's healthcare arena.

6.6.6 Future practice

The application of the BIS is the tip of a complex decision-making iceberg (Taylor 2016). Obviously, there is more work to do to enhance and consolidate knowledge in the legislation and best interests decision-making. What is reassuring is that participants do appreciate the challenges of best interests decision-making and are patient-focused, although knowledge of the need to ascertain the wishes and thoughts of the person at the centre of the decision-making process could be significantly improved. There needs to be a greater understanding of individuals' roles within decision-making and a consensus to work more closely together to limit negative outcomes and promote positive practice in best interests decision-making.

Often, knowledge is enhanced through collaborating with others and discussing cases where gaps in knowledge are realised and steps are taken to strengthen knowledge. My participants left their interview with an intention to read more about the MCA and best interests and we had a de-brief about each scenario after the interview, discussing what might happen in each case. I hope that, by being involved in the study, participants expanded their knowledge and their desire to improve practice as the interview clarified the criticism that was raised about the legislation and practitioner knowledge. Criticism continues, so it is apparent that the tools and resources available are not fully addressing the gaps in knowledge and practice. With continued efforts and perhaps more research, I hope that this can improve.

Research conducted by Rowley *et al* (2013) concluded that as explicit knowledge was not apparent from the findings of their study, then implementation of the legislation would not be at an acceptable standard. If the same logic is applied from this study, then the previous and current criticisms are likely to persist. Recommendations need to be realistic and achievable to address the criticisms and facilitate tangible improvements in practice.

An important consideration for academia is to distinguish how knowledge is measured and established in health and social care practitioners. Currently, a swathe of literature suggests that practice is unsatisfactory because knowledge and understanding of the legislation is poor. If we continue to measure knowledge as purely a replication of facts, we will fail to identify any other aspects that are hindering the most positive outcomes from successful best interests considerations. If, in pre-registration and post-registration training, the focus on decision-making is from a clinical outcome perspective, we cannot expect these same practitioners to make decisions that are often clinical using non-clinical factors as a guide. We need a culture change to refocus attention on patient wishes rather than clinical judgement in many cases.

6.6.7 Personal impact

When I think about the process of the study and what I have learned and experienced over the past six years; it has been hard going and has often felt out of reach. What has kept me going (apart from my supervisors) is my interest in capacity and best interest issues and additionally, my interest in dementia care. I do not think I can finish writing this thesis without acknowledging the Covid-19 global pandemic and the effect it has had. I am lucky that I was not adversely affected by the virus and my closest family and friends were lucky to only experience mild symptoms. I tried to ‘do my bit’ by returning to clinical practice in the first lockdown to help my colleagues who were struggling to manage. Work was relentless, trying to adapt to a situation that seemed to be changing daily. In the eighteen months since it started, I feel that my feet haven’t touched the ground. My studies lost momentum because of the pressures of work and rapid changes demanded in response to the guidance. I have felt the strain of isolation too – not meeting my students face to face has been difficult and I have felt lonely, and I lacked purpose. Coming out the other side, I appreciate everything I have, including the opportunity to complete my studies and I hope that I regain my sense of purpose as I share the findings of my study with others.

6.7 Summary

This chapter discusses the results and concludes the study, acknowledging that the criticisms around practitioner knowledge and practice within the literature remains valid and is acknowledged by the nurses questioned. Although there is a level of tacit knowledge that can be applied to the BIS, there are gaps in explicit knowledge that reflect the criticisms. The research question about the factors that nurses consider when making best interests decisions is answered through the responses: nurses do follow some of the BIS through their considered responses. The participants would consult others, consider patients' previously expressed wishes, consider all circumstances that impact on the decision and the outcome of the decision; these are evident in the responses. Less evident are assumptions about quality of life, encouraging the patient's participation or considering that capacity may return. Clinical factors are heavily weighted in decisions, participants often defaulted to their clinical knowledge to respond to questions that may not be clinical in nature. Unfortunately, this may reflect the HOLSC (2014) criticism that decisions are led predominantly by clinical judgement rather than patient wishes. There is a desire to preserve life, rather than allow a natural death but this may be due to the knowledge around dementia, rather than best interests considerations.

The literature also asserts that best interests decision-making is complex and multi-faceted and requires several initiatives to improve practice and outcomes. The findings of this study support the notion of the complexity of decisions that need to be made and the circumstances that they need to be made in. This study provides the background to the criticisms in relation to best interests decisions and how people with advanced dementia are disadvantaged through poor application of the legislation in practice. The criticisms maintain that people with advanced dementia are having decisions made on their behalf that are resource driven, that fail to recognise previously expressed wishes and are focused on function rather than outcome. This means that their ability to participate in decisions is minimised because the potential outcome may create a risk (which is to be avoided in line with the principle of non-maleficence). The findings of this study demonstrate that nurses do deliberate the challenges of decision-making and consider the criteria recommended in the checklist associated with the BIS. However, regardless of their field of practice or length of service, they do not rate either knowledge or confidence in relation to the legislation as significantly high and they express that additional education and training is important. The participants of the study also demonstrated a desire to practice in a person-centred way and to be considerate of the person with advanced dementia and their family/carers. There is potential for developing interventions to increase knowledge in the MCA and best interests and in involving people with advanced dementia in decisions about their care and treatment. Continued research is important to continue to impact on practice and improve the experience of both patients and health and social care staff.

Chapter 7
Conclusion and recommendations

Introduction

The aim of chapter seven is to consider the learning and the implications and application to future knowledge and practice. In respect of education and good practice for the MCA and best interests, participants did not have many suggestions but did comment that the availability of education and training needed improvement and that a focus on e-learning did not offer the best opportunity for learning or understanding of the legislation. Both explicit and tacit knowledge were evident from the responses in that participants demonstrated appropriate considerations of the legislation and COP.

The existing research explore explicit knowledge but do not go as far as considering what thought and feelings the individual professionals have in respect of the decision processes and the decisions that are being made. Dementia features in existing research, in respect of capacity and the ability to be involved in decisions for both health and welfare and property and finance. However, advanced dementia is not a focus of any study where the condition and awareness of how it impacts on the person may then impact on how decisions are considered and made by others. Although this study focuses on the UK legislation and nurses in England, the CRPD has at least 82 signatories and other countries may have legislation that mirrors the UK legislation, therefore they may experience similar issues with the application of the legislation, therefore this study can inform a wider audience than England and the UK.

7.1 Implications for practice

The recommendations for practice taken from the participants' responses are:

- A greater focus on Advance Care Planning and increasing awareness about the implementation of these plans once made
- Quality education and training on the Mental Capacity Act (2005) and Best Interests Standards that is evaluated and measured in respect of outcomes
- Promotion of multi-professional networking to consider best interests decisions so that staff can share knowledge and experience

In respect of ACP, there was significant focus on the lack of and need for ACP for the characters in both vignettes in the study. Although ACP was not a central focus of this study, it does feature in relation to decision-making on behalf of others and it is identified that ACP has happened infrequently for people diagnosed with dementia (Piers *et al* 2018). ACP was part of the legal terminology considered in the responses to establish explicit knowledge about the legislation as the concept is clearly contained in the MCA (Hayhoe and Howe 2011). There were 23 participants (77%) who mentioned ACP in their responses, identifying that it would make best interests decision-making much more straightforward. Therefore it is proposed as a recommendation as it was a factor that influenced the perspectives of the participants when considering the vignettes.

In respect of the education on MCA and BI, the study found that there is participant knowledge on the MCA and best interests but that this knowledge is incomplete. This suggests that the same would apply to nurses generally if Johanssen's (2007) suggestion applies, that any generalisation from case study research occurs in a naturalistic way through the audience using analytical reasoning to apply to a general context. It is therefore important to try to work out the best way to enhance the knowledge of practitioners so that practice reflects their knowledge. The literature highlighted the need for more comprehensive knowledge. Participants did not recommend any approach to education and training that had an impact on them or that they would recommend. The current healthcare training landscape sees traditional face-to-face training being supplemented or replaced with e-learning options (Lawn, Zhi and Morello 2017). However, it does not appear from participants in the study that e-learning is the best way to inform or educate in respect of the MCA. This is supported by Surr *et al* (2017) who reviewed education and training in dementia care and found that e-learning is not favoured by many practitioners.

Shepherd *et al* (2018b) discussed research consent and proposed that confusing legislation can be to blame for poor knowledge. It is possible to argue this even though the MCA legislation has been implemented since 2007. The Deprivation of Liberty Safeguards were criticised alongside the MCA and BI and were due to be replaced in April 2022, which has been further delayed. This may support the notion that the legislation was (or is) confusing and so contributes to the lack of knowledge in those who utilise it.

A lack of resources made an appearance in the responses, with participants suggesting that practitioners do not have time to process and apply their knowledge. Demand for health care has increased across all services since 2009 according to the Kings Fund (2019). If there are greater demands on staff, then there will undoubtedly be consequences, which might have a detrimental impact on patient outcomes. With resources being an issue and education opportunities not meeting the needs of participants, perhaps what is needed is a different approach to training or education. An ethical debate, a clearer way of remembering the legal requirements of the legislation or a combination of both could be an option. It is clear action is required as there is news of continued incidents where best interests decisions do not lead to positive outcomes for the patient and educated and experienced nurses on the whole feel that they need to know more.

The third recommendation relates to where participants referred to experts in the field being a useful resource for best interests. As mentioned, participants suggested a lack of resources meant that practitioners do not have time to process and apply their knowledge. Multi-professional networking in real-time situations may consolidate learning or reduce demand for lengthy education sessions as research by Gough and Kerlin (2012) demonstrated, with managers wanted less training ‘in isolation’ and to be more meaningful to the care setting. Demand for health care has increased across all services since 2009 according to the Kings Fund (2019). If there are greater demands on staff, then there will undoubtedly be consequences, which might have a detrimental impact on patient outcomes. As each year passes with the legislation being in place, but more strain on services as each of those years pass, then there is little opportunity to give the legislation the focus that it deserves.

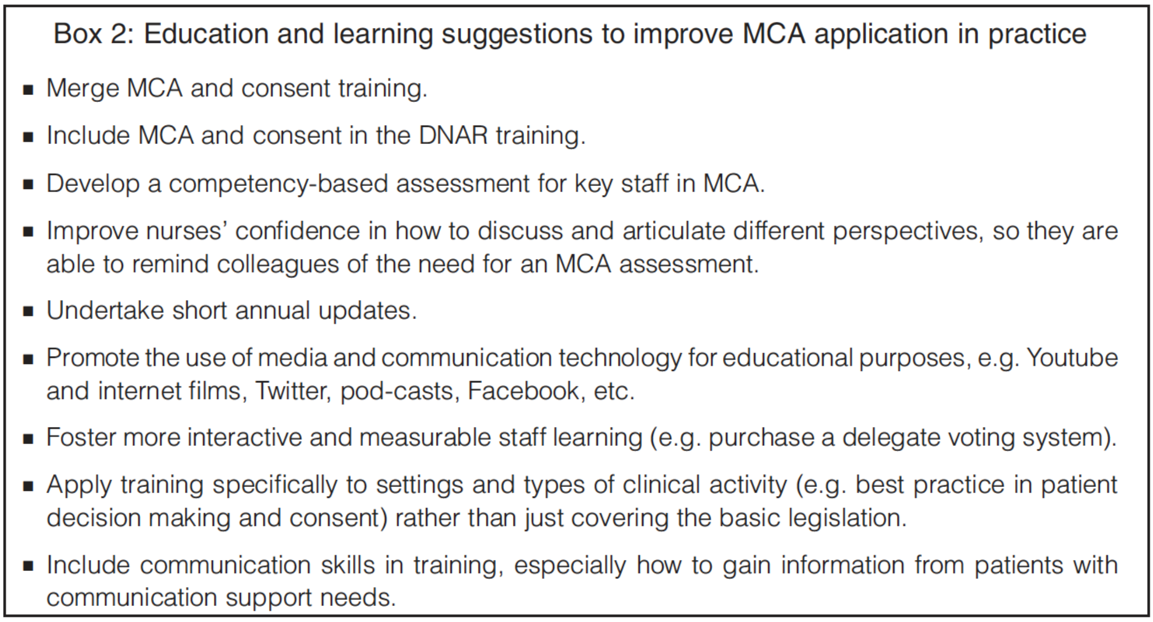
7.2 Recommendations for future research

If there is evidence of tacit knowledge from the study, then it is appropriate to consider if there are other factors that influence best interests processes that result in the poor outcomes suggested by the literature. Participants were aware of aspects of best interests when presented with a scenario, but they were unable to fully articulate the procedural requirements sufficiently clearly to demonstrate that they act in accordance with the legislation. The tacit knowledge demonstrated familiarity with best interests processes but the knowledge was not comprehensive against all the BIS and not across the whole sample. Future research therefore could investigate the extent to which compliance with the legislation correlates with being able to explicitly recall the principles and BI procedure. One idea could be to formulate an education intervention that includes discussing a case and applying the BIS to the case or reading about the criticisms of a real case and how the BIS were not applied. A study could test self-assessed knowledge before and after the intervention and perhaps 1 – 3 months after to see if there is a level of retained knowledge. It would be at least sensible to encourage a different approach to education and training and see if there is any difference to what is delivered already. Another option would be to test recommended processes to see if there is an improvement in understanding or application of the legislation in practice, for instance the aide memoirs such as those shared by Hope, Eccles and Slowther (2009) and Wade and Kitzinger (2019). Research could also focus on other aspects that require improvement to establish if other factors have an influence.

7.3 Recommendations from the literature

Willner *et al* (2013) acknowledge the concern that the breadth and depth of the gaps in knowledge identified from their study raise and discuss an alternative approach to training to consider if it is any better than traditional training. Participants in their study who had experience of dealing with mental capacity issues had reasonably good insight into the extent of their knowledge, as inferred from the significant correlations between self-ratings and interview performance. Most participants said that they would discuss a mental capacity issue with a colleague, which might increase the information available to support decision making. Their results suggest that the knowledge and skill needed to deal with mental capacity issues, as distinct from the ability to identify issues that need attention, may be gained more from experience of actual cases than from formal training. They propose a strategy that the main function of formal MCA training is awareness raising, including encouragement to access available electronic resources and a local MCA 'champion'. Other structures, such as the availability of mentors, easy access to legal advice, and a local forum to discuss mental capacity practice dilemmas as they arise, may also be helpful in promoting good practice in this area (p. 99).

Phair and Manthorpe (2012) presented education and learning suggestions to improve MCA application in practice, which could be adopted in education initiatives and evaluated for effectiveness.



Box 2: Education and learning suggestions to improve MCA application in practice

- Merge MCA and consent training.
- Include MCA and consent in the DNAR training.
- Develop a competency-based assessment for key staff in MCA.
- Improve nurses' confidence in how to discuss and articulate different perspectives, so they are able to remind colleagues of the need for an MCA assessment.
- Undertake short annual updates.
- Promote the use of media and communication technology for educational purposes, e.g. Youtube and internet films, Twitter, pod-casts, Facebook, etc.
- Foster more interactive and measurable staff learning (e.g. purchase a delegate voting system).
- Apply training specifically to settings and types of clinical activity (e.g. best practice in patient decision making and consent) rather than just covering the basic legislation.
- Include communication skills in training, especially how to gain information from patients with communication support needs.

Fig 7.1 Phair and Manthorpe (2012) suggestions to improve application of the MCA

Walji *et al* (2014) refers to studies that linked to insufficient training and suggested that increasing familiarity with the MCA was helpful in gaining confidence. Participants in their study wanted training and guidance focusing on clinical applications of the MCA, rather than theoretical or legislative aspects. They also suggested that case examples were often too specific to certain client groups, as respondents had complained that case examples they had received were not related to the client group they worked with (learning disability case study when they worked with people with brain injury). Walji *et al's* (2014) study found that participants felt training was inadequate in addressing the complexities of implementing the MCA, and all participants had learnt most through clinical practice. This suggests that being exposed to best interests meetings would enhance knowledge of practitioners and subsequently improve practice. The aide memoirs provided by Wade and Kitzinger (2019) give practical guidance on how to apply MCA in clinical practice and may also be used to support practice.

Jenkins *et al* (2020) explored the range of training available, acknowledged the recurrent misunderstandings and poor application of the legislation. The findings suggested that training was limited, and information shared in training events was not retained. They made recommendations that future training, that it should be interactive, scenario-based and relevant to trainees' practice.

7.4 Proposed education model

In this study, participants did not explicitly identify how they would improve training, other than a small number suggesting linking with other professionals or discussing cases to make the legislation more realistic to their own expertise. From the discussions that arose from the vignettes, it appeared that a case-discussion approach provided a platform to identify challenges and deliberate and reach a consensus on how cases could be resolved.

Considering other education frameworks, a model that reflects dementia care could be proposed. For example, the Dementia Training Standards Framework (Health Education England 2018) details the essential skills and knowledge necessary for dementia across the health and social care spectrum. There are three tiers to the framework:

- Tier 1 - awareness, which everyone should have
- Tier 2 - basic skills which are relevant to all staff in settings where people with dementia are likely to appear
- Tier 3 - leadership

A similar approach could be adopted in respect of MCA and DOLS (which would include best interests):

- Tier 1 - awareness, which everyone should have
- Tier 2 - basic skills which are relevant to all staff in settings where capacity and consent are
- Tier 3 – enhanced skills where nominated staff can undertake a ‘champion’ role and mentor others or act as a source of advice for capacity, consent, and best interests issues

Tier 1: Would consist of MCA awareness, including input on the role of the IMCA, the offences and on best interests processes. This would be through completing the e-learning for healthcare training or SCIE e-learning. Although e-learning is not a preference for learning according to Surr *et al* (2017), it is a cost-effective way of getting the workforce aware of topics that are important for patient outcomes. Health professionals increasingly access online learning courses to support their professional development (Bettiol *et al* 2022), so they do have a value in workforce development.

Tier 2: Complete Tier 1 training. In addition a face to face training session, using Court of Protection cases as a discussion topic , an example being Figure 7.2:

Case discussion: debate over severity of dementia in the Court of Protection

Mrs P was diagnosed with Lewy Body dementia, a type of progressive dementia which affects thinking, visual perception and movement, in 2016. Despite her diagnosis, Mrs P was happy living at home, spending her days completing the crossword, going for walks and watching TV. She received some support from her family.

In November 2020, Mrs P was admitted to hospital with an infection. Doctors prescribed antibiotics, which didn’t help, and so she had an operation that same month to remove gall stones. During her recovery, which was going well, Mrs P unfortunately contracted Covid-19 in the hospital, and she needed oxygen. In early December, the hospital planned on making arrangements for her to return home to recover, however, her NG feeding tube was taken out, possibly by Mrs P accidentally.

The hospital Trust took the view that Mrs P lacked capacity to make any decisions around her care herself, and that replacing the feeding tube was not in her best interests as she had ‘severe’ dementia, in line with NICE guidelines. Hospital staff subsequently made plans to put Mrs P on palliative care, which could be done in the comfort of her own home.

Mrs P’s family strongly disagreed with the Trust’s decision and wanted her to have a temporary NG feeding tube, followed by a PEG or RIG tube, which allows for more long term feeding and then discharged home. The case was referred to the Court of Protection for an urgent hearing in January 2021.

Mrs’ P had appointed her husband as an Attorney for her health and welfare, with specific power to consent to life-sustaining treatment, and so one of the most prominent debates was whether Mr P had a definitive say in this situation. Mr P “firmly” wished for his wife to receive clinically assisted nutrition and hydration, and to have a chance at recovery. The Court of Protection found against this but placed great weight on his view as the Attorney.

The NHS Trust (and the entire treating team at the hospital) deemed Mrs P’s dementia as ‘severe’, whereas the family maintained that it was ‘moderate’. The family had, after all, supported Mrs P for the last four years since her diagnosis, and were familiar with her state of mind. The difference between the levels of severity was important here, as NICE guidelines state that it would not generally be in the best interests of a patient with ‘severe’ dementia to have a PEG feeding tube inserted. In this case, the bigger picture was that it was the difference between palliative care, where Mrs P would pass away within days/weeks and recovery, or at least further weeks/months of life.

The Official Solicitor said that the Trust may not be right about ‘severe’ dementia and that Mrs P’s current presentation is heavily influenced by her recent illness, including Covid-19. He felt that some recovery was possible and requested that an independent medical expert should be instructed to determine the severity of Mrs P’s dementia.

The following day, the judge ruled that nutrition and hydration should be reinstated, initially via the NG tube and then by an alternative. She said that the family’s view seemed “reasonable” and that there was uncertainty over the diagnosis of ‘severe’ dementia. The judge also placed “considerable weight” on her Attorney’s view that she should be given a chance to recover. The court emphasised that the clinical team should in no way be criticised for coming to the decision they did.

https://barcankirby.co.uk/court-of-protection-debate-over-severity-of-dementia/

Figure 7.2 Case discussion of Court of Protection referral

Discussion cases would be generic or targeted towards the speciality of the participants of Tier 2 training. Sessions would also involve practitioners experienced in best interests assessments to discuss cases they have been involved in following a seminar format.

Tier 3: would complete Tier 1 and Tier 2 training. They would also complete the Best Interests Assessor Course, which aims to equip experienced practitioners in health and social care with the skills and knowledge required to enable them to undertake a Best Interest Assessment . They would then take on the role of MCA champion for their practice area (or they could registered as BIA for the organisation). This training will be replaced by the Approved Mental Capacity Professional (AMCP) when the Liberty Protection Safeguards are implemented in 2023/24.

The challenge would be to identify an organisation to pilot the 3 Tier training approach and evaluate the impact on the workforce and on patient outcomes through, for example complaints, audit or Court of Protection referrals. Surr *et al* (2020) conducted a study to investigate the barriers and facilitators to implementation of dementia education and training in health and social care services. The findings showed that organisations struggled with resources such as time, finances and availability of staff, in order to support staff to change their behaviour through implementation of learning because it can be challenging to prioritise training attendance and subsequently support staff to implement learning in practice. It is important to consider this when recommending new programmes of study as it places additional pressure on an already pressurised system. However, of the literature reviewed for this study, at least eleven studies recommended a review of available training to improve practice in capacity and best interests assessments. Four of the studies were conducted after the HOLSC (2014), which suggests that the criticisms highlighted in the report are still a problem. Therefore it is important to consider different approaches to education and training to make the required improvements to patient care.

7.5 Summary

Chapter one of this thesis presented that the challenges of dementia are widespread with stigma, the physical and psychological effects on the individual and the loved ones, and how dementia impacts on the person’s ability to maintain insight into their capabilities as a result, decision-making is impaired. Health care professionals are often at the forefront of this process, using the MCA (2005) and the BIS to guide practice. Chapter two gives details of the MCA and BIS as part of the MCA, as well as the NICE guidelines published in 2018 that aim to support the implementation of the legislation in a clinical setting.

Chapter three provides a literature review which explores research in health and social care professionals’ understanding or knowledge of the legal frameworks relating to decision-making in dementia, the MCA and best interests. The research proposes that health and social care professionals have a limited grasp of the legislation and that, as a result, patient outcomes in best interests decisions are significantly flawed. It is apparent that continued research is required to inform continuing practice alongside guidance in the application of the legislation.

Chapter four introduces the methodological approach utilised, namely qualitative, case study research using vignettes and semi-structured interviews to generate data. It explains how a qualitative research approach explored the ‘lived experience’ of best interests decision-making; by encouraging an in-depth discussion of decision-making processes around two vignettes. The case study approach enabled an in-depth analysis of the BIS as an aspect of both the MCA (2005) and decision-making. The chapter analysed the recruitment and ethical approach to the participants and presented how vignettes and semi-structured interviews generated valuable data reflecting the perspectives of the participants.

In chapter five, the findings asserted the various notions that were interpreted through the analysis of the data. Participants were largely receptive to the criticism identified in the literature, acknowledging their limitations in knowledge of the MCA and the BIS. They used some legal terminology when discussing the vignettes, which was evidence of explicit knowledge but did not demonstrate extensive explicit knowledge of the legislation through their responses. Participants often referred to clinical experience to support their perceptions on each of the vignettes and defaulted to the 'clinical comfort zone' if they did not directly answer the question that was posed to them. A significant number of the participants demonstrated a level of tacit knowledge and ethical understanding about the vignettes, recognising the challenging decisions faced within the situations depicted in them. Thirty nurses were recruited to the study, from a range of disciplines and post-qualifying experience, representing the demographic of nurses registered by the Nursing and Midwifery Council in age and ethnicity. Thematic analysis of the results identified four key areas; firstly, that participants overall accepted the criticism presented about the MCA and best interests, secondly, that there was evidence of both explicit and tacit knowledge of the legislation through the discussion that participants initiated. Participants also referred to clinical experience to support their responses and fourthly, person-centredness influenced responses about what should happen to the characters in the vignettes.

Chapter six discussed the results and considered the research question and whether the factors that nurses consider when making best interests decisions is answered through the responses. The HOLSC (2014) criticism that decisions are led predominantly by clinical judgement rather than patient wishes remain relevant through the responses. Chapter seven has explored the recommendations for future research and education and training opportunities that may go some way to improve the situation and allay the criticisms that continue to arise.

This study has focused on factors that nurses consider when making best interests decisions for patients with advanced dementia. It has established that nurses consider the BIS in relation to hypothetical situations that reflect practice. Participant responses considered the circumstances that surrounded the patient case and deliberated on these when discussing the potential decision. They discussed the importance of consulting others about the decision and considering any previous wishes the patient may have expressed. What was evident was that participants focused heavily on the clinical aspects of the situation, which has the potential to override any previous wishes the patient may have expressed according to the HOLSC (2014). There were areas where practice could be improved, such as encouraging participation in decisions and remembering that capacity is decision and time specific, so any chance that capacity will be regained should be at the forefront of any best interests consideration.

Given all of these points, education and training should focus on aspects of practice that require improvement, rather than generic e-learning that is focused on the factual aspects of the legislation rather than the application to practice. Participants were unable to specify how they felt that their knowledge could be enhanced but did say that experience consolidated their knowledge, so perhaps a more practical focus may have the positive impact that theoretical training has not.

Further research is needed to explore knowledge and practice in capacity issues, best interests considerations and specific cases relating to conditions such as dementia. It would be interesting to see if perspectives are influenced by other conditions that limit autonomous decisions and evoke best interests processes. Research testing the impact of specific education and training initiatives might also have a positive effect on future education and training needs.

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Appendices

Appendix 1 – Timeline of the development of the legislation

Year	Publisher	Title	Comment
1986	Greengross, S. Age Concern	The Law and Vulnerable Elderly People.	Contained proposals for the governing body to accept as the basis for requesting legal reform. It reviewed current legislation, consent, protection and representation.
1989	The Law Society	Decision-making and Mental Incapacity: A Discussion Document	The paper addressed several issues regarding mentally incapacitated people and made various suggestions for alterations to the law.
1989	The Lord Chancellor invited the Law Commission of England and Wales to carry out a comprehensive investigation of all areas of the law affecting decisions on the personal, financial, and medical affairs of those who lack capacity. This was in response to concerns raised by professional bodies and voluntary organisations dealing with mental disability (as mentioned above).		
1991	The Law Commission * Best interests discussed in document	Mentally Incapacitated Adults and Decision-Making: An Overview. Consultation paper number 119.	The preliminary stage of consultation to consider if reform of the law is needed.
1993	The Law Commission * Best interests discussed in document	The Law Commission Consultation Paper No. 128, 129, 130 (Mentally Incapacitated Adults and Decision-Making):	A second round of separate consultations on particular topics to obtain more precise proposals for Reform: A new jurisdiction (128), Medical Treatment and Research (129), Public Law Protection (130).
1995	The Law Commission * Best interests discussed in document	Mental Incapacity. Item 9 of the fourth programme of law reform: mentally incapacitated adults	The consolidation of the aforementioned consultation documents that acknowledges the law as unsystematic, patchy, out of date and failing to keep up with social and demographic changes.
1997	Lord Chancellor's Department Green Paper	Who decides? Making Decisions on Behalf of Mentally Incapacitated Adults	A consultation paper from the Government where they sought views on the Law Commission's recommendations for reform.
1999	Lord Chancellor's Department (policy statement) White Paper * Best interests discussed in document	Making decisions : the Government's proposals for making decisions on behalf of mentally incapacitated adults: a report issued in the light of responses to the consultation paper Who decides?	This white paper set out the Government's proposal for reform, in the light of the responses to the consultation from 'Who decides?'
2003	Department for Constitutional Affairs * Best interests discussed in document	Mental Incapacity Bill	Draft Mental Incapacity Bill published in June. It did not follow all of the recommendations in the Law Commission's 'Mental Incapacity' paper.

2004	House of Lords and the House of Commons The Stationery Office Limited * Best interests discussed in document	Joint Committee on the Draft Mental Incapacity Bill	Pre-legislative scrutiny conducted by the Joint Committee within 3 months of the original publication. 99 recommendations made in respect of further amendments.
2004	Department for Constitutional Affairs * Best interests discussed in document	Mental Capacity Bill	Re-named Mental Capacity Bill. Introduced to Parliament in June 2004.
2005	Department for Constitutional Affairs	Mental Capacity Act	MCA receives Royal assent 7th April 2005.
2006	The Law Commission	Post-legislative scrutiny	Called for a more systematic approach to post-legislative scrutiny to be controlled by Parliament.
2007	Implementation of MCA October 2007		
2007	Department for Constitutional Affairs The Stationery Office	MCA Code of Practice	The COP provides guidance and information about how the MCA works in practice
2007	Department of Health	Deprivation of Liberty Safeguards published	DOLS were introduced as an amendment under the Mental Health Act 2007 but form part of the Mental Capacity Act.
2008	Ministry of Justice The Stationery Office	Deprivation of liberty safeguards Code of Practice	COP to supplement the main MCA 2005 Code of Practice
2008	Office of the Leader of the House of Commons	Post-legislative Scrutiny – The Government's Approach	This document proposed that a law should be reviewed by Parliament three years after it has been passed to see how it has worked out in practice and in some cases a parliamentary body such as the House of Lords may conduct further scrutiny.
2009	DOLS implemented April 2009		
2013	The House of Lords Select Committee (HOLSC) was established in May 2013 to conduct post-legislative scrutiny of the MCA (2005), the task being to answer the question of whether the Act was working as Parliament intended.		
2014	The House of Lords Select Committee The Stationery Office	Mental Capacity Act 2005: post-legislative scrutiny	The findings suggested that the implementation has not met the expectations that it rightly raised and has suffered from a lack of awareness and a lack of understanding.
2014	HM Government The Stationery Office	Valuing every voice, respecting every right: Making the case for the Mental Capacity Act. The Government's response to the House of Lords Select Committee	Government response to HOLSC report

		Report on the Mental Capacity Act 2005	
2015	The Law Commission	Mental Capacity and Deprivation of Liberty A Consultation Paper	Commences review of DOLS at the request of the Department of Health
2017	The Law Commission	Mental Capacity and Deprivation of Liberty	Publishes recommendations and draft bill
2018	NICE Guidelines published		
2018	UK Parliament	Final Government Response to the Law Commission's review of Deprivation of Liberty Safeguards and Mental Capacity	The Government response agreed that the current DOLS system should be replaced and broadly agreed with the Commission's Liberty Protection Safeguards model.
2018	UK Parliament	Mental Capacity Act Amendment Bill	The Bill was debated in the House of Lords. The amended Bill returned for a Third Reading before being progressed through the House of Commons. Both Houses then considered final amendments before the Bill became an Act of Parliament.
2019	The Stationery Office	The Mental Capacity (Amendment) Act (2019) Chapter 18	LPS receives royal assent in May 2019 and reforms the process under the Mental Capacity Act 2005 for authorising arrangements enabling the care or treatment of people who lack capacity to consent to the arrangements, which give rise to a deprivation of their liberty.
2022	MCA (Amendment) Act (2019) and associated Liberty Protection Safeguards to be implemented in April 2022		
2022	New Code of Practice to be published		

Appendix 2 – Collection of tweets criticising application of the MCA


Matt Graham @MattHGraham · May 21

I had this very discussion this afternoon where it was discussed how the BASICS of the Mental Capacity Act are still not even vaguely understood.

Nicola Kohn @NicolaKohn · May 21

The MCA is over 15 years old. Why am I still reading reports that say P has capacity to make x decision which then explain why a best interests decision has been made on his behalf?!


Claire Webster @ClairetheQSW · Jan 8

Nothing sheds light on varied understanding of the Mental Capacity Act like a mass roll out of medical procedures on people who are unable to consent to it.


Rob Mitchell @RobMitch92 · Dec 11, 2020

Replying to @Capacitylaw and @MCAteamBradford

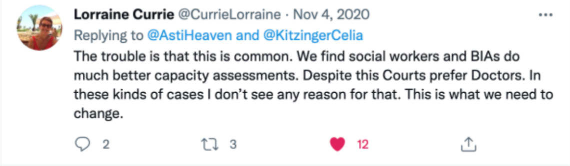
In practice I find the misuse of the presumption very rare. What isn't rare is the pressure practitioners are under to base their judgements on age, disability & presentation and to disregard the presumption at pretty much every turn.


Celia Kitzinger @KitzingerCelia · Nov 11, 2020

Such a sad story. I have supported several patients and their families through similar situations recently, where GPs won't accept a capacitous decision to refuse treatment.

David Lock: Suicide, refusing treatment, and consent in the dying process

blogs.bmj.com
David Lock: Suicide, refusing treatment, and cons...
This is an anonymised story about how a doctor's misunderstanding of the law around managing the ...


Lorraine Currie @CurrieLorraine · Nov 4, 2020

Replying to @AstiHeaven and @KitzingerCelia

The trouble is that this is common. We find social workers and BIAs do much better capacity assessments. Despite this Courts prefer Doctors. In these kinds of cases I don't see any reason for that. This is what we need to change.


Rob Mitchell @RobMitch92 · Oct 29, 2020

A reminder - 'Professionals and the court must not be unduly influenced by the "protection imperative"; that is, the perceived need to protect the vulnerable adult'. t.co/E6ow4nZbgO

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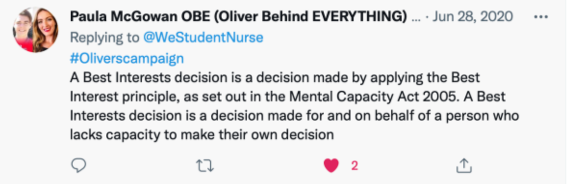

Paula McGowan OBE (Oliver Behind EVERYTHING) ... · Jun 28, 2020

Replying to @WeStudentNurse

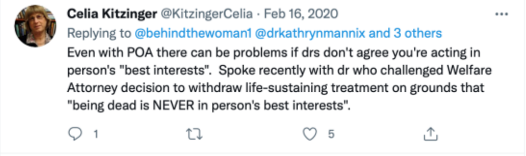
#Oliverscampaign

A Best Interests decision is a decision made by applying the Best Interest principle, as set out in the Mental Capacity Act 2005. A Best Interests decision is a decision made for and on behalf of a person who lacks capacity to make their own decision


Celia Kitzinger @KitzingerCelia · Nov 23, 2019

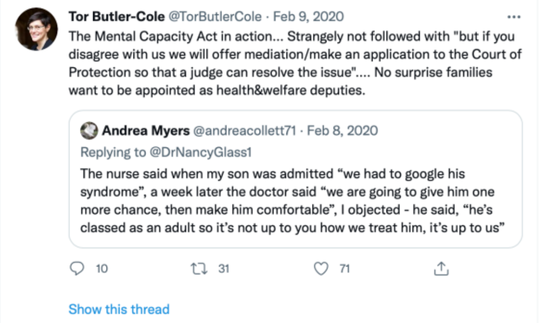
Replying to @KitzingerCelia @mancunianmedic and 9 others

[2] The fact that someone does not consent to a treatment you are offering and think is in their best interests is NOT evidence of lack of capacity.


Celia Kitzinger @KitzingerCelia · Feb 16, 2020

Replying to @behindthewoman1 @drkathrynmannix and 3 others

Even with POA there can be problems if drs don't agree you're acting in person's "best interests". Spoke recently with dr who challenged Welfare Attorney decision to withdraw life-sustaining treatment on grounds that "being dead is NEVER in person's best interests".


Tor Butler-Cole @TorButlerCole · Feb 9, 2020

The Mental Capacity Act in action... Strangely not followed with "but if you disagree with us we will offer mediation/make an application to the Court of Protection so that a judge can resolve the issue".... No surprise families want to be appointed as health&welfare deputies.

Andrea Myers @andreacollett71 · Feb 8, 2020

Replying to @DrNancyGlass1

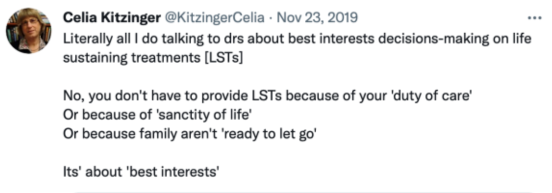
The nurse said when my son was admitted "we had to google his syndrome", a week later the doctor said "we are going to give him one more chance, then make him comfortable", I objected - he said, "he's classed as an adult so it's not up to you how we treat him, it's up to us"


Celia Kitzinger @KitzingerCelia · Feb 1, 2020

Still puzzling with why doctors find it SO hard to involve families appropriately in 'best interests' decision making. Referring another GP to this article today.

Making healthcare decisions in a person's best interests

journals.sagepub.com
Making healthcare decisions in a person's best interests when they lac...
Objective: To clarify the concept of best interests, setting out how they should be ascertained and used to make healthcare decisions for ...


Celia Kitzinger @KitzingerCelia · Nov 23, 2019

Literally all I do talking to drs about best interests decisions-making on life sustaining treatments [LSTs]

No, you don't have to provide LSTs because of your 'duty of care'
Or because of 'sanctity of life'
Or because family aren't 'ready to let go'

Its' about 'best interests'


Celia Kitzinger @KitzingerCelia · Oct 26, 2019

I'm reading the minutes of a best interests meeting act feeding tube held recently for a patient whose family I'm supporting. Dismayed at what passes for BI.
Nothing about P's values, wishes, feelings + beliefs (except from family who were silenced)

journals.sagepub.com
Making healthcare decisions in a person's best int...
Objective: To clarify the concept of best interests, setting out how they should be ascertained and ...

Celia Kitzinger @KitzingerCelia · Sep 3, 2019

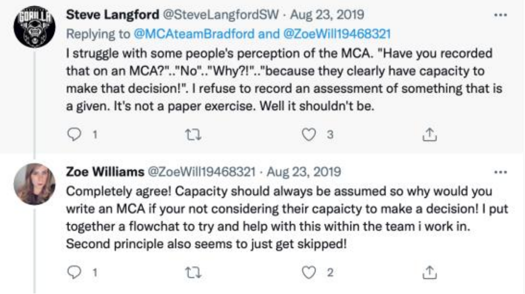
Lovely to meet Ben Troke @brownejacobson at the Court of Protection Practitioners Conference here in Leeds. Great networking opps. Looking forward to watching this:
brownejacobson.com/health/trainin...
@coppa_yh
#COP #CourtOfProtection #MentalCapacity

brownejacobson.com
The protection imperative
Ben explains what the courts have described as the 'protection imperative' and considers some case la...

MCAteamBradford @MCAteamBradford · Aug 23, 2019

Replying to @ZoeWill19468321

Yep. Sounds like a good dissertation topic 😊. We see it every day in our line of work (DoLS). Very worrying.



Steve Langford @SteveLangfordSW · Aug 23, 2019

Replying to @MCAteamBradford and @ZoeWill19468321

I struggle with some people's perception of the MCA. "Have you recorded that on an MCA?".."No".."Why?!".."because they clearly have capacity to make that decision!". I refuse to record an assessment of something that is a given. It's not a paper exercise. Well it shouldn't be.

Zoe Williams @ZoeWill19468321 · Aug 23, 2019

Completely agree! Capacity should always be assumed so why would you write an MCA if your not considering their capaicty to make a decision! I put together a flowchat to try and help with this within the team i work in. Second principle also seems to just get skipped!

DrawMyCare @MaryOToole10 · Mar 1, 2020

One of the problems with #LearningDisability is the cloak of #secrecy imposed around #safeguarding issues: #dataprotection is also cited to prevent wise sharing of information. This is not in the #bestInterests of ppl lacking #mentalCapacity in many aspects of life @BBCR4Sunday

BBC Radio 4 Sunday @BBCR4Sunday · Feb 29, 2020

How to break bad news to people with intellectual disabilities? @tuffreywijne tells Sunday about how @LArcheUK told its members about Jean Vanier abuse

Appendix 3 – Best Interests checklist described by Regan and Sheehy (2016), in the COP (DCA 2007) and the MCA (DCA 2005)

Regan and Sheehy (2016) adapted from COP	COP	MCA
Encourage the individual's participation	Every effort should be made to encourage and enable the person who lacks capacity to take part in making the decision (paragraphs 5.21–5.24).	He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.
Consult all those close to the individual	The views of other people who are close to the person who lacks capacity should be considered, as well as the views of an attorney or deputy (paragraphs 5.49–5.55)	He must take into account, if it is practicable and appropriate to consult them, the views of: (a)anyone named by the person as someone to be consulted on the matter in question or on matters of that kind, (b)anyone engaged in caring for the person or interested in his welfare, (c)any donee of a lasting power of attorney granted by the person, and (d)any deputy appointed for the person by the court, as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).
Consider the individual's views, whether expressed verbally or in writing, including their feelings, religious beliefs and past habits	The person's past and present wishes and feelings, beliefs and values should be taken into account (paragraphs 5.37–5.48).	He must consider, so far as is reasonably ascertainable— (a)the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity), (b)the beliefs and values that would be likely to influence his decision if he had capacity, and (c)the other factors that he would be likely to consider if he were able to do so.
Consider all circumstances, including emotional bonds and family obligations	All relevant circumstances should be considered when working out someone's best interests (paragraphs 5.18–5.20).	"Relevant circumstances" are those: (a)of which the person making the determination is aware, and (b)which it would be reasonable to regard as relevant.
Avoid making assumptions	Working out what is in someone's best interests cannot be based simply on someone's age, appearance, condition or behaviour. (see paragraphs 5.16–5.17).	In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of:

		(a)the person's age or appearance, or (b)a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.
Consider whether capacity will be regained in the future and whether this discussion could be delayed until then	If there is a chance that the person will regain the capacity to make a particular decision, then it may be possible to put off the decision until later if it is not urgent (paragraphs 5.25–5.28).	The person making the determination must consider all the relevant circumstances and, in particular, take the following steps. He must consider— (a)whether it is likely that the person will at some time have capacity in relation to the matter in question, and (b)if it appears likely that he will, when that is likely to be.
Consider the potential decision the individual might have made if they still had capacity	Section 4(6)(c) of the Act requires decision-makers to consider any other factors the person who lacks capacity would consider if they were able to do so. This might include the effect of the decision on other people, obligations to dependants or the duties of a responsible citizen. (5.47 p. 83)	He must consider, so far as is reasonably ascertainable: (b)the beliefs and values that would be likely to influence his decision if he had capacity, and
Consider whether the least restrictive option has been taken in making the decision	The person proposing to take action must have reasonable grounds for believing that the action is in the best interests of the person who lacks capacity. They should apply all elements of the best interests checklist (see chapter 5), and in particular consider whether a less restrictive option is available (chapter 2, principle 5) (6.28 p. 102)	In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.
If the decision is about life-sustaining treatment, ascertain that no one involved in the decision-making process has a desire to end the life of the individual and that no assumptions have been made about their quality of life	Special considerations apply to decisions about life-sustaining treatment (paragraphs 5.29–5.36).	Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death. “Life-sustaining treatment” means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.

Appendix 4 – Evidence statements for the BIS checklist

BI Standard/Topic	Evidence
Encourage the individual's participation	There is limited evidence of studies that explore how the individual's participation in decision-making is encouraged. Williams *et al* (2014) conducted a national study about the operation of the best interests principle to provide a picture of current professional practices in best interests decision-making. As part of the study, they conducted face to face interviews and one participant reported in the results demonstrates the attempt to involve the person with dementia in decision-making. However, two studies contradicted these notions. McDonald (2010) conducted a study with social workers and how they assess risk but found that there were few examples of practicable steps to assist the older person to make a decision. Poole *et al* (2014) conducted an ethnographic study on assessment of capacity and best interests for people with dementia being discharged from hospital and suggested that there was very little evidence of "all practicable steps" being taken to help people with dementia to participate in decisions being made about them.
Consult all those close to the individual	There is considerable evidence of studies that explore how those close to the individual are consulted. There were a number of studies from the UK, post-implementation of the legislation. Livingston *et al* (2010) acknowledged that the MCA may give rise to more carers being involved in decision-making on behalf of people with dementia and interviewed carers to establish what their most significant concerns were with decision-making and how they addressed them. McDonald (2010) completed a study of social workers and discussed how one social work team had devised a format for best interests meetings where they discussed with families and considered situations where families were relying on information that did not fit present circumstances. Williams *et al* (2014) conducted a national study about the operation of the best interests principle to provide a picture of current professional practices in best interests decision-making. Participants were universally eager to see the 'decision' itself as a joint process of agreement and consultation. Family members, care home staff or long-term friends not only knew about the person's preferences but crucially could often advise on how the person communicated. Clarke *et al* (2015) conducted observations of a multi-disciplinary team making decisions on assisted nutrition, although not a best interests meeting, participants demonstrated that family would be part of the decision-making process. Within the past few years, Carter *et al* (2018) explored the experience and preparedness of family carers in their caregiving role as best interest decision-makers of a relative living with advanced dementia and suggested that carers were requested to contribute to advance planning decisions. Scott *et al* (2018) conducted a study with multi-professional team members from renal centres about conservative kidney management in people

	with dementia. The majority of staff preferred family members to be in agreement with the decision made. Participants were generally unwilling to make best interests decisions regarding dialysis without the family's agreement; however, some expressed doubt regarding the ability of relatives to act as reliable surrogate decision-makers, although they were willing to act against the wishes of relatives. One study that questioned the involvement of other's as stipulated by the legislation included Willner *et al* (2013) conducted a study to evaluate the extent to which NHS staff benefitted from attending MCA training courses. They found that a high proportion of participants appeared unaware that before making a best interests decision on behalf of a patient who lacks capacity, there is a legal duty to consult 'all those involved in caring for the person or interested in his welfare'.
Consider the individual's views, whether expressed verbally or in writing, including their feelings, religious beliefs and past habits	There is some evidence of studies that explore how the individual's previously expressed wishes were considered or fail to be considered. Livingston *et al* (2010) found that informal carers referred to previously expressed wishes when considering aspects of care such as end of life care decisions and Carter *et al* (2015) found that carers were requested to contribute to advance planning decisions for patients in nursing homes. However, McDonald (2010) found that there was a difference between support for outcomes that enabled previous lifestyle choices to be continued and approaches that sought to improve the situation of the older person by the imposition of services. More recently, Rogers and Bright (2019) conducted a study to investigate the way that those involved in DOLS assessments approach the required assessment of capacity to consent to residence in the care setting. They found that there was limited consideration of people's previously expressed wishes.
Consider all circumstances, including emotional bonds and family obligations	There is some evidence of studies that explore how all circumstances involving the person who lacks capacity were considered. There are limited UK studies, Clarke *et al* (2015), when conducting observations of MDT making decisions on assisted nutrition, stated that participants demonstrated that they considered the patient's situation and the impact of intervention and non-intervention.
Avoid making assumptions	There was limited evidence about assumptions, or rather assuming facts about care or treatment was not a clearly specified criteria in the studies identified. Heslop *et al* (2014) conducted a review of deaths of people with a learning disability found a lack of adherence with the MCA and that the learning disability was often used as a factor in the decision, which was detrimental to the person's care, which demonstrates that assumptions are made and are also detrimental to outcomes. Scott *et al* (2018) conducted a study with multi-professional team members from renal centres about conservative kidney management in people with dementia. Many staff reported taking into account a patient's quality of life (QoL), when considering

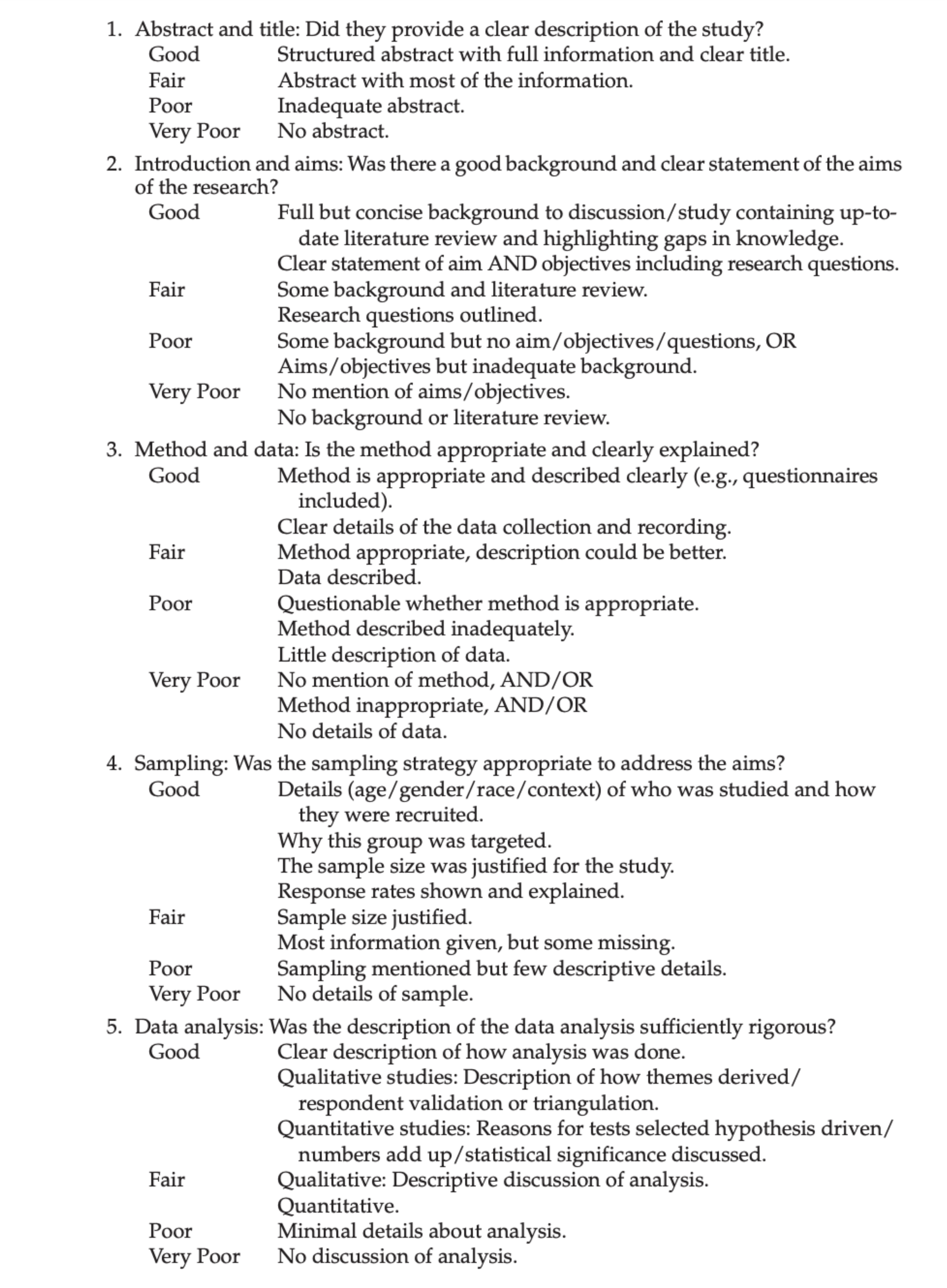
	suitability for Renal Replacement Therapy. Clinicians recognised deterioration in the QoL in patients receiving haemodialysis and many felt this was reason to avoid dialysis in those with poor QoL at baseline. This could be considered as exploring all circumstances, rather than making assumptions about quality of life and how appropriate a treatment may be.
Consider whether capacity will be regained in the future and whether this discussion could be delayed until then	There was very limited evidence about whether it was considered that capacity may be regained in respect of Best Interests Standards. McDonald (2010) conducted research with social workers and discussed in the findings that there was general acceptance that capacity could fluctuate and final conclusion 'capacity or not' tended to be an aggregate of different assessments over time. However, there were few examples of 'practicable steps' other than oral discussion being taken to assist the older person to make a decision. Poole *et al* (2014) conducted an ethnographic study and found that patients with fluctuating capacity were recognised as complex and additional measures put in place to address the challenges with decision-making.
Consider the potential decision the individual might have made if they still had capacity	Again, limited evidence to demonstrate a consideration of what decision might be made if the person still had capacity. Livingston *et al* (2010) found that carers referred to previously expressed wishes when considering aspects of care such as end of life care decisions, suggesting that they were cognisant of whether a previous wish would still stand.
Consider whether the least restrictive option has been taken in making the decision	The least restrictive option being considered had limited evidence. Howarth *et al* (2014) completed a survey on the possibility of a person living with dementia receiving forced care, considering this as part of a best interests determination and whether forced care is appropriate to the circumstances. Clarke *et al* (2015) demonstrated that their participants considered all treatment options and not just the most invasive in their study observing the MDT making decisions on assisted nutrition. Scott *et al* (2018) conducted a study with multi-professional team members from renal centres about conservative kidney management in people with dementia. Clinicians commented on the feasibility of dialysis and conducted trials of treatment that were discontinued if not appropriate.
If the decision is about life-sustaining treatment, ascertain that no one involved in the decision-making process has a desire to end the life of the individual and that no	With decisions about life-sustaining treatment, the evidence was relatively developed. Livingston *et al* (2010) conducted research with informal carers and found that they referred to previously expressed wishes when considering aspects of care such as end of life care decisions, demonstrating that they were considerate of what the individual may have expressed. Clarke *et al* (2015) suggested that participants demonstrated that prognosis and quality of life were considerations but not final in respect of the decision.

assumptions have been made about their quality of life	In contrast to these studies, Heslop *et al*'s (2014) review of deaths of people with learning disabilities found that DNACPR decisions were made without any consideration of best interests and were made in an emergency with limited information.
Exploring knowledge of the legislation and/or best interests	There was substantial evidence that explored knowledge of the MCA legislation and BI standards. Suggesting the practice is in line with the legislation, Wilson, Seymour and Perkins (2010) conducted a study that explored the views and opinions of staff about their use of documentation for the recording of issues relating to mental capacity. Findings show that staff generally had a good understanding of issues around capacity but felt unclear about some of the terminology related to the Mental Capacity Act, impacting on their confidence to discuss issues with service users and complete the documentation. Walji *et al* (2014) interviewed seven clinical psychologists and found that psychologists who had been in practice prior to the MCA already had awareness of issues such as capacity and informed consent. The introduction of the MCA embedded these concepts in clinical practice, and brought about changes to professional responsibilities, accountability, and governance around capacity issues. All participants thought experience of implementing the MCA was directly linked to confidence and reflected on how their competence and therefore their confidence had developed. Studies suggesting that knowledge or practice are not as developed as they should be included Willner *et al* (2011; 2012; 2013) conducted studies to evaluate the state of knowledge of mental capacity issues among health and social services professionals working in community teams for people with learning disabilities (2011), then in response to that a study reviewing staff working in three specialist residential settings catering to people with intellectual disabilities (2012), and finally a study to evaluate the extent to which NHS staff benefitted from attending MCA training courses (2013). Health and social care professionals performed in a similar way but there appeared to be significant gaps in knowledge. They had good insight into the extent of their knowledge and were aware of further training needs (2011). The study in 2012 found that the problems with performance identified in the 2011 study were still present for residential care staff and in some cases, to a greater extent. Participants in the generic NHS staff group felt less confident about their abilities in relation to mental capacity issues after the interview, suggesting that when confronted by the need to answer questions in this area they realize that they know less than they thought they knew. The 2013 study found that training improved performance overall, but there was no improvement with best interests decisions following training. The study also suggested that relevant experience does enhance performance.

	A 2-stage study conducted by Manthorpe and Samsi (2011; 2016) looked at training, roles and activity and predictions of the potential impact in stage one and found huge variations in participants' understanding of the MCA and perceptions of its impact on their work. In stage two there was some improvements in knowledge but not significantly so and training remained an area where improvements were required. Cairns *et al* (2011) completed a comparison study where participants were asked to make binary judgements about whether real-life situations amounted to a deprivation of liberty and found that the overall level of agreement between all professionals who rated the case vignettes was slight, suggesting that current approaches did not lead to reproducible and reliable outcomes. Carpenter *et al* (2014) also completed a study relating to deprivation of liberty and found that Best Interests Assessors were generally confident in their decision-making and there were no difference in confidence associated with their professions (social workers, nurses or OTs). However, as Best Interests Assessors, they would have additional knowledge to conduct their role. Heslop *et al* (2014) conducted a review of deaths of people living with a learning disability found that premature deaths were directly affected by a failure to adhere to the principles of the MCA and Best Interests Standards and Howarth *et al* (2014) conducted a survey linked to a training event about forces care for people living with dementia and found that these interventions require an assessment of capacity and a best interests decision, but the frequency with which it is reported here raises doubts about how often that process is followed. Carter *et al* (2018) Carers expressed that employed staff had poor understanding of processes such as exploring past wishes as part of the decision-making process. Suggested a need for ongoing training of professionals. Shepherd *et al* (2018) conducted a cross-sectional online survey was conducted using a series of vignettes. Participants were asked to select the legally authorised decision-maker in each scenario and provide supporting reasons. Responses were compared with existing legal frameworks and analysed according to their level of concordance. Participants demonstrated a lack of knowledge about the legal frameworks, the locus of authority and the legal basis for decision-making. Rogers and Bright (2019) conducted a study to investigate the way that those involved in DOLS assessments approach the required assessment of capacity to consent to residence in the care setting. They found that there are significant number of mental capacity assessments conducted which do not follow good practice standards. Chapman *et al* (2020) Evaluate staff knowledge of Mental Capacity Act (MCA) capacity assessments. Results show high variability of MCA capacity assessment knowledge within the LD division but

	qualified staff and those from health services scored significantly higher across all categories on the questionnaire compared to non-qualified and social care staff.
Exploring education and training interventions for MCA/best interests	There was a significant amount of evidence that explored training interventions for MCA and BI. McDonald (2010) conducted a study with social workers on decision-making and risk and stated that there was a paucity of training and that training that was available did not address ways that assessments could be culturally sensitive. Wilson, Seymour and Perkins (2010) conducted a study that explored the views and opinions of staff about their use of documentation for the recording of issues relating to mental capacity. At the time of the study, a number of staff reported that they had missed training sessions, felt they had had insufficient training or did not feel their learning was optimized by the training delivery method. A 2-stage study conducted by Manthorpe and Samsi (2011; 2016) looked at training, roles and activity and predictions of the potential impact in stage one and found there appeared to be a perception of training as events to be attended rather than an ongoing process where, through new information, staff members actively learn and apply new understanding. In stage two some participants had attended in-house training sessions at their workplace, generally lasting one afternoon, but others had received no training and did not know about the Act. Not one member of staff referred to the online materials that are available to the sector or referred to the material sent to all care homes in England to augment training. Willner *et al* (2013) conducted a study to evaluate the extent to which NHS staff benefitted from attending MCA training courses. Basic and advanced training was delivered with a post training interview. Training improved performance overall, but there was no significant difference between the basic and advanced training. There were four questions relating directly to best interests and there was no improvement following training. There is a suggestion that the long-term retention of information acquired in training may be minimal. Howarth *et al* (2014) conducted a survey linked to a training event about forced care for people living with dementia and found that staff questioned the level of training staff have to deliver such interventions. Poole at al (2014) conducted an ethnographic study on assessment of capacity and best interests for people with dementia being discharged from hospital and suggested that more support and training for practitioners around the MCA and the importance of functional as opposed to outcome assessments of capacity. Walji *et al* (2014) interviewed seven clinical psychologists and found that nearly all had attended some form of NHS Trust training, but this was largely thought to be too basic. Participants wanted training and guidance focusing on clinical applications of the MCA, rather than theoretical or legislative aspects.

Appendix 5 - Hawker *et al* (2002) appraisal protocol



1. Abstract and title: Did they provide a clear description of the study?

Good	Structured abstract with full information and clear title.
Fair	Abstract with most of the information.
Poor	Inadequate abstract.
Very Poor	No abstract.

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?

Good	Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge. Clear statement of aim AND objectives including research questions.
Fair	Some background and literature review. Research questions outlined.
Poor	Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background.
Very Poor	No mention of aims/objectives. No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?

Good	Method is appropriate and described clearly (e.g., questionnaires included). Clear details of the data collection and recording.
Fair	Method appropriate, description could be better. Data described.
Poor	Questionable whether method is appropriate. Method described inadequately. Little description of data.
Very Poor	No mention of method, AND/OR Method inappropriate, AND/OR No details of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?

Good	Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.
Fair	Sample size justified. Most information given, but some missing.
Poor	Sampling mentioned but few descriptive details.
Very Poor	No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?

Good	Clear description of how analysis was done. Qualitative studies: Description of how themes derived/ respondent validation or triangulation. Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up/statistical significance discussed.
Fair	Qualitative: Descriptive discussion of analysis. Quantitative.
Poor	Minimal details about analysis.
Very Poor	No discussion of analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

Good	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias.
Fair	Lip service was paid to above (i.e., these issues were acknowledged).
Poor	Brief mention of issues.
Very Poor	No mention of issues.

7. Results: Is there a clear statement of the findings?

Good	Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
Fair	Findings mentioned but more explanation could be given. Data presented relate directly to results.
Poor	Findings presented haphazardly, not explained, and do not progress logically from results.
Very Poor	Findings not mentioned or do not relate to aims.

8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?

Good	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
Fair	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
Poor	Minimal description of context/setting.
Very Poor	No description of context/setting.

9. Implications and usefulness: How important are these findings to policy and practice?

Good	Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.
Fair	Two of the above (state what is missing in comments).
Poor	Only one of the above.
Very Poor	None of the above.

40	Good	30	Fair	20	Poor	10	Very Poor

Appendix 6 – methodological quality of included study (organised by theme)

Knowledge

Reference	Abstract and title	Introduction and aims	Methodology	Data analysis	Sample	Ethics	Results	Generalisability	Usefulness
Evans, Warner and Jackson (2007) **(Fair)** **280**	No abstract but aims - conclusion	Yes	Cross-sectional survey with a structured questionnaire	Percentages and tables of responses	86 mixed healthcare professionals in one trust – some asked to complete whilst in training courses	Not discussed	Emergency healthcare workers do not have adequate knowledge about how to assess capacity and treat people who either refuse treatment or lack capacity. This is especially true for ambulance workers, who, in this study, were unable to identify the stages in testing capacity.	Main limitation of this study is the small number of Respondents. The small numbers make it difficult to assess differences between grades within the groups	Very early in the implementation of the study but useful to see if things have progressed
Luke *et al* (2008) **(Good)** **310**	No abstract but aims - conclusion	Yes	Mixed methods Quantitative data describing all referrals to the seven pilot IMCA services (January 2006–March 2007) and qualitative data from semi-structured interviews	Used tables and quotes to support findings	Semi-structured interviews with 18 doctors, 21 senior nurses and one Discharge planning manager in four general hospitals in England.	Not discussed	The study suggested that clinicians' ambivalence to the role suggested that they fail to pay due regard to the IMCA service as a statutory measure to safeguard patients' interests Clinical training will need to address a tension between the MCA's principle of empowering patients and medical expertise of individual clinicians and/or multidisciplinary teams..	Could replicate study although finer detail not available in the article	It corresponds to the later HOLSC (2014) criticisms that suggest that the involvement of IMCAs is inconsistent and also indicates clinician's initial perspectives of others' roles in decision making.
Alonzi, Sheard and Bateman (2009) **(Good)** **310**	Title, no abstract	Background but no clear aims – although it did say why study was conducted to develop guidance on use of the legislation.	Questionnaire to gauge the extent to which adult community services staff felt they were familiar with the MCA's principal requirements and the extensive	Statistically analysed with SPSS frequency tables (for both PCTs combined), graphical output and cross-tabulation tables – none published in the article	51 questionnaires to half of staff in 2 trusts	Ethical approval	Staff indicated they wanted to receive further guidance. These areas were then used to inform the content of the guidance, to ensure it would meet the needs of all staff. Two trusts had similar results.	Would be good to collect information for local dissemination and support.	Sought staff views on whether they needed further training and guidance on the MCA, the implications for practice showing the importance of gathering and analysing the views and needs of healthcare staff when developing guidance.

			guidance in the MCA code						
Manthorpe *et al* (2009) **(Good)** **320** Manthorpe, Samsi and Rapaport (2013) second part of study	Yes	Yes	Telephone interviews covering participants' own training and understanding of the Act, confidence in practice and thoughts about public's understanding. In 2 phases. 2008 and 2010	Thematic analysis – tables and quotes to support findings.	The study was limited in number and to just one London borough 15 adult safeguarding leads, well placed to comment on the early implementation of the legislation 12 SACs were interviewed at Time 2 (11 of the original)	Not discussed	Sacs have incorporated the principles of the MCA into their practice and systems of work. They are well informed in the main and constitute an expert resource for local professionals and communities. No great differences between the views of those interviewed in Time 2, whether they were new to the post or had not been interviewed previously	Acknowledged limitations - early snapshot of views and experiences but was confined to the London area	Showed that specialists have a substantial knowledge of the legislation (with some gaps) so showed that not all studies support a lack of knowledge.
McDonald (2010) **(Good)** **340**	Yes	Yes	Grounded theory - Participants were asked to select a case that was current During the period November 2007 to May 2008, and to compare practice And recording in this case with a similar case concluded before the Coming into force of the Act.	Interviews were tape recorded and transcribed and analysed for Emerging themes arising directly from the data.	Purposive sample Charity got a group of social workers and they discussed 14 cases (but doesn't state actual number of participants)	Ethical approval	Thematic analysis of the case material showed that three basic types of decision making were emerging: legalistic, actuarial and rights-based. Social workers operating under the MCA may, to some extent, have abandoned, or feel that they have abandoned, a rights-based approach in favour of risk-based legalistic and actuarial approaches.	Not sure it could be generalised as grounded theory by discussion of cases might be useful to explore perspectives of professionals	This study explored perspectives of the legislation and how it impacted on practice.
Wilson, Seymour and Perkins (2010) **(Good)** **360**	Yes	Yes	Semi structured interviews – different types in different units	Framework analysis Used direct quotes to support findings	26 staff members working in palliative and neurological care centres	Ethical approval	Some staff were unclear about when it was necessary to record these 'best interest' decisions and when it was not	This type of 'implementation in practice' research allows us to Report on the current challenges staff are facing as	Related to best interests so was useful to inform study

								This Act is implemented across England and Wales. It is clear from this research that ACP in the context	
Samsi et al (2011) **(Good)** **360**	Yes	Yes	In-depth qualitative methodology using interviews (T2 Manthorpe article)	Thematic analysis – use of statements	Convenience sampling of 15 admiral nurses	Ethical approval	Themes and sub-themes on knowledge	UK but with specialist nurses The study is limited as it is difficult to ascertain accuracy of reflections of practice and participants might have been inclined to report positively to appear knowledgeable. It was not possible to observe their interactions with carers or people with dementia or to scrutinise case records, which might have provided explanatory information about individual perceptions.	Identify implications for practice for generalists even though they may not have the specialist knowledge of the participants in this study.
Samsi, Manthorpe and Rapaport (2011) **(Good)** **330**	Yes	Background not specific aims	Part of a wider body of research focusing on implementation of the legislation, practitioner's experiences and the legislation's relevance to older people with dementia	Framework analysis – themes and used quotes to support findings	Convenience sampling - 9 staff from Age concern - interviews	Not discussed but part of EVIDEM programme of research	Most had a lack of confidence in providing detailed advice about the legislation and that knowledge was varied	Small study-recognised the limitations of the study in respect of the numbers of participants and the area in which they worked	Helped to show some good practice to balance not everything is bad
Willner *et al* 2011a **(Good)** **360**	Yes	Yes	Questionnaires 16 true/false statements, half True and half false to Assess the extent of knowledge of	Total scores were analysed by analysis of variance or t-tests. Performance on individual items	The participants were new recruits to the Trust attending Their mandatory induction training.	Ethical approval	Knowledge of the MCA among newly appointed NHS staff is patchy, with some strengths but also significant weaknesses. The results demonstrate a benefit of the brief	Could replicate as published the questionnaire	All of these useful for comparison with each other and combined they told me a lot about the legislation and how to structure my research

			the Mental Capacity Act (MCA) (2005) among new recruits To a National Health Service (NHS) Trust	was analysed by x2 or Mcnemar tests.	Four induction sessions, 150 participants. Clinicians and non-clinicians. 116 valid questionnaires were returned		training experience, but also question how much information is retained by participants in MCA training.		
Willner *et al* 2011b **(Good)** **320**	No abstract but aims background and title	Yes	Structured interview was constructed around Three scenarios, based on actual cases Used vignettes	The presentation of the results is largely descriptive. Although it could be considered inappropriate to use Percentages when the sample size is small, percentages Are used in the presentation and discussion in order to Facilitate comparison between results based on different Sample sizes.	40 professionals working in 10 Multidisciplinary community teams (MDTs) for people With learning disabilities, in an area of south Wales	Not discussed	Participants, particularly those who had experience of dealing with mental capacity issues, had good insight into the extent of their knowledge, and Most participants said that the interview had made them aware of further training needs. Fourteen areas of concern were Identified where there appeared to be significant gaps in Knowledge.	Acknowledges small size – could repeat similar exercise	See above
Willner *et al* 2012 **(Good)** **350**	Yes	Yes	Assess the extent of knowledge of the MCA among new recruits in an NHS Trust	Statistical analysis using p-values	Interviews with three groups of participants (total n . 53) were recruited for this study, all of whom worked in specialist residential services for adults with intellectual disabilities in south Wales	Not discussed but supported by a small grant from the Welsh Office for Research and Development in Health and Social Care (WORD).	Staff working in residential services for people with intellectual disabilities have only a limited understanding of mental capacity issues and their confidence in their own knowledge may not be a good guide to their ability to deal with such issues when they arise in practice.	Specifically states - we cannot generalize these Findings to other organizations within the each of the residential care sectors that we have Surveyed. However, it does appear that there can be different levels of confidence among groups of staff for the same level of performance.	See above

Willner *et al* 2013 **(Good)** **360**	Yes	Yes	Participants were assessed before and after MCA training using a structured Interview, which included three scenarios describing mental capacity dilemmas, Four vignettes addressing the role of the Independent Mental Capacity Advocate (IMCA), And 16 true–false items.	Statistical analysis - Administered the same structured interview as in the earlier study, which Was constructed around three scenarios concerning a financial/legal issue, a health issue, and a relationships issue, as well as a set of ten ‘’true/false’’ statements.	Were 86 professionals who enrolled in MCA training in late 2009 And early 2010 Various professionals	Ethical approval	40% of participants who attended the relevant training sessions were interviewed (basic training: N=44; advanced training: n=42). Interviews were conducted on average 16 days (range 3–31) before the training session and 19 days (range 5–42) after the training session.	The detailed analysis of where the gains were made suggests that the Benefits provided by MCA training are very limited	Useful to see if training had any impact and also to consider in recommendations if a specific approach to training might be beneficial
Gough and Kerlin (2012) **(Good)** **360**	Yes	Yes	Reviewed MCA training in residential homes in their 2012 study, using interviews and focus groups with residential care home staff	Thematic analysis using quotes to support findings	Four in-depth semi-structured interviews were Conducted with expert informants semi-structured interviews and focus group was conducted with a group of nine managers/deputy managers working in East Midlands local authority residential care homes	Not discussed	There was a variation in knowledge displayed by managers, and it was discovered that a gap exists between the care homes that understand the MCA and those that do not, as Identified by the dols team.	Small sample size This paper has been limited to the perspectives of managers and key stakeholders w3ith oversight of MCA implementation in one local authority area. Covered a geographical area that had been recognised as having Several indicators of good practice relating toward the MCA. As such the areas for Development relating to training and MCA practice integration that were key will logically have lessons for other locations too.	Worthwhile to consider different approaches to training
Phair and Manthorpe (2012)	Yes	Yes	Survey Interviews	Thematic analysis – themes identified	A sample of staff was surveyed a range of staff 42 staff in	Ethical approval	Analysis of replies revealed that the level of knowledge among participants varied,	Able to replicate as questions and vignettes provided in article	This paper adds to the literature about the implementation of the MCA in this case study of

(Good) **300**				No quotes, just narrative	Clinical settings		although all reported being aware of the MCA and all but one had undertaken training on it.	Limited as it focused on one Trust and therefore may not be generalisable to other hospitals or other providers of health and social care	an acute hospital NHS Trust and analysing its links to the safeguarding of patients. Difficulties of implementing the MCA and other cross-setting policies and practice changes are multifaceted
Emmett *et al* (2013) **(Good)** **360**	Yes	Yes	Ethnography – Observations and interviews with a mix of participants	Nvivo Thematic analysis Used quotes to support findings	Purposive sampling Interviews patients (N=29), family member (N=28), Healthcare Professionals, (N=35). Interviews	Ethical approval discussed in detail	Whilst professionals profess to be familiar with broad legal standards governing The assessment of capacity under the MCA, these standards are not routinely applied in practice in general hospital settings when assessing capacity to decide place of residence on discharge from hospital.	Very robust study. Detail to replicate not in article but considered generalisability in the design.	More about the application of the legislation and in slightly different circumstances but did show about knowledge
Manthorpe *et al* 2011 **(Good)** **350**	Yes	Yes	32 exploratory interviews with care home managers and Staff regarding their knowledge and use of the Mental Capacity Act 2005 (Phase one of a five-year study	Thematic analysis	Five homes with 17 senior staff and 15 care workers During May–July 2008	Not discussed but part of a 5 year study	Work within the spirit of the MCA Variation in participants' understanding Of the MCA and perceptions of its impact on their work. Facilitating learning and introducing change within health and social care organizations can Be complex and slow, requiring a range of approaches, skills and means of support.	The methodological limitations of a case study approach relate to The sampling strategy and the potential for bias among those who voluntarily agree to participate, the honesty of their responses and the ways in which knowledge may translate Into care practices. In other words, we do not know if this care provider was exceptional in Its training and professional development efforts, whether the	CASE STUDY – not explained in detail

								participants were atypical, or how their expressed views apply in practice. Small study	
Manthorpe, Samsi and Rapaport (2012a) **(Good)** **360**	Title no abstract – but aims – conclusion	Yes	Qualitative interviews	Framework analysis	Purposive sampling - Interviewed 17 staff from 23 carers' organisations known to have an information and advice role	Not discussed but part of part of the EVIDEM programme of research	Participants' experiences of using the MCA varied; centring mostly on the information and advice sought by clients or offered to them. Voluntary sector staff generally perceived the Act as largely benefiting people with dementia in the exercise of their rights. They also thought that carers would benefit from the Act's provisions, whilst their own involvement in advice, information-giving and referral to other sources of expertise in relation to the MCA differed according to their role and confidence. Ongoing training, local coordination and auditing seem warranted.	Study is limited in that the experiences of the participants might have been atypical or impressionistic as they were reliant on memory and not systematic reviews of activity	Questions around training useful – what was helpful, not helpful, etc.
Manthorpe *et al (*2016) **(Good)** **360**	Yes	Yes	Audit - Semi structured interviews as part of a 5-year research program investigating the implementation and adoption of the MCA In dementia practice - South East England.	Thematic analysis with quotes to support the findings	Interviewed staff working in different care homes at two Time points (32 staff at Time 1 in 2008 and 27 staff at Time 2 in 2012) i	Formal ethical approval was not Required. However, adhered to ethical principles	The study found that not all staff members were aware of the MCA and some were not generally aware of the legal framework they were working under. Some staff struggled to articulate the fundamentals of their practice. In phase 2, participants were asked to provide their opinions of any training they had received, and some responded that they had	Study is limited by the small size of the participant group and a reliance on their own Accounts of practice. Data may be food for thought for trainers but the Findings also enable us to consider more broadly the negotiations surrounding decisions And choices that take place	Study is cited in other studies

							received no training and did not know about the legislation.		
Rowley *et al* (2013) **(Good)** **300**	Yes	No	To gauge health-care professionals' level of knowledge and usage of the Mental Capacity Act 2005 within the hospital trust, an anonymous questionnaire	Tables to display the results	249 10-part questionnaires with doctors, nurses and allied health professionals.	Study was requested by hospital ethics committee	Imposed a 70% pass mark but only 24% scored 70% or above and responses showed variable knowledge with no professional group appearing any more knowledgeable than another.	Could replicate in a trust and compare to the original results	Not a very detailed article but the study does show a lack of knowledge in one particular Trust
Heslop *et al* (2014) **(Good)** **330**	Yes	Yes	CIPOLD reviewed the deaths of all known people with intellectual Disabilities (ID) aged four years and over who had lived in the study area and died between 2010 and 2012. A retrospective, detailed investigation into the sequence of events leading to the deaths of people with ID	Narrative discussion of the findings	247 people with ID aged four years and over at the time Of their death, and of 58 comparator cases	Ethical approval	Two key issues regarding how the MCA was related to premature deaths of people with ID. The first was of the lack Of adherence to aspects of the Act, particularly regarding assessments of capacity and best interests decision-making processes. The second was a lack of understanding of specific aspects of the Act itself, particularly the definition of "serious medical treatment" and in relation to Do Not Attempt Cardiopulmonary Resuscitation guidelines.	Recognises it may be that there were other aspects relating to the MCA that were of note, but were not directly related to the deaths of individuals	The consequences of failing to adhere to the MCA may be a risk for other vulnerable groups and so the findings are important to consider.
Manthorpe, Samsi and Rapaport (2014) **(Good)** **340**	Yes	Yes	Stage 2 of Samsi – interviews Stage 1 was Samsi (2011)	Thematic analysis using direct quotes to strengthen findings	15 interviews – only 10 the same as first stage	No mention in the article but T1 (Samsi) had approval	Still showed lack of understanding	Identified limitations – no comparison to stage 1 of study and relies on self-report	Rating knowledge – could compare to my study
Walji *et al* (2014) **(Good)**	Yes	Yes	Qualitative study with interviews	Thematic analysis – 6 themes	Seven participants, clinical psychologists	Ethical approval	This study explored clinical psychologists' experiences of implementing the MCA. Since there have not been	Considers all professionals' knowledge even	Supports the need for continued training

350				supported by quotes			any previous studies in this area, an exploratory stance was taken where many different aspects of experience were investigated, although previous qualitative research on the perspectives of other professionals implementing the MCA informed some of the interview topics.	though study is on psychologists Small study Outcomes of this study represent the experiences of the participants and cannot be assumed to apply to all clinical psychologists. However, the presence of a shared narrative among the participants despite differences in their contexts and roles may increase the generalisability of these findings.	
Manthorpe and Samsi (2015) **(Good)** **320**	No abstract but aims and objectives	Yes	Qualitative longitudinal methodology	Framework analysis with quotes to support points	279 practitioners from different services, in the London And South-East area of England, two or three times over 3 years	Not discussed but author is member of NHIR	Knowledge of the MCA was sketchy. Professionals offering advice and information about decisions planning (e.g. Lasting powers of attorney) to the public Simply did not know about the offences. Where the new offences were known, they were welcomed. However, concern was evident about the interpretation, scope and procedures surrounding the new offences	The study is limited in that participants may not be Representative and that practice in the London/ South-East area may differ from that in the rest of England and Wales. However, the region is large, and there are considerable variations within it. To the best of our knowledge, this is the first study of the MCA offences in practice	Focused on dementia and knowledge of the MCA and so was pertinent to inform the literature review
Cliff and McGraw (2016) **(Good)** **360**	Yes	Yes	Semi-structured interviews interview also included the use of a vignette.	Thematic analysis	A purposive sample of 14 community staff	Ethical approval	The conduct and process of mental capacity assessments in home healthcare settings is an inherently complex endeavour	Interview also included the use of a vignette, which was Based on a scenario where a patient refused to consent to care and which asked participants how they	Used vignettes. It considered both influencing factors and perspectives of the staff involved and was therefore useful for the literature review

								would approach the assessment of capacity	
Marshall and Sprung (2016b) **(Good)** **340**	Yes	Not in the abstract – methods explained and aim in the methods	A mixed method Approach. A sequential explanatory design in 2 phases. Electronic questionnaire and a focus group	SPSS with quotes to support findings.	Snowball and volunteer sampling of community nurses 60 out of 340 responded to questionnaire and 7 attended the focus group.	Ethical approval	There appeared to be a lack of awareness amongst community nurse's regarding LPA arrangements and Advanced Decisions. Knowledge and confidence of the MCA among community nurses must be improved.	This is the first piece of research which addresses community nurses' experience and viewpoint of using the MCA in practice. Could be replicated.	Supports much of current research – supporting points of lack of knowledge.
Murrell and McCalla (2016) **(Good)** **360**	Yes	Yes	Qualitative methods	Thematic analysis using quotes to support findings.	Non-probability purposive sampling 6 semi structured interviews	Ethical approval	Highlighted that the interplay with other assessments, and the competing demands thereof, also effected how assessments of decision-making capacity were carried out.	Useful findings relevant to practice, policy and Research. Small-scale study completed within one local authority setting and therefore the results cannot be generalised to other settings. Very small scale.	Echoed criticisms in the HOLSC (2014) report
Shepherd *et al* (2018) **(Good)** **330**	Yes	Yes	A cross-sectional online survey was conducted using a series of vignettes.	Results compared with existing legal frameworks and analysed according to their level of concordance – narrative explanation of the results	127 participants, from a range of professions	Ethical approval	Participants demonstrated a lack of knowledge about the legal frameworks, the locus of authority and the legal basis for decision-making. The findings raise concern about the accessibility of research for those who lack capacity, the ability to conduct research involving such groups and the impact on the evidence base for their care.	First study to examine health and social care professionals' knowledge and understanding of the dual legal frameworks in the UK. Health and social care professionals' understanding and attitudes towards research involving adults with incapacity may warrant further in-depth exploration. Limitations of this study include that this was a self-completed online survey, which may have resulted in selection and response biases.	Used a series of vignettes. Support need for extra education and training.

Chapman (2020) **(Good)** **320**	Yes	Yes	12-item multiple choice questionnaire	Results presented in tables with p-values	262 health and social care staff	Not discussed	High variability of MCA capacity assessment knowledge within the LD division. However, qualified staff and those from health services scored significantly higher across all categories on the questionnaire compared to non-qualified and social care staff.	Strength of the current study is that the questionnaire used was generated using the consultation of our experienced MCA trainer within the trust. As such, the questionnaire should be valid and relevant to the capacity assessment part of the MCA. Acknowledged limitations.	Utilised a novel and more comprehensive questionnaire. This focused on case scenario questions to assess staff situational judgement – could consider this in my recommendations.

BI, DOLS and general decision-making

Reference	**Abstract and title**	**Introduction and aims**	**Methodology**	**Data analysis**	**Sample**	**Ethics**	**Results**	**Generalisability**	**Usefulness**
Dunn *et al* (2010) **(Good)** **330**	Yes	Introduction but no aims	Constructivist grounded theory 176 hours of observation 21 semi-structured interviews with support workers	Interview analysis was undertaken with the assistance of the qualitative data analysis software ATLAS.ti 5.0 Themes and direct quotes to support findings	3 care homes selected and theoretical sampling strategies	Ethical approval	Support workers draw on the Personal decisions that they make in their own lives As a starting point for thinking about how to make Substitute decisions on behalf of residents. In so Doing, support workers believe that residents might Be helped to live 'a life like ours' and that the Quality of residents' day-to-day lives will be Enhanced.	Proposals for the ongoing reform of the regulation of substitute decision-making in residential care homes Instead of wholesale criticism of the procedures introduced by the MCA, or making the claim for better training in the MCA they argue for a reconfiguration of the MCA's regulatory framework. They contend that this reconfiguration should be more carefully tailored to the realities of the everyday residential support of adults with intellectual disabilities.	To give an idea of what influences decisions on behalf of a person who is not able to decide for themselves – what values are considered and in whose best interests are the decisions made?

Livingston *et al* (2010) **(Good)** **360**	Yes	Yes	Focus groups and interviews	Coding and use of statements – well defined analysis	Purposive 43 in focus 46 interviews	Ethical approval	Family carers identified five core problematic areas of decision making	Yes – UK based No limitations identified	The study informs what carers struggle with in respect of decision-making so may suggest that professionals have similar struggles.
Cairns *et al* (2011) **(Good)** **330**	Title Abstract is the aims to conclusion	Yes	12 clinical vignettes were selected from real-life cases	Summary of responses in data table with kappa values	23 different professionals	Ethical approval	Lawyers were more likely to identify the presence of Deprivation of liberty than either psychiatrists or best interest assessors. For the majority of the case vignettes there was no clear agreement between professionals about whether deprivation of liberty had occurred. This reinforces the concern that in the absence of legal clarity about how deprivation of liberty should be distinguished from restriction of liberty, potential deprivation of liberty assessors are unable to make reliable decisions about this. In addition, a number of the reasons listed by professionals as important in influencing their judgements were, arguably, idiosyncratic and ultimately reflected clinical rather than legal judgements.	Limitation of this study is its small size which limits the statistical power that can be attached to the findings.	Helped with design of vignettes – based on real life scenarios. Could consider some of the recommendations for potential training resources – i.e. real-life cases to explore.
Harris and Cohen Fineberg (2011)	Yes	Yes	Qualitative research methods were used to interview professionals	Thematic analysis with direct quotes to support findings.	11 face-to-face interviews with nurses, social workers and occupational	Ethical approval	Variable understanding of the MCA and best interests with almost half of participants demonstrating a lack of clarity	The study was limited in terms of its size and geographical scope. A larger sample size selected from multiple geographic regions and	This study was useful as it considered the process of best interests decisions and how they are conducted.

(Good) **360**					therapists from two palliative care teams.			representing more professions would have enabled greater extrapolation of the results to the wider population. In addition, the small sample size and considerations of anonymity meant that it was not possible to analyse differences between the professions represented by the participants. Finally, the study did not attempt to ascertain the reasons for participants' lack of knowledge of the MCA guidance and best interests checklist.	
Manthorpe, Samsi and Rapaport (2012b) **(Good)** **360**	Yes	Yes	Qualitative interviews	Thematic analysis with quotes to support findings	Purposive sample of 123 dementia care professionals working in community and care home settings were interviewed (2007–2010)	Ethical approval	Across the board, there were a few individual examples where, in spite of personal experiences, participants claimed that the Act had made no impact on their professional role or decision making, or giving advice on, planning, or stating personal wishes.	There are limitations to this study in that the accounts are subjective experiences and this study did not include any scrutiny of practice or input from carers receiving support about the impact of engaging with a practitioner who spoke of their own personal experiences. The practitioners interviewed may be not representative.	Having caring experiences may help dementia care practitioners to have more empathy with carers. Some of those interviewed in this study reported that their experiences had made them more focused and more confident in their practice with carers. Useful to compare with my findings.
Boyle (2013) **(Good)** **330**	Yes	Introduction but no aims	Ethnographic and creative methods – observations and interviews	Thematic analysis using direct quotes to support findings	21 couples via wellbeing dementia cafes	Ethical approval	Gender influenced whether people with dementia were given the support necessary to exercise their capacity. In particular, women carers were usually more facilitative of the autonomy of their	Limitations – small scale and not ethnically diverse so may not be generalisable.	This was useful in respect of factors that might influence the perspective of the person making a best interests decision, that gender may be a factor and should be considered in the design

							partners than their male counterparts (at least in relation to minor Decisions).		or choice of data collection tool.
Brown and Marchant (2013) **(Good)** **310**	Yes	Aim is within the abstract Introduction not titled but within the article	Qualitative and guided by grounded theory	Thematic analysis	16 complex cases from 11 social services and primary care trusts	Not discussed	A number of issues were identified that underlay the complexity of the cases examined. The cases drew attention, in particular, to the way in which practitioners were confronted with mounting concerns as opposed to single, discrete decisions, with the risk that decisions could be delayed until positive choices were much less available	To give practitioners confidence in applying its principles across a wide range of diverse circumstances. Although the original study specifically related to the English legislation, the factors that led people to consider a case ‘‘complex’’ would apply equally in other jurisdictions. The study also shed light on difficulties that arise when intervening in less formal ways.	Useful to inform the design of the approach to data collection, considering complexity as it reflects real-life decisions made by health care professionals
Samsi and Manthorpe (2013) **(Good)** **360**	Yes	Yes	Phenomenological approach, qualitative interviews	Thematic analysis with quotes to support findings	Snowball sampling 15 people with dementia and 15 carers T1 11 people with dementia and 12 carers interviewed at T4	Ethical approval	Carers may gradually take on decision-making for people with dementia. This can bring with it added stresses, such as determining their relative’s decision-making capacity and weighing up what is in their best interests. Practitioners and support services should provide timely advice to carers and people with dementia around everyday decision-making and be mindful how abilities may change.	limited by the size and possible non-representativeness of the study sample. However, by aiming to recruit a range of participants, we achieved a diversity of caring relationships and living situations. Further work on decision-making is needed to understand it in the context of different networks, including those from different cultures, and where individuals have lived alone for many years and are newly facing possible “intrusions” in their domestic and personal lives.	Carers reported that they struggled with weighing up what was in their relative’s best interests and how to determine their relative’s capacity. Professionals may have similar issues.

Williams *et al* 2012 **(Good)** **360**	Yes	Yes	Multimethod design including an online survey followed by qualitative research telephone survey face-to-face semi-structured interviews	Thematic analysis using Nvivo using direct quotes to support points.	Online survey with 385 participants telephone survey of 68 participants 25 face-to-face semi-structured interviews	Ethical approval	The findings indicate that the MCA was successful in providing a structure for these practitioners, and that the five principles of the MCA were in general adhered to. A variety of perceived risks led to best interests processes being undertaken,	The paper reports only on the qualitative findings. The limitations identified were that the initial brief was ambitious. Researchers did not succeed in capturing the viewpoints and issues facing family carers, nor those lacking capacity themselves, and some of the points raised in the current paper could usefully be pursued further with those participants. In particular, the findings relating to disputes and conflict resolution should be viewed from the perspectives of different parties involved in those processes.	Used real practice Examples, which may be useful for training ideas.
Carpenter *et al* (2014) **(Good)** **360**	Yes	Yes	Factorial survey of BIAs with randomly varied vignettes and open questions	Binary logistic regression analysis was used using P values.	93 Best Interests Assessors – contacted by e-mail through manager (sampling approach not specified)	Ethical approval	The factors which Best Interests Assessors take into account are rooted in the fundamental principles of the DOL Safeguards and an informed appreciation of case law.	A copy of the survey is available on request from the corresponding Author, so could be replicated.	BIAs are specialists yet the study showed that DOLS deliberations were challenging.
Howarth *et al* (2014) **(Fair)** **260**	No	No	Survey	Uses table to display results from survey	86 staff various roles	Not identified	Concerns about capacity assessment	Not enough detail to replicate	Vague in detail Acknowledges small sample and limitations
Poole *et al* (2014) **(Good)** **360**	Yes	Yes	Ethnography, interviews, observations and field notes	Themes and use of statements to support	Theoretical sampling 92 interviews with stakeholders	Ethical approval	Capacity assessments were complex, and that more training was required	Yes – UK based and gives implications for practice	Implications for practice and future research
Clarke *et al* (2015)	Yes	Introduction and aims in	Service evaluation – observation of	Thematic analysis using Nvivo using	Four meetings sampled for observation –	Service evaluation – ethical approval	Decision-making was not a singular decision, but rather involved many	Only remarks about generalisability were	This study did not focus on MCA assessments or BI meetings but the

(Good) **310**		the methodology		quotes to support findings	no indication of who was represented at the meetings only who the team was comprised of. Quotes only labelled as 'clinician'		different steps. Discussions involving relatives and other clinicians, often took place outside of meetings. Topics of discussion varied but the outcome relied upon balancing the information along four interdependent axes: (1) Risks, burdens and benefits; (2) Treatment goals; (3) Normative ethical values; (4) Interested parties.	that the findings from this service evaluation illustrate that within multi-professional team decision-making; decisions may contain elements of both substituted and supported decision-making, and may be better represented as existing upon a continuum. No mention of limitations	routine clinical practice of a team and some observations included patients with dementia. The discussions concerning CANH for patients lacking decision-making capacity were complex and multi-faceted, including topics such as risks, burdens and benefits, treatment goals, ethical values and interested parties. Useful to consider what influences BI decisions.
Carter *et al* (2018) **(Good)** **340**	Yes	Yes	RCT and semi structured interviews	Thematic analysis	20 semi structured interviews	Ethical approval	Themes - Need Of adequate support availability and of enhancing nursing staffs' dementia expertise To maximize their role in facilitating best interest decision-making.	A particular strength of this study is the individual interviews held with current carers of individuals living with advanced dementia and residing in a nursing home. Conducting semi-structured interviews allowed individuals to reflect on issues important to them and provided the context of their previous and current experiences. However a possible limitation is that those who completed the individual interviews were a self-selected sample, 12 of which were exposed to an ACP intervention which may have guided the respondents' thinking.	Knowledge and understanding of dementia. The authors felt that the findings had implications for nursing practice and the education of healthcare staff and service users.
Clerk *et al* (2018)	Yes	Yes	Delphi study sought to understand health	Narrative presentation of findings, giving	Purposive sampling mixed	Ethical approval	Participants did not respond consistently to the scenarios, but	Questionnaire presented several scenarios describing practice	Use of scenarios to consider application of the legislation – can

(Good) **350**			and social care practitioners' knowledge of MCA/DoLS; how these frameworks are applied in practice	percentages of participants who shared the same ideas on each scenario.	professions – 100 in the first round but dropped to 12 in round two.		disagreed most significantly when patient decisions conflicted with clinical advice, and when to conduct a capacity assessment. These responses suggest that clinical responses vary significantly between individuals (even within settings or professions), and that the application of Mental Capacity Act (MCA) is complicated and nuanced, requiring time for reflection to avoid paternalistic clinical interventions.	situations, with questions requiring participants to demonstrate knowledge and understanding of the MCA and to describe how they would respond to these scenarios. The findings present more developed understanding of the complexity and challenges for practitioner responses to some relatively common clinical scenarios, suggesting the need for greater clarity for practitioners.	compare to my own findings.
Scott *et al* (2018) **(Good)** **360**	Yes	Yes	Interviews – secondary analysis	Thematic analysis	Purposive 60 interviews in 9 centres	Ethical approval	Two themes – decision making and factors that influence	UK study – limited to decision making on dialysis	More about capacity assessment but it is hard to separate from BI because they are linked. Does mention best interests
Rogers and Bright (2019) **(Good)** **360**	Yes	Yes	Telephone interviews on 4 vignettes	Thematic analysis using direct quotes to support findings.	Recruitment took place via a range of networks – 16 participants	Ethical approval	Most assessors did not refer to the required two-stage test of capacity or the "causative nexus" which requires that assessors must make clear that it is the identified "diagnostic" element which is leading to the inability to meet the "functional" requirements of the capacity test. The normative element of capacity assessments is acknowledged by a number of assessors who suggest that	Relevance to all of those working in health and social care who undertake assessments of mental capacity, and will be helpful to all of those tasked with designing and delivering Training in relation to the MCA 2005. Limitations were that the findings reported were from a university funded pilot. Individuals self-selected and the only exclusion criteria applied by the researchers was that participants needed to be currently active in	Identified some good practice, which balances the criticisms and also gives information about what training might be warranted.

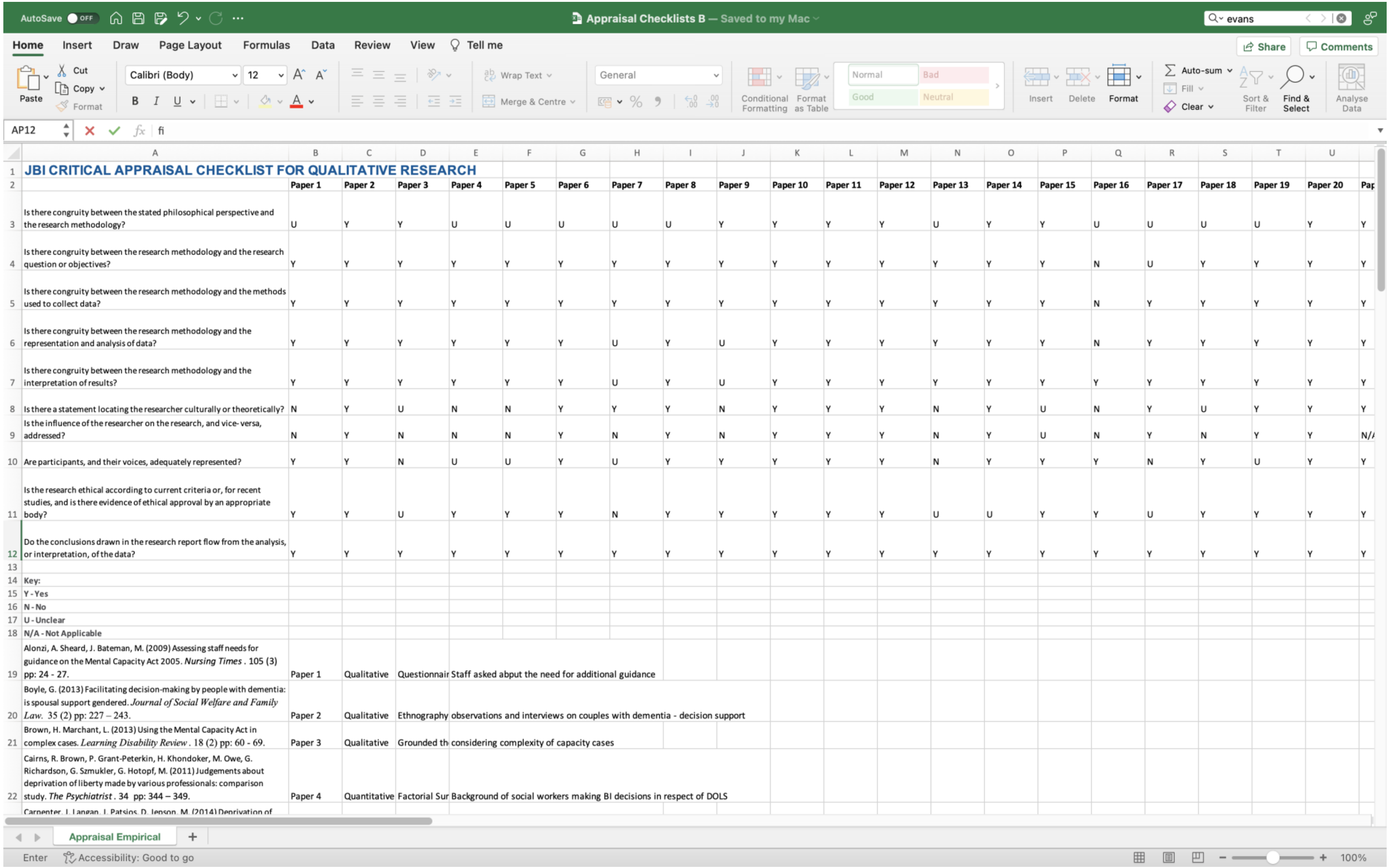
							judging a person's ability to "weigh" information, in particular, is a subjective and value-based exercise, which is given pseudo objectivity by the language of the Mental Capacity Act (MCA). A number of elements of good practice were also identified.	one of the three main roles described, which may have excluded some participants.	

Appendix 7 - Joanna Briggs Institute Critical Appraisal Tools Checklist for Qualitative Research

JBI CRITICAL APPRAISAL CHECKLIST FOR QUALITATIVE RESEARCH
Is there congruity between the stated philosophical perspective and the research methodology?
Is there congruity between the research methodology and the research question or objectives?
Is there congruity between the research methodology and the methods used to collect data?
Is there congruity between the research methodology and the representation and analysis of data?
Is there congruity between the research methodology and the interpretation of results?
Is there a statement locating the researcher culturally or theoretically?
Is the influence of the researcher on the research, and vice-versa, addressed?
Are participants, and their voices, adequately represented?
Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

https://jbi.global/sites/default/files/2019-05/JBI_Critical_Appraisal-Checklist_for_Qualitative_Research2017_0.pdf

Appendix 8 - JBI critical appraisal checklist for qualitative research (screenshot)



JBI CRITICAL APPRAISAL CHECKLIST FOR QUALITATIVE RESEARCH

	Paper 1	Paper 2	Paper 3	Paper 4	Paper 5	Paper 6	Paper 7	Paper 8	Paper 9	Paper 10	Paper 11	Paper 12	Paper 13	Paper 14	Paper 15	Paper 16	Paper 17	Paper 18	Paper 19	Paper 20	Pap
Is there congruity between the stated philosophical perspective and the research methodology?	U	Y	Y	U	U	U	U	U	Y	Y	Y	Y	U	Y	Y	U	U	U	U	Y	Y
Is there congruity between the research methodology and the research question or objectives?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	U	Y	Y	Y	Y
Is there congruity between the research methodology and the methods used to collect data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
Is there congruity between the research methodology and the representation and analysis of data?	Y	Y	Y	Y	Y	Y	U	Y	U	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
Is there congruity between the research methodology and the interpretation of results?	Y	Y	Y	Y	Y	Y	U	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is there a statement locating the researcher culturally or theoretically?	N	Y	U	N	N	Y	Y	Y	N	Y	Y	Y	N	Y	U	N	Y	U	Y	Y	Y
Is the influence of the researcher on the research, and vice- versa, addressed?	N	Y	N	N	N	Y	N	Y	N	Y	Y	Y	N	Y	U	N	Y	N	Y	Y	N/
Are participants, and their voices, adequately represented?	Y	Y	N	U	U	Y	U	Y	Y	Y	Y	Y	N	Y	Y	Y	N	Y	U	Y	Y
Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Y	Y	U	Y	Y	Y	N	Y	Y	Y	Y	Y	U	U	Y	Y	U	Y	Y	Y	Y
Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Key:
Y - Yes
N - No
U - Unclear
N/A - Not Applicable

Alonzi, A. Sheard, J. Bateman, M. (2009) Assessing staff needs for guidance on the Mental Capacity Act 2005. *Nursing Times* . 105 (3) pp: 24 - 27.	Paper 1	Qualitative	Questionnair	Staff asked abput the need for additional guidance
Boyle, G. (2013) Facilitating decision-making by people with dementia: is spousal support gendered. *Journal of Social Welfare and Family Law.* 35 (2) pp: 227 – 243.	Paper 2	Qualitative	Ethnography	observations and interviews on couples with dementia - decision support
Brown, H. Marchant, L. (2013) Using the Mental Capacity Act in complex cases. *Learning Disability Review* . 18 (2) pp: 60 - 69.	Paper 3	Qualitative	Grounded th	considering complexity of capacity cases
Cairns, R. Brown, P. Grant-Peterkin, H. Khondoker, M. Owe, G. Richardson, G. Szmukler, G. Hotopf, M. (2011) Judgements about deprivation of liberty made by various professionals: comparison study. *The Psychiatrist* . 34 pp: 344 – 349.	Paper 4	Quantitative	Factorial Sur	Background of social workers making BI decisions in respect of DOLS
Carpenter, J. Langan, J. Patsios, D. Jenson, M. (2014) Deprivation of				

Appendix 9 – Papers reviewed in order of theme

Knowledge:

Authors	**Findings**
Evans, Warner and Jackson's (2007)	Doctors, nurses and paramedics did not know how to assess capacity
Luke *et al* (2008)	Doctors and nurses indifferent about the value of IMCAs in decision-making
Alonzi, Sheard and Bateman (2009)	Interviews with nursing staff showed that training received by nursing staff on the MCA was insufficient to equip them for good practice. Nursing staff lacked confidence in how to best proceed in virtually every aspect of the MCA, from making assessments to decisions involving disputes
Manthorpe *et al* (2009) (Manthorpe, Samsi and Rapaport 2012a, 2013)	Interviews with adult safeguarding leads in two phases. There were concerns that the legislation was not widely known and about how it would be incorporated into everyday practice. More positive reports in the second phase and participants viewed the legislation favourably
McDonald (2010)	Social workers reported their views of the legislation and stated that it had forced them to take a legalistic view of cases
Wilson, Seymour and Perkins (2010)	Palliative care staff (including nurses) generally had a good understanding of issues around capacity but felt unclear about some of the terminology, which impacted on their confidence
Samsi *et al* (2011) Manthorpe *et al* (2014)	Admiral nurses reported low confidence in application of the MCA (not specifically best interests) in first phase. Improvements in second phase but more training was needed.
Samsi, Manthorpe and Rapaport (2011)	Age concern staff – a lack of knowledge and varied knowledge of the legislation. Training was needed to improve knowledge and confidence
Willner *et al* (2011a, 2011b, 2012 and 2013)	NHS staff, health and social care staff. There were gaps in knowledge in all 4 studies but knowledge did improve following training. There was both optimism and concern as there was a relatively good understanding of some aspects of the MCA and discernible improvements following training but there were also limitations in understanding
Gough and Kerlin (2012)	Gaps in understanding of residential care home staff in areas where good practice had been identified. Training required review
Phair and Manthorpe (2012)	Hospital staff interviewed and the participants felt that the MCA was not embedded into practice. Most participants lacked knowledge, confidence and training needed review

Emmett *et al* (2013)	Health and social care staff professed to understand the need to respect unwise decisions but putting it into practice appeared problematic. The legal standards under the MCA were perceived and implemented in varied ways in practice
Manthorpe *et al* (2011; 2016)	Care staff reported that confidence in their knowledge of the legislation as low and there were mixed levels of awareness regarding details of the legislation. The principles of the legislation were congruent with their expressed practice values. In phase 2, participants were asked to provide their opinions of any training they had received, and some responded that they had received no training and did not know about the legislation
Rowley *et al* (2013)	Questionnaires with Trust staff, including nurses that showed knowledge of the legislation was lower than anticipated and therefore implementation was not up to the expected standard
Heslop *et al* (2014)	A review of deaths of people with learning disabilities revealed that decisions were made on prejudice, a lack of information about the person or a lack of holistic assessment of the person's situation
Walji *et al* (2014)	Clinical psychologists reviewed revealed training gaps and misunderstanding of the legislation in relation to its complexities, such as best interests decisions
Manthorpe and Samsi (2015)	Interviews with practitioners revealed that knowledge of offences under the legislation was partial to non-existent
Cliff and McGraw (2016)	Semi structured interviews with nurses and AHPs considered both influencing factors and perspectives of the legislation. It acknowledged that capacity assessments were complex and recommended providing opportunity to develop systems to support practitioners to manage the challenges, encouraging interprofessional working and utilising the knowledge, skills, and experience within the interprofessional team
Marshall and Sprung (2016)	Interviews with community nurses to explore their experience in using the MCA in practice. The vast majority of the participants had received training but still felt that they would benefit from additional training. Confidence was not rated highly and there was no significant increase in confidence relating to years of experience in their role
Murrell and McCalla (2016)	A small-scale study with social workers found that there was varied knowledge and in some cases was fairly limited. It echoed findings in the HOLSC (2014) report.
Shepherd *et al* (2018)	Participants, from a range of professions, including nurses, showed that there was a broad spectrum of understanding about the legal frameworks, overall, the participants

	demonstrated a lack of knowledge about the legal frameworks. The findings suggested that greater education and training is required
Chapman (2020)	The study acknowledged the existing evidence that the MCA is not empowering vulnerable people and the lack of knowledge in healthcare professionals but suggested that there is sparse knowledge that investigates staff knowledge of the MCA. It found that there was a high level of variability in MCA knowledge across the individual professions. The shortcomings identified highlighted areas for potential improvement, training needs to extend beyond theoretical knowledge and direct staff in how to apply their knowledge to positively influence practice and the quality of care that patients experience

Best interests, DOLS and general decision-making:

Authors	**Findings**
Dunn *et al* (2010)	A study with support workers found that they draw on the personal decisions that they make in their own lives as a starting point for thinking about how to make substitute decisions
Livingston *et al* (2010)	Family carers making decisions relating to health and accommodation. Focused on considering previous wishes and if LPA was available
Cairns *et al* (2011)	The study asked lawyers, psychiatrists, Best Interests Assessors and IMCAs to make binary judgements about whether situations in 12 detailed vignettes amounted to a deprivation of liberty. All participants had similar experience that the situations were complex and the legislation made the decisions difficult, which highlighted issues with the legislation itself
Harris and Cohen Fineberg (2011)	Interviews with practitioners (including nurses) around processes and practice as well as knowledge/ understanding. The study found a variable understanding of the MCA and best interests with almost half of participants demonstrating a lack of clarity of the concept of best interests
Boyle (2013)	A qualitative study of couples with dementia found that female carers were more facilitative of decision-making with their male spouses and that male carers were less facilitative, limiting the autonomy of their spouse. Boyle suggested that this gender disparity should be recognised by health care professionals.
Brown and Marchant (2013)	A study reviewing complex cases found that in respect to best interests, the study identified that some practitioners passed responsibility for the decision to a medical

	professional, thinking that it was the correct procedure. This study suggested through identifying the complexities that some of the criticisms could be because cases requiring consideration under the MCA do not fit into the linear, cognitive model of decision-making
Samsi and Manthorpe (2013)	Interviews with people with dementia and their carers found that carers struggle to weigh up what was in their relative's best interests and how to determine their relative's capacity. The need for support was highlighted
Williams *et al* (2012)	The aim of the study was to provide a picture of practice in best interests decisions. The findings suggested that people with dementia were disadvantaged in relation to capacity assessment and best interests processes, in comparison with other client groups
Carpenter *et al* (2014)	A study that included health and social care professionals (including nurses). Overall, the judgements were made with a high level of confidence and there were no statistically significant differences associated with the variables of gender, age, ethnicity and profession, with the exception of number of years in post. DOLS were generally welcomed albeit with concerns about the clarity of making judgements
Howarth *et al* (2014)	Care home staff questionnaire on whether they engaged in 'forced care', which found that forced care is carried out regularly and therefore not supportive of person-centred care.
Poole *et al* (2014)	Interviews with range of healthcare professionals including nurses about capacity and discharge arrangements for people with dementia. They acknowledged the complexity of assessments required, that risk and safety was a focus rather than preserving the rights of the individual.
Clarke *et al* (2015)	A study about decision-making around CANH focused on the principles of beneficence and non-maleficence. Discussions concerning CANH for patients lacking decision-making capacity were complex and multi-faceted, including topics such as risks, burdens and benefits, treatment goals, ethical values and interested parties
Carter *et al* (2018)	Interviews with family carers about Advance Care Planning found that peer support was needed, that family carers were anxious about making decisions and they need support from healthcare professionals to make best interests decisions.
Clerk *et al* (2018)	A Delphi study that considered the application of the MCA and DOLS with practitioners (including nurses). The authors suggested that application of the MCA is complicated and nuanced, requiring time for reflection to avoid paternalistic clinical interventions. The Delphi study

	found that participants did not respond consistently to the scenarios used but disagreed most significantly when patient decisions conflicted with clinical advice.
Scott *et al* (2018)	Interviews with healthcare professionals, including nurses about dialysis treatment in people with dementia. The considerations about treatment included comorbidity, social support, quality of life and the feasibility of dialysis
Rogers and Bright (2019)	A study to investigate the approaches of different groups of assessors to the MCA assessments required as part of DOLS Most assessors did not refer to the two-stage test of capacity and they suggested that judging a person's ability to weigh-up information is a subjective and value-based exercise. There were some elements of good practice identified by this study

Appendix 10 – Poster for recruitment

ARE YOU INTERESTED IN DEMENTIA CARE?

WOULD YOU LIKE TO PARTICIPATE IN A RESEARCH PROJECT?

I am looking to recruit registered nurses who are interested in dementia care to participate in a research project about decision-making for people with advanced dementia.

If you are interested in finding out more, please e-mail me via J.S.Murphy@keele.ac.uk and I will send you details of how you can participate.

Information Flyer
Version 1
Date 20/06/2018

Appendix 11 – Participant details form

PARTICIPANT DETAILS FORM

Study Title: Best Interests Decisions for People with Advanced Dementia: An Exploratory Study of Nurses' Perspectives.

Name and contact details of Principal Investigator: Jayne Murphy, Post Graduate Researcher. Keele University Staffordshire, UK. ST5 5BG. J.S.Murphy@keele.ac.uk

MALE	
FEMALE	

AGE	

QUALIFIED:	MONTH	YEAR	RN – ADULT/MH/LD

What field of nursing do you work in:

COMMUNITY	HOSPITAL	VOLUNTARY/ CHARITY	PRIVATE	OTHER

What regional area do you work in:

BIRMINGHAM	DUDLEY	SANDWELL	STAFFORDSHIRE	SHROPSHIRE
WOLVERHAMPTON	WORCESTERSHIRE	OTHER (INDICATE WHERE)		

What education and training have you received about the Mental Capacity Act (2005)? How recently was this e.g. this year, last year, in the past 5 years?

Mandatory Training	Half-day session	Full day session	Clinical Supervision/Action Learning Sets	Other

Participant info V3 05/03/2019

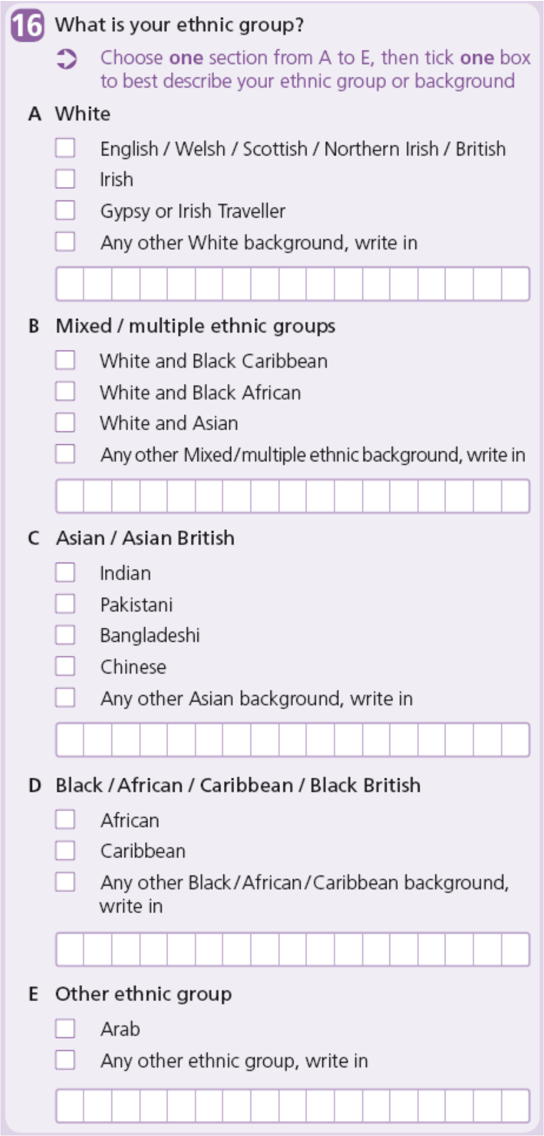
Have you recently cared for or are you currently caring for a family member with dementia?
YES/NO

On a scale of 0 – 10 (0 poor 10 excellent) where would you rate your knowledge of the Mental Capacity Act (2005)?

MCA

On a scale of 0 – 10 (0 poor 10 excellent) where would you rate your knowledge of the Principle of Best Interests?

BI



16 **What is your ethnic group?**

Choose **one** section from A to E, then tick **one** box to best describe your ethnic group or background

A White

☐ English / Welsh / Scottish / Northern Irish / British
☐ Irish
☐ Gypsy or Irish Traveller
☐ Any other White background, write in

B Mixed / multiple ethnic groups

☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other Mixed/multiple ethnic background, write in

C Asian / Asian British

☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background, write in

D Black / African / Caribbean / Black British

☐ African
☐ Caribbean
☐ Any other Black/African/Caribbean background, write in

E Other ethnic group

☐ Arab
☐ Any other ethnic group, write in

Participant info V3 05/03/2019

Appendix 12 - Interview guide

Sequence of events for interviews		✓
1	Introduce yourself and housekeeping	
2	Confirm invitation e-mail received/read	
3	Confirm participation information received/read (withdrawal info)	
4	Complete demographic form	
5	Complete consent form	
6	Explain recording process of interview	
7	Allow the participant to read the vignettes	
8	Ask each question in sequence or in response to answers	
9	Give the participant the opportunity to add any information	
10	Complete the interview	
11	Offer de-brief (what would happen in each case)	

Appendix 13 – Interview questions

QUESTIONS FOR SEMI-STRUCTURED INTERVIEWS (V5 15/10/18)

For the chosen vignette, allow the participant to read through at their pace and make any notes if they choose. Ask the following questions:

1. What are your initial thoughts about the situation?
   a. From Alan's/Kashi's perspective.
   b. From his granddaughter's/her husband's perspective.
   c. From his son's/her son's perspective.
   d. From your own perspective.
2. What would your key priority in this situation?
3. Can you tell me what you might consider from a Best Interests Perspective?
   a. In respect of the legal requirements.
   b. From a clinical perspective.
   c. From a social/personal situation perspective.
4. Do you think there are any conflicts of interest?
   a. Between the Person Living With Dementia (PLWD) and family.
   b. Between clinicians and family.
   c. Between family members.
5. What (if anything) do you see as positive or helpful in the situation?
   a. With the person/significant others.
   b. With the best interests decision making process.
   c. With the information provided
6. What (if anything) do you see as negative or challenging in the situation?
   a. With the person/significant others.
   b. With the best interests decision making process.
   c. With the information provided
7. Is there anything missing, or any other information you might like to have?
8. What do you think would actually happen in the situation (the outcome)?
9. Is it helpful not to have any 'investment' in the situation? (Not to be directly involved).
10. Do you have anything else you would like add?
11. If the participant has not made mention of the age of the PLWD, ask if this would be a factor in the decision-making process
12. There is still a lot of criticism about practitioners' knowledge about the MCA and BI – why do you think this is?
13. Are there any examples of good practice you have experienced or can think of that would support practitioners with the application and understanding of the MCA and BI decisions?

Appendix 14 - Transcript of interview

PILOT TRANSCRIPTION (34:57)

Interviewer	You've read the vignettes, so and we're just going to have a conversation about the vignettes now but I've just kind of got set questions as an aide memoire, more for myself really, erm I don't need necessarily to make any notes but because this is a pilot, what I might just do is write little things down if it jogs my memory to think 'I need to ask about that or clarify that'. So, if we talk about the first vignette, er Kashi, 83 with vascular dementia, she's got an ischaemic right foot, er and she needs an amputation and although she's said in the past she wouldn't want an amputation, er her daughter wants her to have an amputation and her grandson, er, wants to respect her wishes. Erm, she's been assessed as lacking capacity to decide on the amputation and she doesn't have any advance decision to refuse treatment, any advance care plan or lasting power of attorney, erm but her grandson does have lasting power of attorney for property and finance. So, if you were faced with this situation, what would your key priority be? What's the first thing that comes to your mind about this?
Respondent	Ah, I'd look at her safety first, I'd want to know if she is mobilising. Cos my worry would be if she has the amputation and she's still mobilising, would she forget …and be at risk of falls, so I'd want to take that into consideration. But […] eh obviously the daughter and the grandson are completely on different… and really conflicting, so maybe looking as well at what the consultant thinks, the risks of surgery, what's, you know is she gonna get a better quality of life from the surgery or, you know, is it, is it gonna improve her quality of life, I'd wanna know those risks as well. […] If she's getting any pain from.., is it causing her any concerns, you know, in the sense of her day-to-day activities […]
Interviewer 2:31	Lovely. Thank you. Obviously, I don't want to rush you through, so there might be little silences but that's for me just to know that you've said all that you need to say. And if you want to kind of, don't think that you're repeating yourself, if you wanna go back to anything. Just, you know, talk freely really cos it is meant to be, like a discussion and a conversation. Erm, so how do you think Kashi feels in this situation?
Respondent	We don't really know. So, although it says she is lacking capacity, she could still be able to communicate and she might still have some opinion as well, erm, so we really would like to ask and talk to her and get a bit to know a bit more information about Kashi's unders- although she's says she's lacking capacity, she might still…be ref-, I mean she might be kicking a screaming, not wanting to be in the hospital, so she could be in distress, with that, so I'd want to know a bit more about Kashi really and what's going on with her. Is she happy, is she com- cos although, cos I think her daughter says she's happy, what do they mean by that?

Interviewer 3:41	So, what do you think, erm how do you think her grandson feels about this situation?
Respondent	He's gone to want to respect her wishes …. but it's hard because they could've changed and as there's nothing written down, say he's gonna feel is if he's let her down if she has the surgery, but obviously then, it could be for the right thing when there's nothing lega- like paperwork-wise to say….
Interviewer 4:14	And what about er, her daughter, how do you think her daughter feels?
Respondent	She doesn't wanna lose her mom. So, she desperately wants to like prolong her life. Maybe she's not thinking of what quality her mom is gonna have. She just wants to get rid of the problem of the ischaemic foot. Maybe not looking at the whole picture as such.
Interviewer 4:39	If this was you in this situation, if you were Kashi how would you feel?
Respondent	If I'd specifically said I didn't want my leg off or any amputation, I would be upset if my family tried to do that. Regardless of…. I, she's got to have said it for some reason, it's not something you discuss randomly. Like um, if the time comes don't let em take my leg. So, I'd say this has been a problem for some while. When she had capacity if she could make that statement, so I'd say it's still something that she was always knew would happen. So, I'd feel a bit upset if it was me and I wanted to definitely not have an amputation.
Interviewer 5:34	So, if we think about er from Best Interests, er, are there any aspects of it that you would identify, particularly about Best Interests from a legal perspective?
Respondent	So, like a quality of life, would she get anything?
Interviewer 5:53	Yeah, erm, from erm, *tut*, so I want you to try to think of it from three different aspects, so it is testing your knowledge a little bit about best interests er decision-making, so what might we need to do legally in respect of Kashi's situation?
Respondent *Could have been referring to deputyship here*	[…] look at, er I dunno if it, I've forgot what it's called. Could you look at getting erm, […] no I don't think you can, I was gonna say the lasting power of attorney but she's *(not)* got the consent to give that anymore. So it'd be the best, would you fill out the best interests, like in an assessment to see erm and have an MDT meeting and look at it from that point of view with the consultant, everybody gathered; physios, OT, family as well and look at it as a whole, Kashi as a whole person with regards to what's safe, the medical.. is it going to be quality of life and take in to account the grandson and the daughter's concerns and also what Kashi said previously. I can't think of the erm, thing you can put in place..
Interviewer 7:30	So, but you think there might be something legal that you might be able to put in place
Respondent	I think so yeah, but I can't think of it for the life of my, I've gone blank.

Interviewer 7:40	Think about this multidisciplinary meeting then, what erm and you've kind of explored it a little bit really, what would you think from a clinical perspective?
Respondent	[…] what the risks of surgery are really and the risks of healing, cos as I've said, she's got diabetes. Is the wound ever gonna heal, is she gonna get an infection post-op, so is she gonna, is she gonna come back out of hospital erm is that wound gonna then heal up. Does she understand that she's got the wound, er is it gonna heal and improve her quality of life or is it just gonna, is she gonna get an infection and, you know that could shorten her life. So, I'd want to know all the risks; surgery and post-surgery really.
Interviewer 8:33	And then, the socially. I know you've said initially about erm her mobility, whether being an amputee will affect her ability, what about anything else socially or from a caring perspective?
Respondent	Would she need a package of care putting in place, would she need physiotherapy, erm would she need like carers, equipment to keep her …. if she, you know, is she get returned to home, is the home okay, is it adaptable for her to be there if she's lost her amputation she probably needs to now live downstairs, does she live downstairs, is there a bathroom, is there everything that would be in place to support her and the family, at home. Or would it be that they'd have to look for alternative accommodation and is that gonna make her dementia *(worse)* she's no longer in her environment that she knows, is that gonna make her, you know, feel worse in that sense, erm you know, her behaviour could change, she could be quite settled at home and if she doesn't know the environment she's gonna become unsettled.
Interviewer 9:47	Lovely. Erm do you think there is any conflict of interest between Kashi and the rest of the family?
Respondent	[…] *tut,* er the finance, the grandson – he could have an (laughs) ulterior motive for the finance so you know he could be not wanting to prolong her life. He could be, I know it sounds horrible, but he could want, want her to die, in that sense, if he's got the money, what, what does that mean? Does that mean that he gets all the money or is it just that he is looking after it for her and it's gonna be split between the family if she's got any or, you know is there a will in place or is he having it all and that's why he wants her to not have the operation cos it's gonna shorten, it could shorten her life.
Interviewer 10:40	And what about the clinical staff, so if you were in a multidisciplinary team meeting do you think there would be any conflict between the clinical staff and the family?
Respondent	If the clinical staff can put that case that yes she does need the operation, yes she's gonna get a better quality of life, he still might be putting barriers up or be difficult for him to see the whole picture erm, even if the clinical staff like had explained the risks weren't high or, you know that she would be able to heal better than they thought he still might be putting barriers in place. But, on the flip side, they could be saying, you know they don't advise it, but the daughter could also, you know, keep pushing for the surgery even if they don't think it's the best option.

Interviewer 11:35	And that kind of covers the next point really, is there conflict between the family members. We've talked, well you've talked about the daughter and the grandson erm, so not sure if there's anything that you would add there. The conflict between them.
Respondent	I think they, with each other, they'd have conflict as well cos one is seeing that they are doing the best for their, for Kashi and the other one's seeing that they're doing the best so obviously they could be at each other as well, arguing. And ultimately, Kashi might not be getting the best interests out of it.
Interviewer 12:12	So, is there anything from the er, situation itself, form the information that you do know that is helpful. Anything that you know about Kashi, or the clinical aspects it that would help you to kind of influence the decision that you would make?
Respondent	So, that you're taking into, like past medical history, […] erm, that would be the key thing really […] knowing the risks for the surgery, post-op but also like what Kashi had said herself, erm from her wishes, that would also affect it.
Interviewer 13:05	And is there anything with the situation that you think erm you kind of challenging, er either with Kashi or er the way you'd make a Best Interests decision or would the information that's in front of you anything that you'd erm you'd wanna know more about or struggle with that might impact on your ability to make a decision on behalf of Kashi.
Respondent	I wanted to know more about Kashi's, how she is in herself, erm is she able to communicate, erm I'd want to know more about her mobility, what her social, what her house is like, where she's living, erm know more about the, what the consultant, what everybody like in the MDT meeting, what all their opinions would be. Erm and investigate more about that finance, off the grandson as well. […] But I suppose that wouldn't really be my role in the sense, it would be more the social work … to look into really. But just to know, as a, you know, has he got her bet interests or is there something else.
Interviewer 14:30	So, that's really the… If I was to change or to add to the detail of this vignette, what would you ask me to change or add to the information?
Respondent	Just probably more the social side really
Interviewer 14:50	And what do you think, reading through this, what do you think the possible outcome would be, if you could kind of predict what is gonna happen?
Respondent	I think they'd probably look more in to the risks and possibly look more as the consultant making the decision erm as the best interests if the family … are at two different …. things. Obviously keep on talking to them and discussing it. But possibly the consultant making more of a decision for the best interests of the patient.
Interviewer 15:30	Do you see a decision being made?
Respondent	[…] I think if it wasn't, (oh), it did say that there's risks both sides of her not having it and having it…. so, I think it depends which way they would swing. I think if there's more… no quality of life from it I

	don't think they would do the amputation. I think if she would get a quality of life, and you know going back home, her mobility, all that taken in, I think they would amputate.
Interviewer 16:09	And then, do y-, is it easier for you reading this to make a judgement on it for you to make a decision on it because you haven't got any personal investment or professional investment in it. It's just a situation that you're reading about. Does it make it easier for you to judge what's going on?
Respondent	It, because like you haven't got anything, like you don't know the family or anything, it can keep you not biased but then you don't know what the full situation is so you're not getting, you can't get a sense of what's going on. Like you can't see Kashi, you don't know how she is in herself … so (coughs). With all the facts in there it makes you not bias but me personally I'd want to see Kashi with for own eyes to make.. before I made a decision.
Interviewer 17:07	That's interesting, thank you. Now I've got 2 questions that I'll leave to the end cos they're more general questions. So, if we can move to erm Alan's and it's just the same process, so the same questions.
Respondent	Okay
Interviewer 17:30	So, with Alan, erm, he's 63 years old erm, he's been in a nursing home for 3 years. Jeanette, his wife, er visits him every day. He's had Alzheimer's Disease since the age of 55 but he can't communicate, er he's got minimal nutritional intake, he only weighs about 45kgs, he's incontinent, he's got skin breakdown but he still enjoys things like music, he smiles and appears to enjoy the company of his wife and holds her hand. Erm but he's been admitted to hospital with pneumonia and they are now deciding as a Best Interests meeting whether to initiate IV antibiotics to treat his pneumonia erm and they're looking at the viability of treating it and whether it would be successful treatment or not. So again, your key priority for Alan in this situation?
Respondent	Er, his overall health, really, erm […] yeah, his overall health, to make him feel better and get him and get him back ho-, get him back to the nursing home really, cos that's where he is most comfortable, his wife's there, things he likes are there. So, it would be, getting priority would be finding out what's going on, treating it and getting him home.
Interviewer 19:00	So, from, how do you think Alan might be feeling in this situation?
Respondent	Scared, he's gone in to hospital, he's not feeling well and they're looking at not giving him antibiotics, so he might feel afraid that they're just gonna leave him to just sort of suffer and not be treated.
Interviewer 19:28	And how do you think his wife feels?
Respondent	Probably the same, probably wants to know why they won't give him antibiotics. She can't, you know, he still, erm can communicate with her. So, she just wants him, you know, it's an illness, just to get him with the antibiotics and get him back home.
Interviewer 19:55	And his daughter's as well do you think they would feel the same?

Respondent	Yeah, probably. If they all… It says they are a very supportive family. I think they'd take into consideration what the doctors are saying but I think ultimately, they'd want to know why they aren't treating the pneumonia, unless it's not treatable in that sense.
Interviewer 20:20	Mmm, so, again, put yourself in Alan's position, how, how do you think you would feel if you were Alan (or Alana)?
Respondent	Erm, I think as long as I'd got a chance of it being cured I'd want to have the medic- I'd want the IV antibiotics I'd just wanna get back home really, I wouldn't wanna stay in hospital. And if they think that there's nothing else I'd still want to be at home and not be in hospital and enjoy what's left really.
Interviewer 21:03	Mmm, so from a Best Interests perspective, do you think there is anything legally, here that you think you would want to consider?
Respondent	[…] whatever the, erm his it says that doesn't it - there's no erm, whether the wife's got lasting power of *attornety* or if there's anything written if he's got like erm a written decision to say that he doesn't want further care or anything like-, types of care that he doesn't want in hospital. He might not want IV antibiotics he might have something that says that. So just to find out if he's got anything, any of the documentation. If he's got a DNAR in place, things like that, erm that he might have already had erm when he found out he's got the erm Alzheimer's Disease at 55 he might have put all those things in place. Erm, so to find out erm what legal er paperwork he's already got, if any.
Interviewer 22:24	What about from a clinical perspective?
Respondent	I'd want to know what erm, if he could, if he can have IV antibiotics if they would improve, if they would help, clear the pneumonia erm and then obviously looking at ways to help him when he's back in the nursing home because obviously he's at risk of getting it again. Erm… it says he has a recurrent respiratory tract infection so is there something that they can do to try and prevent these infections… if it can erm help him. But if the pneumonia, obviously if they are saying there is nothing they can do, it would be looking at like, if they are saying he is palliative, then to start looking at the palliative care route for him.
Interviewer 23:11	And I think you've kind of picked up on the social bit really cos you've talked about if he goes back to the nursing home what erm support you can put in place so that he can be safe and comfortable whether he lives or dies er when he's at home.
Respondent	*Echoes 'lives or dies' at the same time as the interviewer*
Interviewer 23:27	So, do you think, with this one are there any conflict of interests between erm family members and clinicians.
Respondent	Although it doesn't say anything, if he'd got something in place his wife might not agree with it any more. She, she might still want to prolong his life or if he hasn't said anything she might not want him to have the IV antibiotics, so it just could be a conflict of int - or. She might want one thing and the children might want something different.

Interviewer 24:01	Erm and is there anything that you can see with this situation that kind of helps you in your decision-making and what considerations you would make in respect of whether he has treatment or not. Any of this information that's helpful?
Respondent	Again, his Past Medical History, taking that into consideration. His diagnosis, erm those would be the main things to take into consideration really, of how he is.
Interviewer 24:39	And what about anything in the er scenario that's quite challenging and difficult to er process?
Respondent	[…] He's not able to actually communicate his, his thoughts and feelings really, erm although he smiles with his wife. Erm, does it say he hasn't got capacity? (**No**) So, he, he could have capacity he might just not be able to verbally speak what he wants. So that could be challenging because obviously he could want some, you know he might want the treatment or he might not want the treatment, but… he can't communicate verbally. So, the, we need to be, if he, if I was looking after him, we'd need to be aware of that and see if there is a way he could communicate. Because although he can't verbally communicate it doesn't mean he hasn't got capacity.
Interviewer 25:39	So, is there anything from that situation that you would want to know more information about?
Respondent	His capacity.
Interviewer 25:40	And you've said other things as well haven't you, cos you've said about whether there's a Power of Attorney, whether he'd made an advance decision, er, if there's a DNAR in situ, erm anything else you can think that you would you'd like to know more about?
Respondent	Erm, probably just social side as well again. What's erm, what's er it like at the nursing home. And you know, the wife, it does say that she goes every day or how often she goes. So, maybe just a little bit more on that side. And if he was to go down the palliative route, you know just to support the wife and what things would be in place for them really.
Interviewer 26:36	And erm again what do you think would be the outcome of this situation? What could you see happening?
Respondent	I think more than likely he'd to have the IV antibiotics to treat the pneumonia or at least erm to see if it made any difference to him and I think that would be the main decision and to go from there really.
Interviewer 27:10	And does it help again not having any kind of investment in making decisions here?
Respondent	I think again it does in the terms of you're not biased towards one side or the other. But I think as me I'd still want to get to know them and to see with my own eyes to see what's going on in the situation. I know that sounds funny but…..
Interviewer 27:34	So, is there anything from either of the two vignettes that you would want to add?
Respondent	I don't know if I said it for that one, for vignette one but again id want to check their DNAR status as well.

Interviewer 27:49	Why would that be particularly?
Respondent	Just to see if they had got anything in place. I mean she might have put that in beforehand. And I think that could affect her, you know with the knee amputation. I think if she doesn't want to be resuscitated and she's gonna have a high-risk surgery and she's could potentially die on the table, as such, would she want that? Would she want that medical intervention as such or would she be happy, you know to face the complications of not having the amputation?
Interviewer 28:30	Erm, I have got one question that I haven't got on my schedule erm and it was a kind of deliberate thing, so we'll cover that in 'anything else you'd like to add'. Did you notice or did it have any impact at all about the age of either Kashi or Alan?
Respondent	Erm, I did notice it, but I don't think I really took it in to much consideration. But looking at it now I think….. I think it would now I've realised their ages that would influence the decisions that they're making. I know it sounds awful, but I think they might try and fight for Alan at 63 more than what they could do with Kashi at 83. Erm but that's also gonna have a big impact on the risks of her surgically cos of her age, so I think, I think it would affect it clinically when you are looking at the risks, but I didn't really take it in to consideration.
Interviewer 29:40	Mmm okay, thank you. And then there's just two general questions now, so there's a lot of criticism about practitioners' knowledge about both the Mental Capacity Act and within that Best Interests Decision Making. Why do you think that is?
Respondent	I don't think we get enough training on it. Erm, my knowledge is poor, and I will admit that, erm and you only seem to learn from it when you are stuck in the situation and you are trying to find out what needs to be in place. And I think that's why we are criticised, and we make the wrong decisions, because I think our knowledge is poor. Erm my personal training is just on line, so I do feel like that affects the sort of erm situations that we come in to and I have to turn to my manager a lot to look at when we have anything like this because I'm lost and I don't know what to do.
Interviewer 30:43	Does that help you, like discussing it with others like your manager?
Respondent	Yes
Interviewer 30:45	How do you feel it helps you?
Respondent	Erm, cos then I start, like she'll say to me 'we need to look at putting this in place…' and then I'll look a bit more about it why are we doing that, what is it, and look around the Trust policy and look around it as a whole then. And then I learn for like the next time sort of thing. So, my experien-, so I experience it there and then in practice. Where I think sometimes when you are just looking on a computer you just sort of just task - I don't know what the word is really, you are just, just getting through the training to say you've done it and it shouldn't be like that. But then I've also attended

	some training and it’s just death by PowerPoint and you just lose the will to live. I know it’s such a big area, but I think because it’s not applied to practice as such I think people lose the will to live in training.
Interviewer 31:47	So, is there anything that you have experienced or anything that you can think of that would be good practice such as like you’ve just said a discussion group or the choices that are on the form?
Respondent	I personally think it should be more smaller groups and it should be scenarios and that would help you then pull together what bits and pieces you actually need instead of it just being online multiple choice or a long PowerPoint with lots of things and Acts and everything and you don’t, it’s just in one ear and out the other. It is for me cos I just can’t take it in, I like to apply it to something, I mean it could be just me that thinks like that but I just think that nurses on a whole haven’t got that information because it’s not been applied to ‘em as a practical thing in my opinion. But I’ve also had the situation, we had a patient that had got dementia and they had to have a daily insulin injection and they refused insulin and we couldn’t give it them and it was a very grey area because I felt like sometimes I was giving it and I thought like ‘well have I got consent?’ and I didn’t like it and didn’t know what to do and we’d got no support from the GP and we just kept being told off because, you know he was just literally kicking and screaming, he didn’t want this insulin and all they cared about was us getting his blood sugars down and we had to put in, we had to assess his capacity so we did a capacity assessment and we assessed that he hadn’t got capacity but then nothing was done with it and you know that really upset me cos I thought he still doesn’t want it, he clearly doesn’t want it although he can’t tell me the time or the date or what month we’re in, he knows he doesn’t want this injection and that’s what upset me I think because we didn’t really know much about mental capacity or the mental capacity act or anything I think that hindered our ability to protect that patient just from having the insulin injection because the GP wanted to get his blood sugars lower.
Interviewer 34:04	That’s purely target driven, like a paper exercise
Respondent	But when he left our care home and went to another care home they took him off insulin the next day and yet we were begging the GP and the diabetes team to do that, and they wouldn’t do it.
Interviewer 34:05	And put him on medicine?
Respondent	Yes
Interviewer 34:07	And he’s survived?
Respondent	He’s still alive now and that’s been 3 years ago. But I still think we could have done more, and I kick myself cos I still don’t know anything about it even though I’ve had that experience I still haven’t been able to get round to looking more into things like this. Because we are an ageing population, we do need to know more about it but I think the training needs to change.

Interviewer 34:54	Thank you.

Reflection

This was the first interview so I was nervous about how it might go and whether I would obtain any useful data. The respondent was sensitive in how they considered each case and demonstrated empathy with the characters involved.

The respondent did acknowledge a lack of educational opportunity for MCA and gave an example of how they had experienced challenges in practice.

They were able to consider the practicalities of each situation and suggested that the amputation would be decided upon quality of life issues post-surgery; if QOL would be improved then the surgery would go ahead. For the pneumonia case there was little deliberation around whether the treatment should be initiated or not – the respondent thought that it was right to treat. There was some consideration around end of life, but this did not influence the decision to treat.

From a legal perspective, ADRTs were considered, no COP consideration but deputyship did appear to be a consideration.

I felt that the questions were fit for purpose provided I could explore some responses in more detail if required. I was not sure of the order of questions at this point, a re-order might be appropriate.

Scores: 5/10 for both MCA and BI

Appendix 15 – Invitation e-mail

Best Interests Decisions for People with Advanced Dementia: An Exploratory Study of Nurses' Perspectives

Invitation E-mail

Dear colleague,

You are being invited to consider taking part in the research study Best Interests Decisions for People with Advanced Dementia: An, Exploratory Study of Nurses' Perspectives. I am conducting the study as part of a PhD at the University of Keele.

My name is Jayne Murphy and as part of a PhD research project at the University of Keele I would like to develop some research about nurses' thoughts, feelings and opinions in making Best Interests decisions for patients living with advanced dementia. I intend to explore how nurses evaluate a situation in relation to the patient with advanced dementia and the Best Interests decision that needs to be made. The results of the study will be measured against the Mental Capacity Act (2005) guidance on Best Interests Decision Making. The subsequent provision of any identified support required in such circumstances will hopefully facilitate improved quality of care for patients.

The research will take the form of one to one semi-structured interviews, to which you are invited to participate. All information will remain confidential and anonymous and you have the right to withdraw at any time up to the point of transcription of your responses. The interview should take no more than one hour of your time. The interview is not to question you on your practice but simply an opportunity for you to reflect on hypothetical situations involving decisions about or on behalf of patients living with advanced dementia.

The interview will be structured around a short story about a hypothetical person and you will be asked questions about a hypothetical situation. The interview will be audio recorded so that the interview can be captured accurately and the responses recorded electronically.

The interviews will be held at the University of Wolverhampton on a mutually convenient time and date. All contributions will be anonymised and all responses will be destroyed upon completion of the study in line with Keele University Policy.

In order to participate you should be a registered nurse and interested in the care of patients with advanced dementia. You do not necessarily have to work directly with people living with dementia on a daily basis.

If you are able to attend and would be willing to contribute, please contact Jayne Murphy by e-mail on the address below:

Thank you for your support and contribution.

Kind regards,

Jayne Murphy
Researcher

Jayne Murphy, Post Graduate Researcher. Keele University Staffordshire, UK. ST5 5BG.
J.S.Murphy@keele.ac.uk

If you have a concern about any aspect of this study, you may wish to speak to me and I will do my best to answer your questions. You should contact Jayne Murphy on J.S.Murphy@keele.ac.uk Alternatively, if you do not wish to contact the researcher(s) you may contact Professor Sue Read s.c.read@keele.ac.uk (Director of Studies).

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 write to the Research Governance Officer at the following address:-

Research Governance Officer
Directorate of Engagement and Partnerships
IC2 Building
Keele University
ST5 5NH
E-mail: research.governance@keele.ac.uk
Tel: 01782 733306

Appendix 16 – Participant information

Jayne Murphy

Post Graduate Researcher
Keele University
Staffordshire
UK
ST5 5BG
J.S.Murphy@keele.ac.uk

Study Title: Best Interests Decisions for People with Advanced Dementia: An Exploratory Study of Nurses' Perspectives.

Invitation

You are being invited to consider taking part in the research study Best Interests Decisions for People with Advanced Dementia: An, Exploratory Study of Nurses' Perspectives. I am conducting the study as part of a PhD at the University of Keele.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve. Please take time to read this information carefully and discuss it with friends and relatives if you wish. Please ask if there is anything that is unclear or if you would like more information.

Aims of the Research

The aim of the research is to explore nurses' thoughts, feelings and opinions about Best Interests decisions for patients with advanced dementia. The results of the study will hopefully lead to a better understanding of how nurses define the Best Interests process and identify potential support mechanisms that may assist in future Best Interest decisions.

Why have I been invited?

You have been invited to participate as you are a registered student with the University of Wolverhampton and you are involved with the care of patients living with dementia. There is no requirement for specific post-qualification experience, clinical expertise or working exclusively within dementia care.

Do I have to take part?

You are free to decide whether you wish to take part or not. If you do decide to take part you will be asked to sign a consent form and you are free to withdraw from this study up to the point of data transcription without giving reasons. If you wish to withdraw following the interview you should contact the researcher by (date to be inserted) so that your responses can be identified and deleted.

What will happen if I take part?

The research will consist of one-to-one interviews, conducted using a hypothetical scenario (known as a vignette) of a Best Interests Decision to promote in-depth discussion about the situation. You will be asked for your thoughts on the vignette and Best Interests generally, with additional questions relating to the vignette. The interview will be held at a mutually convenient time and should take up to one hour. Your responses will only be identifiable to you and the researcher during the research and participants' responses will be fully anonymised prior to publication.

What are the benefits (if any) of taking part?

I would hope that you will find this an interesting exercise in relation to your practice and how you consider patients when making Best Interests decisions. The vignette should prompt you to consider how you make decisions for patients with advanced dementia and whether there are aspects that you wish to develop further. You may wish to reflect on the experience for re-validation purposes.

What are the risks (if any) of taking part?

I appreciate that you are a busy practitioner, so the interview should only take up an hour of your time. There are no anticipated significant risks to participants. Individual responses will not be identifiable, and all recorded data will be destroyed in line with Keele University Policy (completion of project + 5 years).

How will information about me be used?

Interviews will be voice recorded and transcribed following the interview. Responses will be coded and identifiable data will be stored separately from the codes until transcription and will be destroyed and digitally deleted in line with Keele University Policy. Responses will be themed and quotes may be used in publication of the findings. The data will not be used in any further research.

Who will have access to information about me?

Your responses will only be available to me as the Principal Investigator and the research supervisory team. It will be stored securely in a locked drawer during the research, recordings on a password protected storage device. Data will be deleted/destroyed within stipulated timescales*. No individual responses will be identifiable or linked to any participant and all responses will be confidential and anonymous on publication of the findings. Only the Principal Investigator will have access to the codes identifying individual participants and these will be destroyed following transcription.

I do however have to work within the confines of current legislation over such matters as privacy and confidentiality, data protection and human rights and so offers of confidentiality may sometimes be overridden by law. For example, in circumstances whereby I am concerned over any actual or potential harm to yourself or others I must pass this information to the relevant authorities.

Who is funding and organising the research?

I am funding the research independently and I am the Principal Investigator with ongoing supervision from a team of supervisors based at Keele University, where I am undertaking the PhD.

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to me and I will do my best to answer your questions. You should contact Jayne Murphy on J.S.Murphy@keele.ac.uk Alternatively, if you do not wish to contact the researcher(s) you may contact Professor Sue Read s.c.read@keele.ac.uk (Director of Studies).

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 write to the Research Governance Officer at the following address:-

Research Governance Officer
Directorate of Engagement and Partnerships
IC2 Building
Keele University
ST5 5NH
E-mail: research.governance@keele.ac.uk
Tel: 01782 733306

Contact for further information

Jayne Murphy, Post Graduate Researcher. Keele University Staffordshire, UK. ST5 5BG.
J.S.Murphy@keele.ac.uk

* hard data will be shredded and digital data deleted within 5 years of the end

V5 20/06/2018

Appendix 17 - Ethical approval

Keele
UNIVERSITY

08/08/2018

Dear Jayne

PI: Jayne Murphy

Title: Best Interests Decisions for People with Advanced Dementia: An Exploratory Study of Nurses' Perspectives

Ref: ERP2395

Thank you for submitting your application for review. The proposal was reviewed by the Panel Chair. I am pleased to inform you that your application has been approved by the Ethics Review Panel.

General	The Panel thank the Applicant for a very well-structured and comprehensive application and agree it is a light-touch project.
Suggestion (not required for Ethical Approval)	The Panel suggest that the Applicant disseminates the promotional flyer to potential Participants, via an administrator.
ACTION	The Panel confirms immediate ethical approval.

If the fieldwork goes beyond the date stated in your application, or there are any amendments to your study you must submit an 'application to amend study' form to the ERP administrator at research.governance@keele.ac.uk. This form is available via https://www.keele.ac.uk/raise/researchsupport/projectassurance/researchethics/

If you have any queries please do not hesitate to contact me, in writing, via the ERP administrator, at research.governance@keele.ac.uk stating **ERP2395** in the subject line of the e-mail.

Yours sincerely
pp

R. Cunningham.

Dr Colin Rigby
Chair – Ethical Review Panel

Appendix 18 – Consent form

Jayne Murphy
Post Graduate Researcher
Keele University
Staffordshire
UK
ST5 5BG
J.S.Murphy@keele.ac.uk

CONSENT FORM

Study Title: Best Interests Decisions for People with Advanced Dementia: An Exploratory Study of Nurses' Perspectives.

Name and contact details of Principal Investigator: Jayne Murphy, Post Graduate Researcher. Keele University Staffordshire, UK. ST5 5BG. J.S.Murphy@keele.ac.uk

Please initial box if you agree with the statement

1. I confirm that I have read and understood the information sheet dated ……………………………….. (version no …….) for the above study and have had the opportunity to ask questions ☐
2. I understand that my participation is voluntary and that I am free to withdraw prior to transcription of the data (within 1 month of the interview) ☐
3. I agree to take part in this study. ☐

Name of participant	Date	Signature
Name of researcher	Date	Signature

CONSENT FORM
(for use of quotes)

Study Title: Best Interests Decisions for People with Advanced Dementia: An Exploratory Study of Nurses' Perspectives.

Name and contact details of Principal Investigator: Jayne Murphy, Post Graduate Researcher. Keele University Staffordshire, UK. ST5 5BG. J.S.Murphy@keele.ac.uk

Please initial box if you agree with the statement

1. I agree that anonymised quotations from my interview may be included in the thesis and any publications resulting from the research ☐

2. I do not agree to anonymised quotations from my interview being used in the thesis or any publications resulting from the research ☐

Name of participant Date Signature

Name of researcher Date Signature

V5 20/06/2018

Appendix 19 – Best interests mapping

BEST INTERESTS PRINCIPLES MAPPING PARTICIPANT 1

No:	Principle	R1 – Vignette 1	Vignette 2
1	Encourage the individual's participation	Although it says she is lacking capacity, she could still be able to communicate and she might still have some opinion as well, so we really would like to ask and talk to her and get to know a bit more information about Kashi's (*understanding)*. **Q2a** I wanted to know more about Kashi's, how she is in herself, erm is she able to communicate, erm I'd want to know more…. **Q6a**	So the, we need to be, if he, if I was looking after him, we'd need to be aware of that and see if there is a way he could communicate. Because although he can't verbally communicate it doesn't mean he hasn't got capacity. **Q6b**
2	Consult all those close to the individual	You fill out the best interests assessment and have an MDT meeting with the consultant, everybody gathered; physios, OT, family as well and look at it as a whole. …take in to account the grandson and the daughter's concerns and also what Kashi said previously… **Q3a** Know more about the, what the consultant, what everybody like in the MDT meeting, what all their opinions would be.. **Q6a** Obviously keep on talking to them and discussing it. **Q6c**	…you know, he still, erm can communicate with her. So, she just wants him, you know, it's an illness, just to get him with the antibiotics and get him back home. **Q2b** It says they are a very supportive family. I think they'd take into consideration what the doctors are saying but I think ultimately they'd want to know why they aren't treating the pneumonia, unless it's not treatable in that sense. **Q2c**
3	Consider the individual's views, whether expressed verbally or in writing, including their feelings, religious beliefs and past habits	Her daughter says she's happy, what do they mean by that? **Q2a** …there's nothing written down… **Q2b** she's got to have said it for some reason, it's not something you discuss randomly..	Whether the wife's got LPA or if there's anything written if he's got a written decision to say that he doesn't want further care. He might not want IV antibiotics he might have something that says that... If he's got a DNAR in place. **Q3a**

		When she had capacity if she could make that statement, so I'd say it's still something that she was always knew would happen… **Q2d** …take in to account the grandson and the daughter's concerns and also what Kashi said previously… **Q3a**	
4	Consider all circumstances, including emotional bonds and family obligations	…obviously the daughter and the grandson are completely on different… and really conflicting… **Q1** He's gonna want to respect her wishes …. he's gonna feel is if he's let her down if she has the surgery… **Q2b** *(daughter)* doesn't wanna lose her mom. So she desperately wants to like prolong her life. …She just wants to get rid of the problem of the ischaemic foot. Maybe not looking at the whole picture as such. **Q2c** …the grandson – he could have an (laughs) ulterior motive for the finance… **Q4a** …one is seeing that they are doing the best for their, for Kashi and the other one's seeing that they're doing the best so obviously they could be at each other as well, arguing. And ultimately, Kashi might not be getting the best interests out of it. **Q4c**	…you know, he still, erm can communicate with her. So, she just wants him, you know, it's an illness, just to get him with the antibiotics and get him back home. **Q2b** It says they are a very supportive family. I think they'd take into consideration what the doctors are saying but I think ultimately they'd want to know why they aren't treating the pneumonia, unless it's not treatable in that sense. **Q2c** And you know, the wife, it does say that she goes every day or how often she goes. So, maybe just a little bit more on that side. And if he was to go down the palliative route, you know just to support the wife and what things would be in place for them really. **Q7**
5	Avoid making assumptions	…although it says she is lacking capacity, she could still be able to communicate and she might still have some opinion as well… …she might be kicking a screaming, not wanting to be in the hospital, so she could be in distress… **Q2a**	He could have capacity he might just not be able to verbally speak what he wants. So that could be challenging because obviously he could want some, you know he might want the treatment or he might not want the treatment, but… he can't communicate verbally. So the, we need to be, if he, if I

		…it's hard because they *(wishes)* could've changed… **Q2b** I think it would now I've realised their ages that would influence the decisions that they're making. I know it sounds awful but I think they might try and fight for Alan at 63 more than what they could do with Kashi at 83. Erm but that's also gonna have a big impact on the risks of her surgically cos of her age, so I think, I think it would affect it clinically when you are looking at the risks but I didn't really take it in to consideration. **Q10**	was looking after him, we'd need to be aware of that and see if there is a way he could communicate. Because although he can't verbally communicate it doesn't mean he hasn't got capacity. **Q6b**
6	Consider whether capacity will be regained in the future and whether the decision could be delayed until then	although it says she is lacking capacity, she could still be able to communicate and she might still have some opinion as well, erm, so we really would like to ask and talk to her and get a bit to know a bit more information about Kashi's *(understanding)* **Q2a**	…see if there is a way he could communicate. Because although he can't verbally communicate it doesn't mean he hasn't got capacity.
7	Consider the potential decision the individual might have made if they still had capacity	…it's hard because they *(wishes)* could've changed… **Q2b** she's got to have said it for some reason, it's not something you discuss randomly.. When she had capacity if she could make that statement, so I'd say it's still something that she was always knew would happen… **Q2d** I'd want to check their DNAR status as well. Just to see if they had got anything in place. I mean she might have put that in beforehand. And I think that could affect her, you know with the knee amputation. I think if she doesn't want to be resuscitated and she's gonna have a high-risk surgery and she's could potentially die on the table,	He might not want IV antibiotics he might have something that says that... **Q3a** …he might want the treatment or he might not want the treatment, but… he can't communicate verbally… **Q6b**

		as such, would she want that? Would she want that medical intervention as such or would she be happy, you know to face the complications of not having the amputation. **Q10**	
8	Consider whether the least restrictive option has been taken in making the decision	…is it gonna heal and improve her quality of life or… I'd want to know all the risks, surgery and post-surgery really **Q3b** …is that gonna make her, you know, feel worse in that sense…. **Q3c** it did say that there's risks both sides of her not having it and having it…. so I think it depends which way they would swing. I think if there's more… no quality of life from it I don't think they would do the amputation. I think if she would get a quality of life, and you know going back home, her mobility, all that taken in, I think they would amputate. **Q8**	if he could have IV antibiotics if they would improve, if they would help, clear the pneumonia…….If the pneumonia, obviously if they are saying there is nothing they can do, it would be looking at like, if they are saying he is palliative, then to start looking at the palliative care route for him. **Q3b**
9	If the decision is about life sustaining treatment, ascertain that no-one involved in the decision-making process has a desire to end the life of the individual and that no assumptions have been made about their quality of life	Does she understand that she's got the wound, er is it gonna heal and improve her quality of life or is it just gonna, is she gonna get an infection and, you know that could shorten her life. So I'd want to know all the risks, surgery and post-surgery really. **Q3b** He could be, I know it sounds horrible but he could want, want her to die, in that sense… that's why he wants her to not have the operation cos it's gonna shorten, it could shorten her life… **Q4a** I'd want to check their DNAR status as well. Just to see if they had got anything in place. I mean she might have put that in beforehand. And I think that could affect	If they are saying there is nothing they can do, it would be looking at like, if they are saying he is palliative, then to start looking at the palliative care route for him. **Q3b** I think more than likely he'd to have the IV antibiotics to treat the pneumonia or at least erm to see if it made any difference to him and I think that would be the main decision and to go from there really. **Q8**

		her, you know with the knee amputation. I think if she doesn't want to be resuscitated and she's gonna have a high-risk surgery and she's could potentially die on the table, as such, would she want that? Would she want that medical intervention as such or would she be happy, you know to face the complications of not having the amputation. **Q10**	

This participant did not identify that Kashi's case might require referral to the Court of Protection
This participant did consider legal aspects such as LPA and (possibly) deputyship
This participant focused on safety with Kashi and how she would continue to function with her ADLs following surgery
This participant did not identify that antibiotic therapy may not be effective in Alan's end stage dementia although they did consider palliative care options.
Rated MCA knowledge as 5/10
Rated BI knowledge as 5/10

Appendix 20 - MCA principles mapping (completed example)

PARTICIPANT/ VIGNETTE	**Participant 2 – Vignette 1**	**Vignette 2**
Presumption of capacity	Suggests that whilst the patient lacks capacity at the time she might have it in other areas. Also says would want to check capacity. Mentions this several times.	Asks whether the patient has capacity.
Consider whether patient can be assisted to make decision	Asks whether patient has had full information to make the decision..	Thinks about the communication challenge and if a pen and paper will work.
Assessment of capacity in terms of impairment/disturbance and 4 tests	Talks about how the patient might interpret the information presented to them and communicate their decision.	See above – thinks about support available to communicate their needs.
Consider past wishes (and evaluate evidence)	Says patient has always expressed the wish not to have the amputation.	Discusses the potential of expressing wishes with an advance decision – made any plans?
Consider present wishes (evaluate evidence, involve patient, ask questions)	Considers if patient might be influenced by place of care if making the decision today. E.g. would they want to remain at home?	No. focuses on physical issues and how to address them.
Consider underlying beliefs and values	Considers what their motivation was for wanting the spouse resuscitated	No.
Consider other factors the patient would be likely to consider if able	Wonders if the patient would consider the risks with surgery.	Thinks patient would want treatment but no rationale as to why.
Consider and evaluate views of relatives etc. (consider whether named by patient, even if no POA, whether 'caring for' or 'interested in his welfare')	Considers views of both relatives mentioned in vignette and their motivation for their perspective.	Considers views of both relatives mentioned in vignette and their motivation for their perspective.
Understanding that BI decision lies with clinician not family.	Thinks the medical team will decide to go ahead with surgery.	Discusses the aims of treatment from the clinical team and thinks they will decide to treat.
Understand distinction between past wishes and ADRT	Recognises no advance decision at this time.	Talks about Advance Decision or LPA in place.
General comments		

Appendix 21 - MCA principles and BIS achieved by participants

Best Interests Mandate:																														
Past wishes and values (30)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	**21**	**22**	**23**	**24**	**25**	**26**	**27**	**28**	**29**	**30**
Least restrictive (16)	**1**	**2**	**3**	**4**	5	**6**	7	8	**9**	10	11	**12**	13	**14**	**15**	**16**	**17**	**18**	**19**	20	21	22	23	**24**	25	26	27	**28**	29	**30**
No assumptions (or assumptions) (8)	1	2	3	**4**	**5**	6	7	8	**9**	10	**11**	12	**13**	14	**15**	16	17	18	19	20	21	**22**	23	24	25	**26**	27	28	29	30
All circumstances including family obligations (24)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	16	17	**18**	**19**	**20**	**21**	22	23	24	**25**	**26**	**27**	**28**	**29**	30
Regain capacity (1)	1	2	3	4	5	6	7	8	9	10	**11**	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
Participation (13)	1	**2**	3	**4**	5	**6**	7	**8**	9	**10**	11	**12**	13	**14**	15	16	17	**18**	**19**	**20**	**21**	22	23	24	25	**26**	27	**28**	29	30
Life sustaining (1)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	**16**	17	18	19	20	21	22	23	24	25	26	27	28	29	30
Make decision now (5)	1	2	3	4	5	6	7	**8**	**9**	10	**11**	**12**	13	14	15	16	17	18	19	**20**	21	22	23	24	25	26	27	28	29	30
Others’ views (20)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	12	13	14	15	16	**17**	**18**	**19**	**20**	**21**	**22**	23	24	**25**	26	**27**	**28**	29	30
4 Arms of decision-making (14)	**1**	**2**	3	**4**	**5**	**6**	7	8	9	**10**	11	12	**13**	**14**	15	**16**	**17**	**18**	19	20	**21**	**22**	23	24	25	26	27	28	**29**	30
MCA Principles (BI and Least restrictive as above)																														
Presume capacity (13)	**1**	**2**	3	**4**	**5**	**6**	7	8	**9**	**10**	**11**	12	13	14	15	16	17	18	**19**	20	**21**	22	**23**	24	25	26	27	**28**	**29**	30
Support (11)	**1**	**2**	3	**4**	**5**	6	7	8	**9**	10	11	**12**	**13**	14	15	16	**17**	18	19	**20**	**21**	22	23	24	25	26	27	**28**	29	30
Unwise (2)	1	**2**	3	4	**5**	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
Total for each participant	7	9	4	9	8	7	3	5	8	6	7	6	5	5	4	4	5	6	6	6	7	4	2	2	3	4	3	7	4	2
Participant	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30

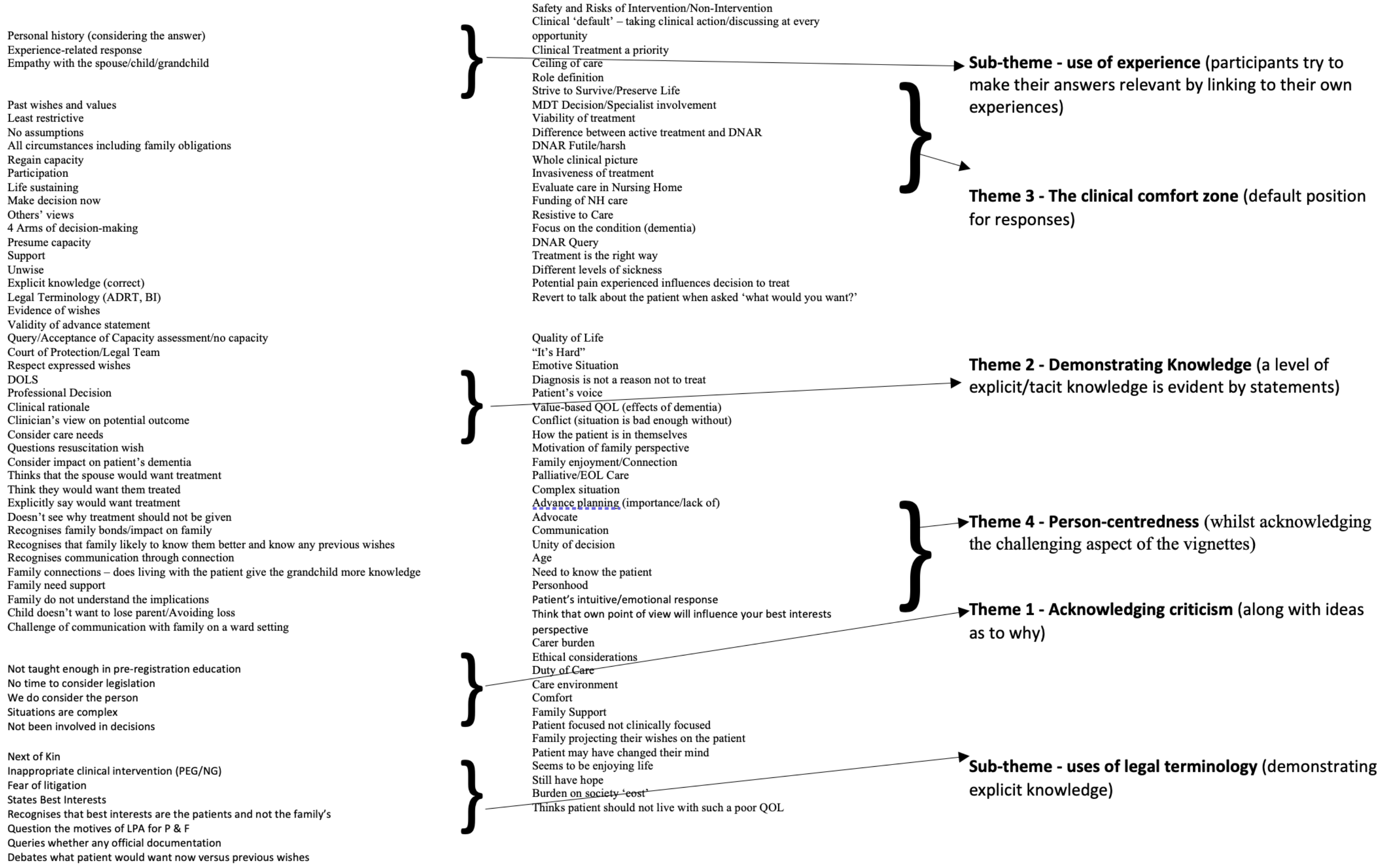
HIGHEST = 9/13 (2 got 9 out of 13)
8/13 (2 got 8 out of 13)
7/13 (5 got 7 out of 13)
6/13 (5 got 6 out of 13)
5/13 (4 got 5 out of 13)
4/13 (6 got 4 out of 13)
3/13 (3 got 3 out of 13)
LOWEST = 2/13 (3 got 2 out of 13)

No one got zero

Appendix 22 – Example of overall coding

"It's Hard"	P1, P2, P3, P5, P6, P12, P14, P16, P21, P23, P24, P25, P28, P29, P30
Safety and Risks of Intervention/Non-Intervention	P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P11, P12, P13, P14, P15, P16, P17, P18, P19, P20, P21, P22, P23, P24, P25, P26, P27, P28, P29, P30 – ALL PARTICIPANTS
Quality of Life	P1, P2, P3, P4, P5, P6, P7, P8, P10, P11, P12, P13, P14, P15, P16, P17, P18, P19, P21, P23, P24, P25, P26, P27, P28, P29, P30 (P9, P20, P22, Missing)
Best Interests Mandate:	
Past wishes and values	P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P11, P12, P13, P14, P15, P16, P17, P18, P19, P20, P21, P22, P23, P24, P25, P26, P27, P28, P29, P30 – ALL PARTICIPANTS
Least restrictive	P1, P2, P3, P4, P6, P9, P12, P14, P15, P16, P17, P18, P19, P24, P19, P28, P30
No assumptions (or assumptions)	P4, P5, P9, P11, P13, P15, P22, P26,
All circumstances including family obligations	P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P11, P12, P13, P14, P15, P18, P19, P20, P21, P25, P26, P27, P28, P29 (P16, P17, P22, P23, P24, P30 Missing)
Regain capacity	P11
Participation	P2, P4, P6, P8, P10, P12, P14, P18, P19, P20, P21, P26, P28
Life sustaining	P16
Make decision now	P8, P9, P11, P12, P20
Others' views	P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P11, P17, P18, P19, P20, P21, P22, P25, P27, P28
4 Arms of decision-making	P1, P2, P4, P5, P6, P10, P13, P14, P16, P17, P18, P21, P22, P29
MCA Principles (BI and Least restrictive as above)	
Presume capacity	P1, P2, P4, P5, P6, P9, P10, P11, P19, P21, P23, P28, P29
Support	P1, P2, P4, P5, P9, P12, P13, P17, P20, P21, P28
Unwise	P2, P5
Emotive Situation	P3, P7, P10, P29, P30
Clinical Treatment a priority	P1, P3, P4, P7, P8, P9, P11, P12, P13, P15, P16, P18, P19, P20, P21, P22, P27
EXPLICIT KNOWLEDGE (CORRECT)	P1, P2, P4, P5, P6, P7, P8, P10, P15, P16, P17, P19, P25, P26
EXPLICIT KNOWLEDGE (INCORRECT)	P3, P4, P5, P7, P10, P19, P20, P21, P20, P22, P24, P26, P30
Legal Terminology ADRT, BI	P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P11, P12, P13, P14, P15, P16, P17, P19, P20, P21, P22, P23, P24, P25, P26, P27, P28, P29, P30 (only P18 missing)
Evidence of wishes	P2, P3, P4, P5, P6, P7, P8, P9, P10, P11, P12, P13, P14, P15, P16, P18, P19, P21, P23, P24, P26, P28, P29 (P1, P17, P20, P22, P25, P27, P30 Missing)

Appendix 23 – Codes and Themes



Personal history (considering the answer)
Experience-related response
Empathy with the spouse/child/grandchild

Past wishes and values
Least restrictive
No assumptions
All circumstances including family obligations
Regain capacity
Participation
Life sustaining
Make decision now
Others' views
4 Arms of decision-making
Presume capacity
Support
Unwise
Explicit knowledge (correct)
Legal Terminology (ADRT, BI)
Evidence of wishes
Validity of advance statement
Query/Acceptance of Capacity assessment/no capacity
Court of Protection/Legal Team
Respect expressed wishes
DOLS
Professional Decision
Clinical rationale
Clinician's view on potential outcome
Consider care needs
Questions resuscitation wish
Consider impact on patient's dementia
Thinks that the spouse would want treatment
Think they would want them treated
Explicitly say would want treatment
Doesn't see why treatment should not be given
Recognises family bonds/impact on family
Recognises that family likely to know them better and know any previous wishes
Recognises communication through connection
Family connections – does living with the patient give the grandchild more knowledge
Family need support
Family do not understand the implications
Child doesn't want to lose parent/Avoiding loss
Challenge of communication with family on a ward setting

Not taught enough in pre-registration education
No time to consider legislation
We do consider the person
Situations are complex
Not been involved in decisions

Next of Kin
Inappropriate clinical intervention (PEG/NG)
Fear of litigation
States Best Interests
Recognises that best interests are the patients and not the family's
Question the motives of LPA for P & F
Queries whether any official documentation
Debates what patient would want now versus previous wishes

Safety and Risks of Intervention/Non-Intervention
Clinical 'default' – taking clinical action/discussing at every opportunity
Clinical Treatment a priority
Ceiling of care
Role definition
Strive to Survive/Preserve Life
MDT Decision/Specialist involvement
Viability of treatment
Difference between active treatment and DNAR
DNAR Futile/harsh
Whole clinical picture
Invasiveness of treatment
Evaluate care in Nursing Home
Funding of NH care
Resistive to Care
Focus on the condition (dementia)
DNAR Query
Treatment is the right way
Different levels of sickness
Potential pain experienced influences decision to treat
Revert to talk about the patient when asked 'what would you want?'

Quality of Life
"It's Hard"
Emotive Situation
Diagnosis is not a reason not to treat
Patient's voice
Value-based QOL (effects of dementia)
Conflict (situation is bad enough without)
How the patient is in themselves
Motivation of family perspective
Family enjoyment/Connection
Palliative/EOL Care
Complex situation
Advance planning (importance/lack of)
Advocate
Communication
Unity of decision
Age
Need to know the patient
Personhood
Patient's intuitive/emotional response
Think that own point of view will influence your best interests perspective
Carer burden
Ethical considerations
Duty of Care
Care environment
Comfort
Family Support
Patient focused not clinically focused
Family projecting their wishes on the patient
Patient may have changed their mind
Seems to be enjoying life
Still have hope
Burden on society 'cost'
Thinks patient should not live with such a poor QOL

Sub-theme - use of experience (participants try to make their answers relevant by linking to their own experiences)

Theme 3 - The clinical comfort zone (default position for responses)

Theme 2 - Demonstrating Knowledge (a level of explicit/tacit knowledge is evident by statements)

Theme 4 - Person-centredness (whilst acknowledging the challenging aspect of the vignettes)

Theme 1 - Acknowledging criticism (along with ideas as to why)

Sub-theme - uses of legal terminology (demonstrating explicit knowledge)