

National University of Ireland Galway

Doctoral Thesis

An Exploration of Personhood in
Dementia in Formal Care in
Ireland

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Declaration

This is to certify that this thesis is all my own work and I have not obtained a degree in this University or elsewhere on the basis of this work.

Signed:

Date:

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Abstract

Personhood in dementia centres on recognising and treating the person with dementia as a person first and foremost. Supporting personhood is a key goal of person-centred care models and a key principle in Irish dementia policy and formal care regulation. However, there is ambiguity around the concept in policy and practice. In particular, there is difficulty in moving from conceptual understandings of personhood to practical manifestations of it. In Ireland, there is little evidence to show that personhood is being supported in practice. This thesis seeks to reduce the ambiguity around this concept by examining how personhood in dementia is conceptualised, expressed, facilitated and actualised in formal care in Ireland. It aims to explore the core elements of personhood and provide guidance to policy and practice in how it can structure formal care provision and formal care relationships around personhood.

The thesis involves three studies. The first analyses personhood in Irish policy-making through a content analysis of the Irish National Dementia Strategy and public submissions made in its development. The second study examines personhood within dementia care settings through a systematic review and qualitative evidence synthesis on the perspectives of people with dementia. The third explores personhood within dementia care relationships, using a multiple perspective research design on the perspectives and experiences of personhood of, people with dementia, family carers and formal carers.

There are five key findings: reducing ambiguity around personhood, supporting core elements of the self, nurturing important relationships, managing change and managing care arrangements. Policy and practice need to focus on reducing ambiguity around personhood in dementia through additional training and education for formal carers. It also must ensure that formal care provision supports the core elements of the self and empowers people with dementia to maintain important relationships. In practice, this means designing care around the person with dementia, their interests and preferences, relationships and the social self. Formal care should also serve to mitigate the impact of change on people with dementia, particularly the impact of care settings, by adhering to ageing in place where possible and practicable, as well as ensuring that care settings do not deny or undermine personhood. However, in Ireland, supporting personhood requires a paradigm shift, from a supplier led, system-centred model to a person-centred biopsychosocial model of care which focuses on the person with dementia. Ultimately, supporting personhood should not be a goal to aspire to, rather it should be the foundation on which formal care provision is built.

Chapter 1: Introduction

1.1 Research background

1.1.1 Dementia

As the population ages, the number of people with dementia will increase significantly. By 2030, there will be approximately 75 million people with dementia worldwide and 103,279 in Ireland (Cahill et al., 2014; Prince et al., 2015). The World Health Organization (WHO) (2012) acknowledge this potential growth and argue for the prioritisation of dementia as a public health concern. This increase brings additional urgency to researching, designing and delivering care and supports for people with dementia which improve their well-being and quality of life. The WHO define dementia as:

“An umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour, and that interfere significantly with a person’s ability to maintain activities of daily living” (WHO, 2017, p. 2).

The most common form of dementia is Alzheimer’s disease, estimated to be between 60-70% of cases. Other forms include vascular dementia, dementia with Lewy bodies and frontotemporal dementia (WHO, 2017). While the chances of developing dementia are strongly correlated with age, it is not solely related to ageing, with some people developing young onset dementia, where symptoms develop before the age of 65 (Cahill, O’Shea, & Pierce, 2012). There are several other risk factors to developing dementia including smoking and alcohol consumption (WHO, 2017).

Dementia and its related symptoms accounts for a substantial degree of disability in older age populations, and there is no denying the significant impact dementia has on the lives of the person with dementia, their families and communities (WHO, 2017). People with dementia experience many issues such as difficulty getting a diagnosis, lack of awareness, stigma around dementia, the denial of rights, autonomy and decision making choices (WHO, 2017). There is also significant cost associated with dementia, to the person with dementia, their families, communities and countries. Globally, the cost of dementia was estimated to be 1

trillion US dollars in 2018; this figure is expected to double by 2030 (Prince et al., 2015). If dementia care were a country it would be the 18th largest economy in the world (Prince et al., 2015).

Dementia is often viewed through a particularly nihilistic lens, seen as a living death and an illness dreaded by many. These beliefs are partially fuelled by how dementia and people with dementia are socially constructed. Historically, people with dementia have been conceptualised as lacking personhood, where the cognitive impairment attributed to dementia was viewed as leading to the loss of the self and personhood (Small et al., 1998; Surr, 2006). This belief is grounded in metaphysical definitions of personhood and the biomedical model of dementia which links the self and personhood to autobiographical memory. Not surprisingly, under this approach, people with dementia have been viewed as non-persons and their perspectives have not been taken into account when designing or providing care. More recently, care has started to focus on and place value on the lived experience of the person with dementia, in particular, through the development of the concept of personhood (Kitwood, 1989, 1997) and the application of person-centred care (Brooker, 2004). At times, though, the idea of person-centred supports is more of an aspiration than a reality, as there is ongoing ambiguity around how to support personhood and implement person-centred care in practice (Brooker, 2004; Colomer & de Vries, 2016).

1.1.2 Dementia models

The traditional model of dementia care is the biomedical model. There is significant discussion in the literature about the negative impact of the biomedical model on the person with dementia and consequently many different alternatives to the biomedical model have been proposed (Bond, 2001; Downs, Clare, & Mackenzie, 2006; Sabat, 2008; Millett, 2011; Innes & Manthorpe, 2013). This section outlines the biomedical model and three main alternatives: the biopsychosocial model, the social model and the citizenship and human rights model (O'Shea et al., 2017; Cahill, 2018).

1.1.2.1 The biomedical model

The biomedical model of dementia care has been the predominant model of dementia care for most of the twentieth century and continues to exert a strong

influence on how dementia is conceptualised and how dementia care is designed and administered (Bond, 2001; Downs et al., 2006). The biomedical model treats dementia as a syndrome or neuropsychiatric condition and seeks to diagnose dementia, provide treatments (mostly pharmacological) and find a cure (O'Shea et al., 2017). It positions the person with dementia as a patient and a passive victim of a brain disease (Downs et al., 2006). It has worked hard to develop methods to diagnose dementia, and target dementia with pharmacological treatments (O'Shea & Carney, 2016). It explains dementia in biological terms ignoring psychological and social elements and defining all behaviour as a medical problem, essentially pathologizing all aspects of the person with dementia's behaviour (Bond, 2001). At times, it is managed by deficit based policies with an over reliance on drugs, restraints and institutions (O'Shea et al., 2017), meaning that the labelling of dementia can be seen as disabling as the condition itself (Downs et al., 2006). Additionally, due to the philosophical correlation between the brain and metaphysical ideals of personhood, in the biomedical model, personhood is viewed as lost.

Bond (2001, p. 56) views "the expectation of the profound loss of self" as the key problem of the biomedical model of dementia care. This conceptualisation of the person with dementia as lost has strong implications for the type and quality of care that the person with dementia receives, as Hughes points out: "the conceptual view we have of the person will affect the care we are prone to give to people with severe dementia" (2001, p. 86). This denial of personhood led to what Kitwood (1997) termed malignant social psychology, positing that this had a detrimental effect on the person with dementia, eroding their sense of self and self-esteem. Due to these shortcomings, by the late 1980s, authors started to question the legitimacy of the biomedical model. Albert and Mildworf (1989) proposed to view dementia as both a disease and an illness emphasising that not only are the clinical manifestations of the disease important, so too are the social and cultural ramifications of the illness. However, the biomedical model continues to be the predominant model of dementia, as not enough has changed to shift the narrative away from the medicalisation of dementia (Sabat, 2019).

1.1.2.2 The biopsychosocial model

In recent times, the biomedical view that dementia leads to the loss of the self was challenged (Caddell & Clare, 2010) and alternate models with a more holistic approach to dementia are now proposed. In the biopsychosocial model the self is not lost but concealed (Edvardsson, Winblad, & Sandman, 2008), and the person with dementia is no longer a passive recipient of care. The biopsychosocial model of dementia evolved from Tom Kitwood's (1989, 1997) work, which posits that other factors, outside solely biology, impact on the experience of the person with dementia. These factors include biological, psychological, social, economic, cultural and environmental elements (O'Shea et al., 2017). Along with biomedical supports, the biopsychosocial model incorporates the use of psychological, social and other types of supports for people with dementia (O'Shea et al., 2017), similar to person-centred models which move away from solely focusing on the biomedical symptoms to focusing on broader psycho-social factors (Wilberforce et al., 2016).

In the biomedical model certain behaviours are interpreted as symptoms of dementia, while in a biopsychosocial model such behaviours are interpreted as communication from the person with dementia about an unmet need (Edvardsson et al., 2008). The biopsychosocial model is person-centred placing the person with dementia at its core, moving the focus away from task driven models of care to those that are holistic and based on values (O'Shea et al., 2017). This includes the development of non-pharmacological services and supports such as psychosocial interventions (O'Shea et al., 2017). However, as dementia continues to be largely dominated by the biomedical model, a key issue facing policy-makers is recalibrating the locus of care in dementia from a medical-based model toward more holistic models of health production.

1.1.2.3 The social model

The social model of dementia applies sociological perspectives to dementia (Bond, 2001). This includes adapting the social model of disability (Oliver, 1990) to dementia, where the focus is on the lived experience of people with dementia and their families and how they are supported or disempowered by the society around them (Oliver (1990) as cited in Bond (2001)). The reframing of dementia as a disability is central to the social model (Cahill, 2018; Shakespeare, Zeilig, & Mittler,

2019). The social model moves away from focusing on the individual with dementia as the 'problem' and instead examines how the physical and social environment can be redesigned to support the person with dementia (O'Shea et al., 2017). There has been an increased realisation that redefining dementia within a social model has the ability to improve the lives of people with dementia (O'Shea & Carney, 2016), through adapting the environment to support the person with dementia to live independently (O'Shea et al., 2017). In practice, the social model is visible in recent efforts to create dementia friendly communities and in awareness campaigns to change societal attitudes towards dementia both in Ireland with the Understand Together Campaign (National Dementia Office, 2019) and internationally as one of the WHO key action areas (WHO, 2017).

1.1.2.4 Citizenship and human rights model

Cahill (2018) argues that dementia is a human rights issue, given that people with dementia are likely to experience injustice, inequality and marginalisation. Redefining dementia as a disability places it directly into a human rights model, where activists in dementia can learn from other groups who have gone before them (Cahill, 2018; Shakespeare et al., 2019). Initially, rights for people with dementia focused on their right to know about the diagnosis and their right to consent (Downs, 1997). Over the past decade, discussions on human rights and dementia have evolved (Kelly & Innes, 2013). A rights based approach will ensure that respect for autonomy and dignity are created as a right and become part of the care culture (Kelly & Innes, 2013).

An emerging area of discussion in dementia is the concept of citizenship (Baldwin et al., 2007), which is inherently associated with a human rights approach. It is argued that a model of citizenship is required for people with dementia to allow their activities to take on political meaning (Bartlett & O'Connor, 2007) and to challenge discrimination and stigma (Gilmour & Brannelly, 2010). Other disciplines such as critical psychiatry and disability studies have used a citizenship lens to examine such issues, support discriminated groups and promote their standing as an equal citizen (Bartlett & O'Connor, 2007). Over the last decade, the increased activism of people with dementia nationally and internationally, epitomises a move towards a citizenship and human rights model. However, as Bartlett and O'Connor

(2007) predicted, the inclusion of people with advanced dementia as an active citizen is problematic. Irish law making has supported human rights through ratifying the UN Convention of the Rights of Persons with Disabilities in 2018 (National Disability Authority, 2019) and creating new legislation in relation to supporting co-decision making ("Assisted Decision Making (Capacity) Act," 2015) for people with dementia and other persons with disabilities.

1.1.3 *Dementia care in Ireland*

There are an estimated 55,000 people with dementia in Ireland of which 36,000 are believed to be living in the community (Pierse, O'Shea, & Carney, 2019). However, many of the people with dementia living in the community are undiagnosed and not in contact with health and social care services (O'Shea, Cahill, & Pierce, 2016). Approximately, 19,000 people with dementia are believed to be living in long-term care. Here, again there is a under diagnosis of dementia and cognitive impairment in such settings (Cahill et al., 2010; Pierse et al., 2019). Family carers provide the bulk of care for people with dementia in Ireland. Current estimates suggest that there are approximately 60,000 family carers of people with dementia in the country (O'Shea et al., 2017), accounting for 48 per cent of the overall cost of dementia (Connolly et al., 2014). It is likely that some family carers are providing 24 hour care to a person with dementia which can cause considerable emotional, physical and psychological strain (O'Shea, 2007). Currently, the estimated annual cost of dementia in Ireland is €1.9 billion (O'Shea et al., 2017).

Historically, dementia care in Ireland has been underfunded and under prioritised (Cahill, 2010), where people with dementia have remained largely invisible (O'Shea et al., 2017). Government spending is biased towards residential care placement, even though the rhetoric of public policy is to support home care and community-based care in the first instance. Spending on services in the community mainly focuses on home help provision and day care services (Keogh, Pierse, & O'Shea, *in press*), while spending on psychosocial services such as Alzheimer Cafés, support groups and social clubs are limited (Keogh et al., *in press*). There are also generic health services and supports available to people with dementia living at home, such as GP, public health nurse and day care services. The current long-term care model in Ireland is a legacy of a institutionalisation (Timonen & Doyle, 2008).

While supporting dementia is referenced in Irish policy, implementation of specific dementia related policies has been poor, until very recently. Dementia was first explicitly mentioned in Irish policy in The Years Ahead Report in 1988 (Robins, 1988). The first dementia specific policy, An Action Plan for Dementia, was published in 1999, (O'Shea & O'Reilly, 1999) but despite promises from government (Department of Health and Children, 2001) and additional calls for its implementation (O'Shea, 2007), little was done to implement it. In more recent years, dementia care and dementia research in Ireland has benefited substantially from investment from Atlantic Philanthropies, a philanthropic organisation. The organisation invested in many areas in dementia in Ireland, such as service transformation, advocacy and awareness, brain health, education and training, measurement, research and evaluation (Carney & O'Shea, 2018). This included support for developing the first National Dementia Strategy (Carney & O'Shea, 2018), published in 2014 (Department of Health, 2014). There are two overarching principles of the Strategy, personhood and citizenship (Department of Health, 2014), emphasising the importance of both concepts to dementia policy and practice in Ireland. However, while the policy rhetoric focuses on personhood and person-centred care, in practice the predominant dementia care model in Ireland continues to be the biomedical model, which results in a provider focused, supply-side led model, which is deficits based, not person-centred (O'Shea et al., 2016).

1.2 The research problem

The focus of this thesis is on personhood in dementia and its practical application in formal care provision in Ireland. The work examines the concept of personhood, its global interpretation by people with dementia in relation to formal care provision and its application within formal care settings and circumstances in Ireland. Personhood is a complex and ambiguous concept, possibly due to its metaphysical foundations and its conflation with other related concepts. Personhood is something which philosophers and thinkers have grappled with for millennia, meaning that it has multiple possible interpretations in philosophy, law, ethics, religion and sociology (Sofronas, Wright, & Carnevale, 2018). Historically, people with dementia were believed to have lost personhood. The cognitive impairment associated with dementia was viewed as leading to the loss of the self and personhood (Small et al., 1998; Surr, 2006). These beliefs evolved from Cartesian definitions of personhood in western philosophy which define

personhood as requiring cognition, along with its legacies of individuality, rationality and informed choice (Dewing, 2008).

As a concept, personhood has both metaphysical and moral roots (Higgs & Gilleard, 2016). Metaphysical definitions of personhood have been described above and refer to attributes of a person in terms of self-consciousness, rationality, and agency (Blackburn, 2005). Moral personhood is concerned with the equal value of all persons (Kant as cited in McCormack (2004). However, both metaphysical and some moral foundations risk excluding people with dementia as non-persons, if they do not possess certain cognitive competencies.

Personhood in dementia is strongly rooted in relational and moral underpinnings (Sofronas et al., 2018), and supporting personhood is now considered to be a key element of quality of life in long-term care (Milte et al., 2016). Personhood in dementia can be traced to Kitwood's (1997) seminal work which redefined personhood as relational, as a 'status' which the carer could choose to bestow on the person with dementia. It did not engage with metaphysical definitions of the person, but instead challenged "the biomedical, capacity-based view of the loss of personhood" (Baldwin et al., 2007, p. 176). Kitwood redefined personhood as something which carers could support or diminish depending on how they treated the person with dementia, placing it in the domain of roles, relationships and social interaction (Tolhurst, Bhattacharyya, & Kingston, 2014). Related work by Sabat and Harré (1992) on the perceived loss of self in people with dementia, suggests that some elements are not lost, but the result of how others view and treat the person with dementia, echoing Kitwood's (1997) relational dimension. The self and sense of self are at times, treated as synonymous to personhood and at other times, viewed as separate concepts (Higgs & Gilleard, 2016). As will be discussed in more detail in Chapter 2, in this thesis the terms personhood, self, selfhood and sense of self are used synonymously.

The ambiguity around personhood is not helped by its conflation with other related concepts, frequently conceptualised as both elements of personhood and mechanisms in which to support personhood. Concepts such as autonomy, dignity, respect and agency are often cited in tandem with personhood. Tranvåg, Petersen, and Nåden (2013) highlight the strong connection between personhood and autonomy, finding that: "a genuine respect for the person as a unique human being,

with an inherent desire or right to make choices according to her or his subjective needs” is fundamental in advocating autonomy and integrity (2013, p. 870). The difficulty is that support for autonomy is easier to imagine in situations where individuals are robust and independent, which is not always the case in dementia, particularly for people with advanced dementia. For this reason, Pullman (1999) argues that dignity is a more useful concept in addressing and promoting personhood. Promoting dignity is an important goal of dementia care with the social environment playing a key role in this regard (van Gennip et al., 2016). While, supporting identity is viewed as part and parcel of promoting dignity (Heggestad, Nortvedt, & Slettebo, 2015).

The concept of respect is prolifically cited in relation to providing care and support to people with dementia. Kitwood’s definition of personhood explicitly states that it implies respect (Kitwood, 1997), and that people with dementia are worthy of respect (Kitwood & Bredin, 1992), with empirical research finding that it is a component part of supporting personhood (Hung & Chaudhury, 2011; Palmer, 2013; Smebye & Kirkevold, 2013). Finally, agency is also frequently referred to in relation to dementia care. Often people with dementia are believed to lack agency (Boyle, 2014) and concepts of agency are closely tied to metaphysical definitions of the self, autonomy and capacity (Hedman et al., 2016).

Kitwood’s (1997) theory merges many of these concepts together, seeing dementia care as oppressive if is not based on the mutual values of trust, respect and communication within caring relationships. Additionally, denying the personhood of the person with dementia is thought to have many negative consequences such as disempowerment, infantilization, ignoring, labelling and stigma, and can lead to a diminution of autonomy, agency and capacity among people with dementia (Kitwood, 1997).

Personhood has a close theoretical link to person-centred care. Person-centred care focuses on the person with dementia and not merely the disease (Brooker, 2007) and supporting personhood is its key goal (Brooker, 2007; Fazio et al., 2018). Supporting personhood by providing person-centred care has become a key policy objective in Ireland, as reflected in both the Irish National Dementia Strategy (Department of Health, 2014) and in national standards for residential care settings (Health Information and Equality Authority, 2016). Similarly, other countries, most

notably the United Kingdom, Australia and the United States of America, have targeted person-centred care as an important goal in dementia policy. However, recent evidence from Ireland demonstrates that person-centred care in some settings is more of an aspiration than a reality; moreover an appreciation of personhood and its core elements is not part of the narrative of care at either formal or informal levels (Meagher & Conroy, 2015; Colomer & de Vries, 2016). This ambiguity around both personhood and person-centred care is equally reflected in practice outside of Ireland (Brooker, 2004; Edvardsson et al., 2008).

While there is significant theoretical discussion on personhood in dementia (as outlined in Chapter 2), there is limited empirical research into personhood and, existing explorations are critiqued for lacking clear theoretical foundations (Caddell & Clare, 2010, 2012). Understanding the perspective of the person with dementia is vital to supporting personhood and providing person-centred care (Brooker, 2007). However, there is a limited body of knowledge into the experience of personhood in dementia from such a perspective (Nowell, Thornton, & Simpson, 2013), and particularly a dearth of knowledge on the perspectives of people with advanced dementia (Downs, 1997; Hellström et al., 2007). There has been little examination of what family carers and formal carers think about personhood in dementia and how it should impact on care delivery. One study focused on exploring the link between beliefs about personhood amongst formal carers and dementia care practices (Hunter et al., 2013), including the consequences when formal carers do not believe personhood exists for people with dementia. However, the ongoing and underlying uncertainty around personhood continues to affect how research into it is conducted and subsequently translated into practice (Hung & Chaudhury, 2011). This thesis seeks to address the ambiguity around personhood in formal care and provide clarity and consensus on this concept, supporting policy to design and implement personhood-supporting practices within formal care provision in Ireland.

1.3 Research purpose and research question

The purpose of this thesis is to examine personhood in dementia within formal care provision and relationships in Ireland, with a view to providing evidence that can be used in planning, designing and implementing services and supports that foster

and enhance personhood for people with dementia. To fulfil this purpose, the thesis examines the concept of personhood within the context of formal care through three different lenses: formal care policy, formal care settings and formal care relationships. Each lens provides different insights and perspectives into personhood in dementia and at both the macro and micro level of formal care provision. For the purposes of this thesis formal care refers to care, services and supports provided to people with dementia by paid professional carers.

The central research question which this thesis seeks to address is:

How is personhood in dementia conceptualised, expressed, facilitated and actualised in formal care in Ireland?

This will be carried out in three phases with three key research objectives.

Research objective one: To examine how personhood in dementia is currently conceptualised in dementia policy in Ireland.

Research objective two: To explore, through qualitative evidence synthesis, how personhood is expressed, realised and practiced by people with dementia in formal care settings.

Research objective three: To identify the core elements, defining natures and fundamental meanings of personhood in dementia as experienced and practiced by people with dementia, their family carers and formal carers in Ireland in different settings.

Research objective one involves examining personhood from the perspective of policy and policy makers in Ireland. It seeks to partially address the central research question by providing insight into how personhood is conceptualised and expressed by policy and what this means for formal care provision, at the system level, in Ireland. Research objective two entails reviewing the existing international qualitative evidence on the experiences and perceptions of personhood of people with dementia in formal care settings, in order to gain insight into how people with dementia conceptualise personhood and the lived experience of personhood in formal care. Research objective two is the only objective which explores personhood on an international basis and not solely from an Irish context. The rationale for doing this is that there is little qualitative evidence on this concept nationally, from the perspectives of people with dementia, and so an international

perspective provides greater insight and knowledge. Research objective two also supports the other two research objectives by providing a base of knowledge on personhood in dementia. Research objective three centres on exploring personhood in formal care relationships by examining the perspectives of all three parties in the care triad, the person with dementia, the family carer and the formal carer. This is not a micro level examination of personhood-supporting relationships as already done by Smebye and Kirkevold (2013), but an examination of how personhood is conceptualised by the parties involved in the formal care relationship and how it can be enhanced or diminished within that relationship. By gathering first-hand accounts, research objective three produces new knowledge providing an in-depth insight into the lived experience of personhood in dementia, from multiple perspectives, in Ireland. Combined the three research objectives seek to fully address the central research question.

1.4 Research approach and methodology

The research approach involves four key stages: understanding the concept of personhood in dementia, examining personhood in dementia policy in Ireland, examining personhood in formal care settings from the perspectives of people with dementia and finally, understanding the concept in formal care relationships in Ireland. The methodology includes desk based and qualitative research. The first phase includes a literature review of personhood in dementia. This feeds into the second phase involving two studies, conducted in parallel, the policy analysis and the qualitative evidence synthesis. The third phase, the empirical study, involves qualitative interviews with people with dementia, family carers and formal carers. Figure 1.1 illustrates the research approach.

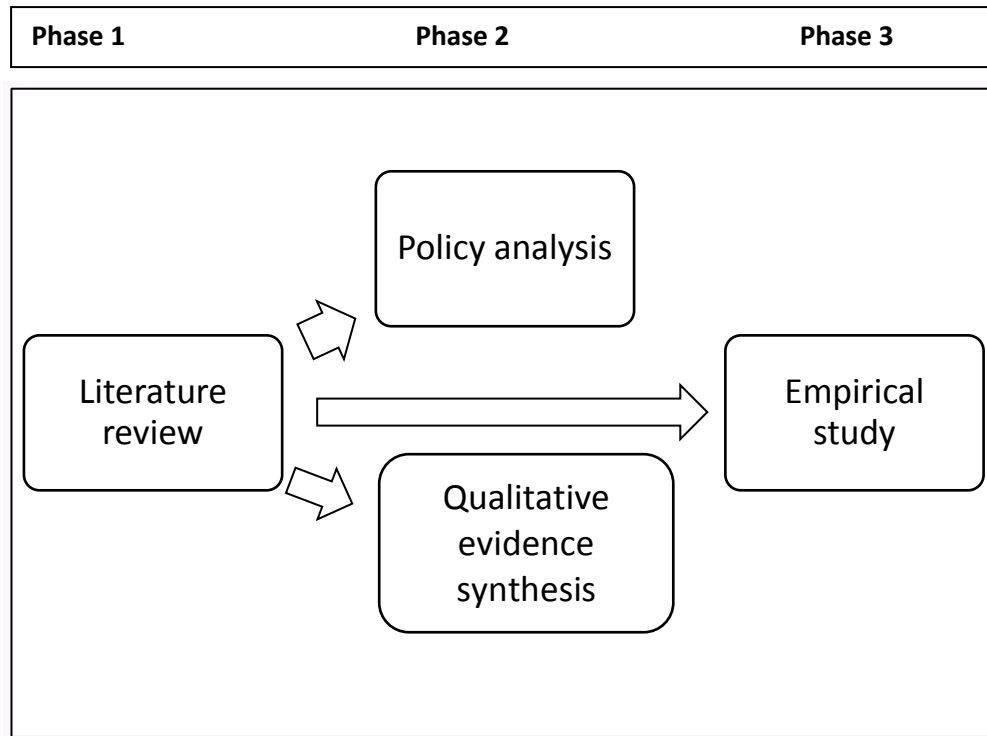


Figure 1.1: Research approach

Table 1.1 outlines the research objectives, including the gaps in the research each study aims to address and the methods to be used to address these gaps. The first phase of the literature review is not included in Table 1.1 as it is not a research objective, but a necessary step prior to carrying out the rest of the research to ensure an in-depth understanding of the concept. Phase Two and Phase Three objectives are included in Table 1.1. Phase Two includes the first and second objectives, which involve the policy analysis and the qualitative evidence synthesis. The policy analysis entails a content analysis of the Irish National Dementia Strategy and 72 written submissions that were provided by interested stakeholders in the development of the Strategy. The analysis explores the degree to which personhood is referenced and how it is conceptualised in these documents. The qualitative evidence synthesis examines the perceptions and experiences of people with dementia of personhood in formal care settings internationally. This is carried out using systematic review methods and thematic synthesis. Phase Three is the empirical study entailing semi-structured interviews with people with dementia, family carers and formal carers, exploring their experiences and perceptions of personhood within formal care in Ireland. These interviews are constructed and analysed using multiple perspective interpretative phenomenological analysis. This thesis uses multiple methods based from different methodologies and

epistemologies. In particular, the evidence synthesis in chapter 4, synthesises data from qualitative studies which are in themselves interpretations of the authors' interpretations of participants' experiences, where there is a danger of building layers of interpretation. This is in contrast to the double hermeneutics used in chapters 5 and 6 for the IPA study. Overall, there is incongruity between using both methods in one study, and an added tension when applying quantitative based methods such as synthesis and GRADE CERQual analysis to qualitative data. However, these concerns are balanced with the practicalities of the project and the limited body of knowledge in this area. For example, a narrative summary of the systematic review findings was considered, however, an evidence synthesis was chosen as it adds to the field of knowledge in this area, particularly when there is limited research into this phenomenon.

Table 1.1: Research objectives

Research gaps	Research objectives	Method	Analysis	Chapter
Lack of research into how personhood is conceptualised and actualised in policy.	Research objective one: To examine how personhood in dementia is currently conceptualised in dementia policy in Ireland.	Policy analysis	Content analysis	Chapter 3
No existing synthesis of qualitative research into the perspectives of people with dementia on personhood in formal care settings.	Research objective two: To explore, through qualitative evidence synthesis, how personhood is expressed, realised and practiced by people with dementia in formal care settings.	Systematic review	Systematic review and qualitative evidence synthesis	Chapter 4
Limited research into how all three parties in the dementia care triad conceptualise personhood in formal care in Ireland.	Research objective three: To identify the core elements, defining natures and fundamental meanings of personhood in dementia as experienced and practiced by people with dementia, their family carers and formal carers in Ireland in different settings.	Qualitative semi-structured interviews	Multiple perspective interpretative phenomenological analysis	Chapter 5 and Chapter 6

1.5 Structure of thesis

Chapter 1 provides an introduction to dementia, dementia care models and dementia in Ireland. It provides details of the research problem and specifies the purpose of the thesis.

Chapter 2 provides a theoretical, conceptual and empirical background to personhood in dementia, its origins, critiques of personhood, and how personhood is related to and supported by person-centred care. This chapter provides a broad overview of the personhood literature, with the aim of setting the scene and context for the remaining chapters.

Chapter 3 examines how personhood is conceptualised and actualised in dementia care policy in Ireland through a content analysis of the Irish National Dementia Strategy and of documents submitted by stakeholders in the development of the Strategy. This chapter addresses research objective one.

Chapter 4 systematically reviews the international qualitative evidence on personhood in formal care settings from the perspectives of people with dementia. This involves a systematic literature search, screened independently by two authors. The final included papers are synthesised using thematic synthesis and confidence in the review findings is assessed using GRADE CERQual. This chapter addresses research objective two.

Chapter 5 details the methods involved in conducting qualitative semi-structured interviews with people with dementia, family carers and formal carers. This includes research methodology, research design, research procedures, ethical considerations, data analysis methods and quality indicators. This chapter addresses research objective three.

Chapter 6 describes the findings of the qualitative interviews by outlining the perspectives and experiences of people with dementia, family carers and formal carers on personhood. It includes how personhood is conceptualised, how it is supported and barriers to supporting it in formal care provision, across and within the three groups. This chapter addresses research objective three.

Chapter 7 discusses the overall findings of the thesis. Five key findings are discussed and overall implications of this work for policy and practice in dementia care. This

chapter also discusses theoretical and methodological contributions of the thesis and areas of future research.

Chapter 8 provides some brief summary conclusions.

1.6 Research contributions

This thesis seeks to contribute to existing knowledge and research into personhood in dementia in the context of formal care provision. The findings of the research will provide an understanding of the defining elements of personhood from the perspectives of people with dementia, family carers and formal carers. The thesis has already resulted in several outputs including peer-reviewed publications and conference presentations. In addition, the research has been disseminated through presentations and talks at events outside of academic conferences. Future plans include disseminating the findings of the thesis to research participants through dementia friendly materials, writing a policy brief on the findings and writing additional academic papers.

Peer-reviewed journal publications

Hennelly, N., Cooney, A., Houghton, C., & O'Shea, E. (2019). Personhood and dementia care: a qualitative evidence synthesis of the perspectives of people with dementia. *The Gerontologist*, doi: [10.1093/geront/gnz159](https://doi.org/10.1093/geront/gnz159)

Hennelly, N., & O'Shea, E. (2019). Personhood, dementia policy and the Irish National Dementia Strategy. *Dementia*, 18(5), 1810-1825.

Hennelly, N., Cooney, A., Houghton, C., & O'Shea, E. (2018). The experiences and perceptions of personhood for people living with dementia: A qualitative evidence synthesis protocol. *HRB Open Res*, 1:18.

Book chapter

O'Shea, E. Cahill, S., Pierce, M., Hennelly, N. and Carney, P. (2017) Introduction. In: O'Shea, Cahill and Pierce (eds.) *Developing and Implementing Dementia Policy in Ireland*. Galway, Ireland.

Peer-reviewed conference presentations

Hennelly, N., Cooney, A., Houghton, C., & O'Shea, E. (2020) A systematic review and qualitative evidence synthesis of the experiences and perceptions of personhood for people with dementia. The Conf 2020, Trinity College Dublin, Ireland.

Hennelly, N., Cooney, A., Houghton, C., & O'Shea, E. (2019) The experiences and perceptions of personhood for people with dementia in formal care: A qualitative evidence synthesis. 29th Alzheimer Europe Conference, The Hague, Netherlands.

Hennelly, N. & O'Shea, E. (2019) Understanding personhood in formal care: the perspectives and experiences of people with dementia, family carers and health care professionals. 29th Alzheimer Europe Conference, The Hague, Netherlands.

Hennelly, N. & O'Shea, E. (2018) Exploring personhood in formal care provision in Ireland: Perspectives from people with dementia. 28th Alzheimer Europe Conference, Barcelona, Spain.

Hennelly, N. & O'Shea, E. (2018) Exploring personhood in formal care provision in Ireland: Perspectives from family carers of people with dementia. 66th Annual and Scientific Meeting, Irish Gerontological Society, Cavan, Ireland.

Hennelly, N. & O'Shea, E. (2017) Personhood, dementia policy and the Irish National Dementia Strategy. ILAS Research Day, Galway, Ireland

Hennelly, N. & O'Shea, E. (2017) From personhood to policy in dementia, lessons from Ireland. 27th Alzheimer Europe Conference, Berlin, Germany.

Hennelly, N. & O'Shea, E. (2016) Personhood and public policy for dementia in Ireland. 64th Annual and Scientific Meeting, Irish Gerontological Society, Killarney, Ireland.

Hennelly, N. & O'Shea, E. (2016) Exploring personhood in dementia through care relationships. 8th Annual Dementia Conference, Dublin, Ireland.

Invited speaker and other presentations

Hennelly, N., Cooney, A., Houghton, C. & O'Shea, E. (2019) The experiences and perceptions of personhood for people with dementia: A qualitative evidence synthesis. North Sea Dementia Group Annual Meeting, Stuttgart, Germany.

Hennelly, N. (2018) Focusing on the person with dementia. HeadSpace Conference, Global Brain Health Initiative, Trinity College Dublin, Ireland.

Hennelly, N. (2018) Personhood, dementia policy and the Irish National Dementia Strategy. Plymouth International Dementia Conference, Plymouth, United Kingdom.

O'Shea, E. & Hennelly, N. (2018) Personhood, Policy and Practice in Dementia Care. Let's Talk About Dementia, Castlebar, Ireland.

Hennelly, N. (2018) Personhood in Dementia: Developing a Person-Centred Research Process. HRB Research Leaders Network Meeting, Dublin, Ireland.

Hennelly, N. (2017) Personhood in Dementia. Health Service Executive Study Day, CESRD, Galway, Ireland.

Hennelly, N. (2017) Personhood and Irish Dementia Policy. Colloquium, Centre for Research on Personhood in Dementia, UBC Vancouver, Canada.

Hennelly, N. (2016) Personhood, Dementia Care and Public Policy. Threesis Final NUI Galway, An Taibhdhearc Theatre, Galway, Ireland.

Hennelly, N. (2016) Exploring Personhood in Dementia and its Importance for Care Relationships, Service Delivery and Regulatory Instruments. Irish Gerontological Society Postgraduate Day, Dublin, Ireland.

Research trips

10.04.19-12.04.19

North Sea Dementia Group Annual Meeting, Stuttgart, Germany.

22.10.18-26.10.18

The Flanders Centre for Expertise on Dementia, Antwerp, Belgium.

17.04.17-12.05.17

Centre for Research on Personhood in Dementia, University of British Columbia, Vancouver, Canada.

Chapter 2: Literature review of the theory and practice of personhood in dementia

2.1 Introduction

This chapter explores the concept of personhood in dementia. It aims to provide insight into and analysis of the existing philosophical, theoretical and conceptual underpinnings of personhood in dementia. Personhood is an ambiguous and complex term meaning that reviews of the concept encompass a broad range of views. The chapter commences by examining personhood in philosophy before delving into its interpretation in dementia. This chapter merges the many different theories and conceptualisations of personhood in dementia into one comprehensive narrative. While the varied conceptualisations of personhood do not always fit neatly together, in this chapter, an attempt has been made to group similar concepts and ideas together. The theoretical discussion on personhood in dementia is followed by critiques of personhood in dementia and an examination of how personhood is supported in practice through for example person-centred care. The chapter concludes by outlining the conceptualisation of personhood used in this thesis.

2.2 Personhood in philosophy

Personhood is an epistemological and ontologically complex concept. Explorations and discussions on personhood have existed for millennia, meaning that it has multiple conceptualisations including philosophical, spiritual, legal, ethical and social (Sofronas et al., 2018). To provide context to the discussion of personhood in dementia, what follows is a short synopsis of personhood in philosophy. This is by no means comprehensive as it is not feasible to examine such discussions in detail here. Fleischer (1999) provides a useful categorisation of personhood theories, dividing them into either physicalism or personalism. Physicalism is what some philosophers argue our everyday definition of the person is, synonymous to 'human

being' and bodily identity (Sapontzis, 1981; Shoemaker & Swinburne, 1984). Personalism, on the other hand, outlines a set of criteria or attributes to define personhood (Brock, 1988; Fleischer, 1999). Both moral and metaphysical definitions of personhood are personalist in orientation.

2.2.1 *Metaphysical personhood*

The Oxford Dictionary of Philosophy describes the concept of a person as "one of the central problems of metaphysics" (Blackburn, 2005, p. 273). It defines the criteria of personhood as, amongst others, self-consciousness, rationality, agency and moral worth. Dennett (1988, p. 176) categorises personhood in philosophy into either a 'moral notion' or a 'metaphysical notion'. The work of Descartes, Locke, Hume and Parfit define personhood as a metaphysical concept (Beauchamp, 1999). These philosophers use different terms for the mind, consciousness, self, identity and soul, at times using them synonymously. One of Descartes' enduring legacies is dualism, the theory that the mind and body were separate to each other and that the mind could exist without the body. His most famous conclusion is that all he can be certain of is that he thinks: "At last I have discovered it – thought: this alone is inseparable from me" (Descartes & Cottingham, 2013, p. 18). This is Descartes *cogito* (Russell, 1946). An unanswered conundrum of Descartes work is the mind-body paradox. It is concerned with interpreting how the immaterial mind interacts with the material body (Popkin & Stroll, 1993).

Locke continues with this conceptualisation of the person as a thinking being, and in turn examines what personal identity is. Locke defined a person as: "a thinking intelligent Being, that has reason and reflection, and can consider itself as itself, the same thinking thing in different times and places" (Locke, 1987, p. 115). Locke was equally concerned with consciousness and how it is experienced through time. He defines self as the sameness of consciousness (Locke, 1987). Hume moves away from other philosophers' views of the self, particularly that we are constantly engaged with the self. Hume considers how he perceives himself and believes that the majority of mankind: "are nothing but a bundle or collection of different perceptions, which succeed each other with an inconceivable rapidity, and are in a perpetual flux and movement" (Hume, 1739, p. 134).

In more recent times, philosophers have continued to examine personhood and identity. Parfit (1984) uses science fiction in his exploration of personal identity, giving the example of someone being teletransported to Mars, where an exact copy of their body is created, while the body on earth is destroyed. Parfit (1984) suggests that those who believe in physicalism, as an explanation of personhood, would not agree that the replica from the teletransportation was the same person. Parfit (1984), however, does not agree with physicalism, instead he builds on the Lockean view of memory to develop a theory of personal identity. Descartes, Locke, Hume and Parfit all focus on a criteria based definition of personhood, one which relies on concepts such as intelligence, memory and rationality, essentially defining personhood along cognitive lines (Beauchamp, 1999).

2.2.2 *Moral personhood*

Strawson (1959) defines moral personhood as being “concerned with assigning rights, duties, obligations, and respect” (Strawson (1959) as cited in (Sapontzis, 1981, p. 607). Kant viewed personhood as a status, which was an important precursor to the notion of personhood as a right (Kant (1895) as cited in Higgs and Gilleard (2016). Kant’s view of personhood is that people should be seen as an ends to themselves, and not as a means to another end, a principle on which many legal, moral and ethical frameworks are based in western society (Kant as cited in (McCormack, 2004). McCormack describes the person on moral grounds, that it is ‘moral personality’ that defines our personhood and ‘humanity’ that separates us from other organisms (2004, p. 33). There is confusion as to whether people with dementia are included in definitions of moral personhood. Some authors view definitions of moral personhood as still reliant on reason, and by extension rationality, autonomy and cognition (Kittay, 2005; Post, 2013).

“From the Stoics and without interruption into Kant, Locke, and modern bioethics we find the rude assertion that the major criterion for moral membership is reason, and this tends to include only the intelligent in the protected community”
(Post, 2013, p. 345).

Kittay (2005) finds the exclusion of people who do not possess such cognitive qualities as morally repugnant comparing this to the historical exclusion of other groups, such as women and ethnic minorities, from definitions of personhood.

However, Adams (1996) posits that personhood in dementia is based in moral personhood, and proposes that Kitwood's (1997) work challenges the moral vacuum that permeates the biomedical model of dementia.

Whether it be metaphysical or moral personhood, some authors have concluded that, thinking about our own personhood, may ask too much of us cognitively. Taylor (1989) points to how it asks us to examine the self from outside of the self, which in essence is impossible, while Dennett (1988) discusses how we are yet to determine a satisfactory set of attributes and conditions of personhood, theorising that this may never happen. Beauchamp (1999) is equally at a loss, at the vagueness of the concept and the blurred lines between metaphysical and moral definitions. Additionally, definitions of personhood in western society give little weight to other potential measures of personhood such as emotional expression or spirituality (Dewing, 2008). However, there is no denying that philosophical definitions of personhood influence how people are conceptualised, and the legacy of metaphysical personhood, in particular, has had difficult and sometimes limiting ramifications for people with dementia and their families.

2.3 Literature review methods

In order to better understand personhood in dementia, a review of the literature was conducted. This literature review provides a comprehensive overview in order to answer a broad research question, in this case: "What is personhood in dementia?" A systematic search was conducted where searches were performed in seven databases Scopus, Web of Science, Ageline, Cinahl, ASSIA, Sociological Abstracts and PsycINFO. All available years were searched. These databases were selected in consultation with an expert librarian at NUI Galway. The following search string was used:

personhood OR person*hood OR selfhood OR self*hood OR self-identity OR self*identity AND dementia OR Alzheimer* OR "Lewy Bod*" OR "vascular dementia" OR pick* OR Huntington* OR frontotemporal OR Parkinson* OR Creutzfeldt-Jakob

The search string was adapted to suit the requirements of each database. In addition, Google Scholar was used to backward and forward search citations of relevant material and hand searches of citations of included articles were

conducted. The search was carried out in November 2016 and rerun in July 2019. The citations were screened by one author (me). Inclusion criteria were applied post hoc as is also often common practice in scoping reviews (Arksey & O'Malley, 2005). The review includes any peer-reviewed articles referencing personhood in dementia. Due to the hand searching of included articles the final review also includes some books. The articles/books had to be in English. It was not the intention of this search to provide a systematic profile of all research in personhood in dementia but a broad overview of research in the field. The search resulted in 995 unique citations after duplicates were removed. 848 citations were excluded as not being relevant, leaving 147 articles included in this review. This literature review also informed the protocol for the systematic review and qualitative evidence synthesis outlined in Chapter 4.

2.4 Personhood in dementia

Tom Kitwood is widely cited as pivotal in the conceptualisation of personhood in dementia and was the first to use the term in relation to people with dementia (Brooker, 2007). In the late 1980s, Kitwood (1989) presented a new theoretical framework for understanding dementia. He argued that the biomedical model (at that time) which assumed a direct causal relationship between neuropathology and dementia was inadequate (Kitwood, 1989). Kitwood referenced post-mortem results which showed that the neuropathic change in the brain was not what was expected given the perceived cognitive impairment of the person and indeed that up to 80% of this variance was unexplained in moderate and severe dementia (1989). He discussed the relationship between mind and brain and the need to include psychological, not solely biological considerations into a model of dementia. His theory being that:

"because of a deterioration at the psychological (and concomitantly, brain-functional) level; the dementing person feels betrayed or abandoned, perhaps; and an iterative 'cycle of dementia', involving progressive changes in neurochemistry ensues" (Kitwood, 1989, p. 12).

He extends this work (1990), by positing a theory of dementia care where dementia is the result of both neurological impairment and malignant social psychology (SD = NI + MP). He argues that having a neurological impairment results in being treated

in a malignant way socially and puts forward a theory that malignant social psychology causes neurological impairment:

“Human beings are far more deeply affected by the social psychology that surrounds them than is commonly recognised. In particular, the maintenance of self-esteem is essential for good learning, efficacy and constructive relationships with others” (Kitwood, 1990, p. 181).

Kitwood (1997) proposed that there were two types of anxieties fuelling this malignant social psychology and the treatment of people with dementia as non-persons: the fear of losing one’s own cognition and the fear of one’s own mortality. Caring professionals could distance themselves emotionally from those they were caring for, resulting in the labelling of people with dementia as incoherent, incompetent, no longer able to function or participate in society and by extension something they could never relate to: “the highly defensive tactic is to turn those who have dementia into a different species, not persons in the full sense” (Kitwood, 1997, p. 14). Kitwood (1997) drew on the work of Martin Buber (1937) to theoretically reconstruct personhood. Buber’s philosophy was concerned with the relationship not the individual. His view was that society had wandered from one of true connection, where individuals relate to each other in an I-Thou modality, one in which there is a true meeting of people, to an I-It mode where there is no true connection. He defines personhood in dementia 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).

Sofronas et al. (2018) review all of the literature on personhood and nursing care (not specific to dementia care) finding that it can be broadly divided into four categories: personhood and nursing ethics (including establishing criteria for personhood), personhood as moral and relational, personhood as lost, and interventions to support personhood. As can be seen from their results, and more generally in this review, research in personhood in dementia has most strongly been concerned with personhood as moral and relational and interventions to support personhood. Buron (2008) defines personhood on three levels, biologic, individual and sociologic. Biologic refers to physicalist definitions of personhood, individual refer to relational personhood, the roles and relationships which make up a person, and societal to the social construction of personhood. O'Connor et al.

(2007) create a framework for research into personhood in dementia. They posit that research should focus on three key areas; the subjective experience of the person with dementia, the interactional environment of the person with dementia and the wider socio-cultural context. While Bryden (2018), reflecting on her own lived experience of dementia, proposes three aspects of the self: the embodied self, the relational self and the narrative self. Kontos (2005) is critical of the strong focus on cognitive aspects of personhood (e.g. the self) and interactionist concepts (e.g. relational personhood) and strongly argues for the need to include embodied selfhood in definitions of the self.

Figure 2.1 depicts how personhood in dementia will be discussed in this chapter. This is not proposed as a model but rather a method to categorise the existing theoretical models referenced above. Three main elements of personhood in dementia emerge from this diverse and contested literature: the self, relational personhood and embodied selfhood. While these elements are discussed individually below, there are commonalities and significant cross over between the concepts, particularly in relation to how they are socially constructed.

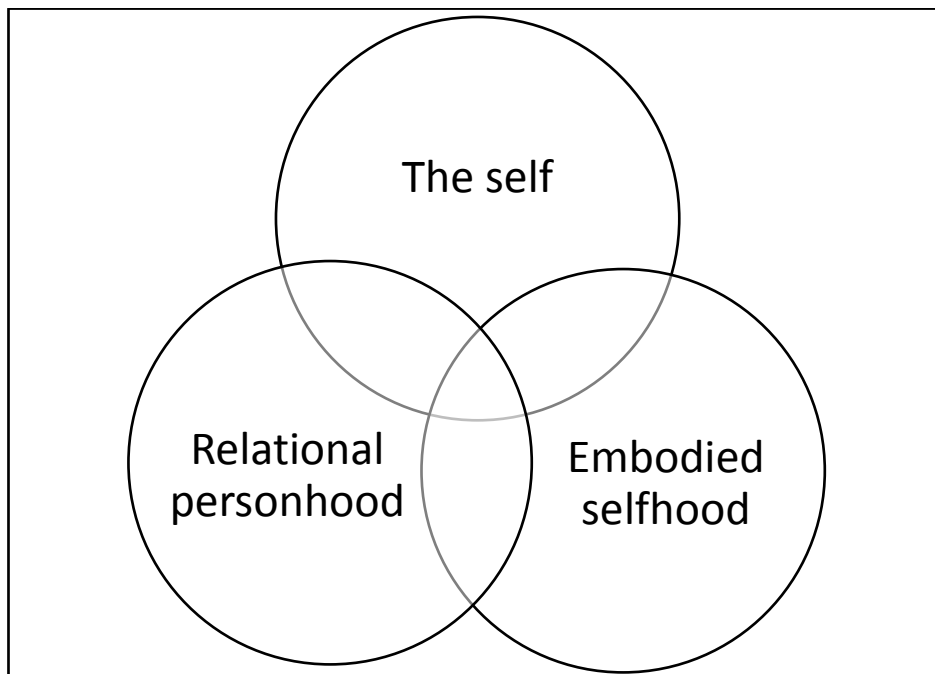


Figure 2.1: Elements of personhood

2.4.1 *The self*

Historically, philosophers such as Locke, Hume and Ricoeur have treated personhood and the self almost synonymously, although, more recently, philosophers have attempted to differentiate between the two concepts (Millett, 2011; Higgs & Gilleard, 2016). Meanwhile, in dementia research, personhood, self-identity, the self and selfhood are often written about or studied separately, but treated synonymously (Millett, 2011). For example, work by Sabat and Harré (1992) on the self and selfhood is frequently cited in tandem with Kitwood and Bredin's (1992) work on personhood. Indeed, Sabat and Harré (1992) celebrate the similarities between the two pieces of work. Other authors also define the terms as synonymous. Cohen-Mansfield, Golander, and Arnhem (2000) define self-identity, personhood and selfhood as the same, while Downs (1997) defines personhood synonymously with concepts of self-identity or self-esteem. For the purposes of this chapter, I discuss concepts of the self, relational personhood and embodied selfhood as separate elements of personhood. However within the thesis generally, they are treated as synonymous, especially when it comes to the policy analysis and the qualitative evidence synthesis of personhood within formal care.

Similar to the rhetoric on the loss of personhood, the original view of the self within dementia care has been the slow and eventual loss of the self (Small et al., 1998; Surr, 2006). This is based on the theoretical link between autobiographical memory and sense of self (Locke, 1987). The belief that sense of self is comprised or supported solely by autobiographical memory means that people with dementia are believed to slowly lose their sense of self. However, since the early 1990's, research in dementia has challenged this conceptualisation. There are several elements to how the self is conceptualised within dementia research. Authors draw on the theory of the social construction of identity as a theoretical base. The work of Sabat and Harré (1992) built on the theory that identity is constructed through linguistics (Wittgenstien (1953) and Vygotsky (1965) as cited in Sabat and Harré (1992), through discursive practices, for example telling stories about oneself or expressing a feeling (Coulter, 1981 and Harré (1983, 1991) as cited in Sabat and Harré (1992), and that people portray different selves or fulfil different roles depending on the social context and who they are interacting with (Goffman (1959, 1963) as cited in Sabat and Harré (1992). They framed their examination of the self

in dementia within this constructionist view, positing that there are two selves (extending this to three selves in later work (Sabat & Collins, 1999; Sabat, 2002)). Self 1 is that of personal identity, Self 2 is the physical and mental attributes of the person and Self 3 are the social personae developed by the person in co-operation with those around them (Sabat, 2002). In this section, Self 1 and Self 2 are discussed, while Self 3 is discussed in the next section under relational personhood.

Self 1 is about the: “singularity of our selfhood, in the personal identity sense, in the use of such discursive devices as the first person pronoun ‘I’, with which we each index our sayings (and indirectly our doings) as ours” (Sabat & Harré, 1992, p. 445). Essentially, the use of first person pronouns is an expression of personal identity and “one’s experience of psychological continuity from time to time” (Sabat & Collins, 1999, p. 16). The concept of Self 1 has been examined empirically showing the existence of Self 1 for people with dementia (Mills, 1997; Sabat & Collins, 1999; Tappen et al., 1999; Batra et al., 2016). However, Golander and Raz (1996) question the meaning behind the use of first person pronouns, arguing that using these first person pronouns does not automatically prove the existence of the self. Self 2 is concerned with one’s physical and mental attributes such as height, weight, sense of humour, educational achievements, beliefs and values etc. It is also concerned with the person’s views about their own attributes (Sabat, 2002). Essentially, Self 2 is about how we view ourselves and what attributes we assign to ourselves be it physical or mental. This can include for example, discussions on the narrative self and spirituality.

The narrative self

The narrative self refers to how we construct and narrate who we are. Baldwin (2008) posits that people find their ‘Selves’ in the stories that they tell about themselves and the stories others tell about them. Mills (1997) examined the narrative self in dementia finding that fragmented versions of people’s narratives were communicated by people with moderate to advanced dementia. Similar support for the narrative self in people with dementia is found in Hydén and Örluv (2009), Usita, Hyman, and Herman (1998) and Robertson (2014). However, Hyvarinen and Watanabe (2017) purport that the traditional view of the narrative self loses meaning in advanced stages of dementia as it becomes fragmented. Increasingly, people with dementia are publicly expressing their personhood and

narrative self through writing, in particular memoirs and autobiographies (Basting, 2003; Ryan, Bannister, & Anas, 2009), which show, for example, how reconstructing identity is an important part of living with dementia (Page & Keady, 2009).

Spirituality

There is some theoretical discussion in dementia about spiritual personhood but few empirical explorations. Spirituality is included here under the Self 2, as it is conceptualised as a value or belief of the person. Allen and Peter define personhood as: “our deepest essence, which is distinct from that of others, but through which we are called into relationship with man and God” (2006, p. 216). Bryden (2018) reflects on the relationship between spirituality and her sense of self as a person with dementia, believing that she is upheld by God. While, McCurdy views spirituality as the need for a relationship with whatever or whoever provides purpose and meaning to life, linking spirituality to self-transcendence and meaning-making (McCurdy, 1998; Little, 2002). Similar to metaphysical personhood, some religious conceptualisations of spirituality are defined along cognitive lines, emphasising rationality and memory and so risk excluding people with dementia (Keck as cited in (McCurdy, 1998; Allen & Peter, 2006). Initially, Kitwood’s (1970) development of a theory of personhood was founded in Christian and theological understandings, which was natural given his role as a Christian minister, and while later work moved away from this, concepts such as grace, transcendence and the divine appear briefly in some of his publications (Kitwood, 1997 as cited in (Baldwin et al., 2007). Indeed, Buber’s (1937) I-Thou relationship, which Kitwood bases his conceptualisation of personhood on, is spiritual by nature and refers to the state in which the divine is encountered (Kitwood, 1997 as cited in (Baldwin et al., 2007). A critique of Kitwood’s work is that by moving too far away from its original religious roots, his theory of personhood loses coherence (Baldwin et al., 2007). More recently, Kevern (2015) posits that spirituality is an essential element of personhood but finds little empirical research into spirituality and dementia and uses social theory and cognitive psychology to support the theory of the persistence of spirituality in late stage dementia. Understanding the spiritual beliefs of the person with dementia, their meaning making process, values and beliefs is important, particularly in how it forms part of their personhood, sense of self and well-being and has implications in particular for the role of pastoral care in long-term care settings (Post, 2000; McFadden, Ingram, & Baldauf, 2001; Bryden, 2018).

Evidence on the self

A systematic review by Caddell and Clare (2010) on the impact of dementia on self and identity reported that all but one study found evidence of the persistence of self in mild and moderate dementia, but also acknowledged some deterioration to aspects of the self. The one study which did not, Fontana and Smith (1989), found that the self was under a process of 'unbecoming' and that it was mainly social practices which supported the self to continue. Eustache et al. (2013) explored sense of identity in Alzheimer patients in moderate to severe dementia, finding that sense of identity was broadly preserved. Additionally, there is evidence that people with dementia attempt to maintain or re-construct a sense of self (Pearce, Clare, & Pistrang, 2002; Harman & Clare, 2006; Frazer, Oyebode, & Cleary, 2012; Pison-Young et al., 2012; Steeman et al., 2013; Borley, Sixsmith, & Church, 2016; Sakamoto, Moore, & Johnson, 2017), affirm their selves through talking about their life story or narrating self (Clare et al., 2008), while at the same time also experiencing changes to the self (Gillies & Johnston, 2004; Harris & Keady, 2004; Harris & Keady, 2009; MacRae, 2010; Caddell & Clare, 2011a; Borley et al., 2016), and threats to the self (Griffin, Oyebode, & Allen, 2016), in some cases, with a new self emerging due to a change in the care setting (Vittoria, 1998). People with dementia also expressed concerns for their future self (Kristiansen et al., 2017). Here we see a contradiction between being the same self but also experiencing changes to the self, with authors describing this as how people with dementia operate on a continuum of self-maintaining and self-adjusting strategies (Clare, 2003; Caddell & Clare, 2011a), with Harris and Keady (2009) calling for further research on the transient nature of the self in dementia. What is clear is that the self is a complex construct, involving how we identify with ourselves as a person and what we see as the attributes, both physical and mental, that define that self. Both Self 1 and Self 2 are, more often than not, conceptualised as independent of other people, but they are also influenced by relationships, as well as being, to some extent, socially constructed. They are not, however, as strongly influenced by society as Self 3 or relational personhood which is discussed in the next section.

2.4.2 Relational personhood

As already referenced, Kitwood's (1997) definition of personhood is relational, defining it as a 'status' which the carer could choose to bestow on the person with

dementia (Kitwood, 1997). Personhood in dementia was thus positioned as something that both formal and informal carers could support or diminish depending on how they treated and interacted with the person with dementia. There is substantial support for Kitwood's model in dementia care, in particular, in the fields of psychology, social work and the social sciences (Leibing, 2008). Many authors agree with how crucial relationships are to personhood and the self. This is epitomised in how Sabat and Harré's (1992) Self 3 is viewed as socially constructed, concerned with roles and relationships and that this perceived loss of self in dementia is just that and is: "directly related to nothing more than the ways in which others view and treat the A.D. sufferer" (1992, p. 444). Other authors agree, with McCormack et al. (2012, p. 286) defining personhood as "a sense of self-identity maintained by relationships" and Surr outlining the socio-biographical theory of self which: "contends that relationships with others, the broader social context in which individuals are situated and narrative and storytelling have a crucial role in the undermining or maintenance of self" (2006, p. 1720). Downs et al. (2006) discuss the idea of the dialectical process of dementia care which views the experience of dementia as a dialectical interplay between cognitive impairment and broader psychosocial and environmental factors including social context. Woods (1999) emphasises the importance of listening to the voice of the person with dementia and treating people with dementia as equals in the care relationship. Ultimately, a person with dementia has personhood when they are valued as such by those around them (Jenkins & Price, 1996), what Zeiler (2014) refers to as the dyadic conception of personhood. Relational personhood is an appealing alternative to traditional definitions of personhood which inform the biomedical model:

"We learn from dementia, equally, of the central importance of relating and relationship in any definition of selfhood. From the earliest stages of dementia, there is a challenge to self-reliance. Our inter-relatedness becomes rapidly more evident" (Brown, 2017, p. 1006).

Relational personhood emphasises the crucial role of those around the person with dementia in viewing the person with dementia as a person and supporting their personhood and social personae (Self 3). While it is difficult to define relational personhood and other related terms precisely, ultimately they are all concerned

with the “socially constituted personal experience of dementia” (Tolhurst et al., 2014, p. 194).

Evidence on relational personhood

While there was substantial support for Kitwood’s theory, initially, there was a lack of empirical evidence to back it up (Nowell et al., 2013). However, in recent years, further work has emerged which supports both Kitwood’s (1997) and Sabat and Harré’s (1992) theories (Kaufmann & Engel, 2016). Studies have explored and tested Sabat and Harré’s (1992) theory, finding existence of all three selves, including Self 3 (Sabat & Collins, 1999; Sabat, 2002; Hedman et al., 2013; Skaalvik, Fjelltun, et al., 2016). There is evidence to show that people with dementia identify as fulfilling many roles such as familial, occupational, hobbies/leisure activities and having their own core values (Cohen-Mansfield et al., 2000; Cohen-Mansfield, Parpura-Gill, & Golander, 2006; Harris & Keady, 2009). Having purpose through occupation, role and activity is important to maintaining a sense of self (Phinney, Chaudhury, & O’Connor D, 2007; Harris & Keady, 2009; Phinney, Dahlke, & Purves, 2013; Hellstrom, Eriksson, & Sandberg, 2015). Role identities are found to decline with the progression of dementia; the role most remembered by participants with dementia is the familial role, and the identity of being a parent, child or spouse (Cohen-Mansfield et al., 2000). It is clear that relationships are important to people with dementia (Johnson, 2016), yet they experience changes to such relationships, for example, a loss of role or diminishing role in familial relationships due to dementia (Gillies & Johnston, 2004; Harris & Keady, 2004), with people with early-stage dementia feeling that they are not valued (Steeman et al., 2013). In addition, people with dementia are concerned by changes to their social identity and others’ reaction to dementia (Pipon-Young et al., 2012). Several authors have explored the idea of a collective social identity in people with dementia (Beard & Fox, 2008; Robbins, 2019). Linking back to the narrative self in the previous section, Crichton and Koch (2007) find that the self-identity of one participant with dementia is curated by those around them, so as Baldwin (2008) states not only is the narrative self constructed by the stories the individual tells about themselves, it is also socially constructed in the stories others tell.

2.4.3 *Embodied selfhood*

Some authors argue that personhood in dementia is framed solely or excessively as relational, ignoring embodied or corporeal elements of selfhood (Kontos, 2005; Baldwin et al., 2007; Kontos & Martin, 2013). That it: “may have inadvertently resulted in the privileging of the social over the corporeal with its focus on interactionist conceptions of self” (Kontos & Martin, 2013, p. 289). Dewing (2008) agrees criticising Kitwood’s (1992, 1993a, 1993b) failure to fully develop the concept of embodied personhood. Critiques of Kitwood’s definition attempt to build on it by tweaking it to include embodied definitions, redefining personhood as “a moral entitlement” in an “embodied self” (Dewing, 2002, p. 162), or a situated embodied agent, one where personhood is ‘embedded’ in the person’s life history as well as in a bodily form (Hughes, 2001). Sabat and Collins’ (1999) Self 2 is concerned with both physical and mental attributes of the self and so by definition includes a notion of embodied self. Work by Phinney and Chesla (2003) on the lived body in dementia, further challenged the Cartesian duality of the medical model. Kontos (2003, 2004) continued this exploration conducting extensive theoretical and empirical work in embodied selfhood, using Merleau-Ponty’s (1962) re-conceptualisation of perception and Bourdieu’s (1977, 1990) exploration of the concept of habitus as its theoretical base. Kontos (2004, 2005) found that selfhood is not solely constituent of mind or socially constructed but that elements of selfhood are demonstrated in how the body behaves and moves. Research has also found links between embodied identity, appearance and dress (Twigg & Buse, 2013). Sandberg (2018) proposes that placing emphasis on the appearance and dress of people with dementia is a mechanism of maintaining gendered embodied selfhood.

Kontos and Martin (2013) believe that the exploration of embodied selfhood has enriched the research landscape on selfhood and memory in dementia, including exploring concepts such as relational embodiment and intercorporeality. Bryden (2018) posits that people with dementia retain a sense of embodied relational self, while similar ideas are proposed by Jenkins (2014) and Zeiler (2014). Jenkins (2014) posits the notion of the inter-embodied self, one where the self is not expected to be re-unified but instead is in a perpetual state of flux. Intercorporeality is where embodied selfhood is expressed jointly between people, and does not confine itself

to the one-body-one-person logic of other personhood models (Jenkins, 2014; Zeiler, 2014). It posits that joint activity allows the person with dementia to physically express themselves in ways they would not be able to alone; this does not mean that such abilities are lost, but rather that support from another party is required to engage such abilities (Zeiler, 2014).

There is significant ambiguity and complexity around the conceptualisation of personhood in dementia, but its key intent, a moral one, is clear. It seeks to ensure that people with dementia are viewed as equals and as people of value. There is agreement that supporting personhood is crucial to good dementia care, and that there is a strong interactional and relational aspect to personhood as it is often upheld, maintained or even constructed in partnership with others. The next section examines critiques on some aspects of personhood in dementia.

2.5 Critiques of personhood in dementia

Most of the critiques of personhood in dementia centre on Kitwood's (1997) conceptualisation of personhood. One criticism of his work has been dealt with above, namely embodied selfhood. This section will examine other critiques of personhood; that it is too individualised, that it lacks political power, that it does not deal with place, that it does not deal with broader socio-cultural influences and that it is philosophically weak.

Authors criticise personhood in dementia as being too individualistic. Baldwin et al. (2007) argue that more attention should be paid to the reciprocity of personhood in care relationships. Hellström, Nolan, and Lundh (2005) agree, referring to how the western focus on autonomy and independence is too individualised and that a spotlight needs to be shone on the reciprocal nature of relationships, and in particular to the reciprocal nature of the spousal relationship, labelling this 'couplehood'. At times this type of personhood is referred to as relational personhood (Chan & O'Connor, 2014), not to be mistaken with the categorisation above which is about the interactional nature of personhood. Genoe et al. (2010) find many examples of reciprocity in caregiving relationships and emphasise the need to support the relationship and interdependence rather than focusing solely on the person with dementia. Tolhurst, Weicht, and Kingston (2017) agree arguing that the experience of dementia should be considered from a wider interactional

perspective. Jenkins (2014) propose using the concept of dividuality, widely used in anthropology, as an alternative. This is where people are not considered as individuals but see parts of themselves in others. Nolan et al. (2004) operationalise the idea that personhood is reciprocal and interdependent through positing the concept of relationship-centred care. While Adams and Gardiner (2005) propose a similar approach towards dementia care, highlighting the nature of communication within care triads. McCormack et al. (2012) highlight the fact that the caregiver must also have their personhood supported to be able to support the personhood of the person with dementia. Suffice to say that there is support within the literature for the theory that personhood is reciprocal and attention should be paid to supporting the care relationship as a whole as well as supporting the individual.

Bartlett and O'Connor (2007) critique concepts of personhood in dementia for conceptualising the person with dementia as lacking agency, as essentially being passive in the care relationship. This view of personhood is ultimately disempowering to the person with dementia as they are not conceptualised as active and willing to assert their own personhood and citizenship. Bartlett and O'Connor (2007, p. 114) argue that ultimately, a citizenship approach is required to extend the research agenda beyond solely a focus on personhood and care to "wider socio-political matters". Baldwin and Greason (2016) point to how combining ideas of personhood with citizenship will help to link the personal to the political. While, Hughes (2001, 2019) argues that citizenship is already implied by their definition of personhood, that part of being a situated embodied agent means that people are situated as citizens. Butchard and Kinderman (2019) explain that there is already a high degree of congruence between the principles which underpin person-centred care and citizenship or human rights-based approaches and that upholding identity is part of promoting human rights. Essentially, extending views of personhood to include citizenship and human rights approaches, some argue, gives broader political meaning to conceptualisations of dementia.

A third critique of Kitwood's (1997) definition of personhood is that it does not address the intersection between person and place (Baldwin et al., 2007). There is a theorised link between the self and place and in particular a sense of home (Baldwin et al., 2007). Memory is naturally specific to a place or is place-oriented

(Chaudhury, 1999) and engaging in reminiscence of place, in particular of home, is important in supporting sense of self for people with dementia, helping maintain or improve quality of life (Chaudhury, 2008). One study found that people with dementia were more likely to remember places from early in life, which were connected to life events and had strong emotional elements (Capstick & Ludwin, 2015). To date this is an underexplored aspect of personhood in dementia, however, more widely within environmental gerontology, there is evidence to support a connection between place and identity (Rowles, 1983; Wiles et al., 2012) and how moving to a long-term care setting impacts on sense of self and connectedness to the community in Ireland (O'Shea & Walsh, 2013).

A fourth critique of Kitwood's work is that it does not take into account the broader sociocultural influences on the experience of the person with dementia, such as the impact of gender, ethnicity or sexual orientation (O'Connor et al., 2007). Hughes (2001) puts forward the concept of the situated self where the person is influenced by external forces including familial, historical and cultural factors. While there has been a strong focus on the interactional or relational level of the impact of malignant social psychology on the personhood of the person with dementia, there has been less focus on broader socio-cultural aspects. More widely within dementia research, Young, Ferguson-Coleman, and Keady (2014) finds that research examining culturally-embedded understandings of dementia is relatively scarce. For example, Mullay et al. (2018) highlight the dearth of research on the intersection between ethnicity, culture and dementia in long-term care. They posit that if cultural background is considered intrinsic to personhood, then the role of person-centred care is to support this cultural element of the self. Their study of Scottish care homes finds that in some homes there was a sense of community identity or cultural identity which is an important mechanism for supporting personhood. Discussion on the impact of cultural experiences on the experience of older people is discussed, more widely, in critical social gerontology (Innes & Manthorpe, 2013; Cahill, 2018).

A final critique of Kitwood's work centres on its philosophical foundations. Dewing (2008) posits that there is a tension in Kitwood's definition of personhood, that people with dementia are positioned as lesser persons who rely on the protection of others, who are essentially waiting for personhood to be bestowed on them,

ultimately meaning that personhood is a secondary status for people with dementia. Dewing (2008) also argues that Kitwood's definition, while very different to metaphysical personhood, continues to be framed within a Cartesian dualist lens. Instead, Kitwood should have rejected personhood theories altogether, as by their very nature personalist views of personhood will exclude someone (Dewing, 2008). However, other writers argue that Kitwood has succeeded in this task:

"Kitwood's view that personhood is socially constructed and maintained, disentangles personhood from autonomy and cognitive function, as personhood is not dependent on cognitive abilities such as rationality, memory or ability to communicate" (O'Connor & Purves, 2009 as cited in McCormack et al. (2012, p. 285).

Then again, others argue that Kitwood moved too far away from personalism, that he has side stepped "consideration of what we have termed the component approach to personhood – those necessary and sufficient conditions that render personhood possible" (Higgs & Gilleard, 2016, p. 778). Ironically, these critiques are in opposing directions, one that his definition risks excluding people and the other that his definition does not provide sufficient conditions to prove personhood. These contradictions in interpreting Kitwood's work demonstrates how the concept continues to be ambiguous, contested, complex and dependant on the ontological positioning of the writer.

Several authors propose abandoning the terms personhood and the self in relation to people with dementia as they are too problematic (Millett, 2011; Higgs & Gilleard, 2016). However, abandoning personhood risks framing people with dementia as other, thereby making it easier to exclude them from political, cultural and social life. While it is not possible to know Kitwood's precise agenda in re-conceptualising personhood, perhaps, his use of the term personhood was an attempt to move the narrative away from nihilistic views of the person with dementia while continuing to speak the same language as his metaphysical ancestors. Ultimately, endless contemplation of personhood through a metaphysical lens may be unproductive, with Post (2006) pointing to how this: "hypercognitive snobbery is moral blindness". As Adams (1996) concludes, personhood has reinstated people with dementia back into the centre of dementia care, placing the emphasis firmly on the practice of that care.

2.6 The practice of personhood in dementia care

Supporting personhood is seen as an important and key aspect of dementia care and in particular, person-centred care (Brooker, 2007; Fazio et al., 2018). However, given the theoretical ambiguity of the concept, at times there is ambiguity in how it can be actualised in practice. The views of family and formal carers are vital to how personhood is supported in dementia care but as we will see below these views are not always consistent with theoretical views of personhood in dementia nor is there consistent views across formal carers.

2.6.1 *Care provision and personhood: the views of providers*

We turn now to a brief examination of research into family and formal carers beliefs on personhood. The literature search, including additional hand searches, found very little on family and formal carers beliefs on personhood. There is a wider literature on family and formal carers' experiences of caring for people with dementia, including interventions in person-centred care, but that is not the focus here. The work that does exist has focused on what supports personhood and how personhood is conceptualised (by formal carers in particular). Some studies include dyads and triads of the person with dementia, family carers and formal carers (Hellström et al., 2005; Cohen-Mansfield et al., 2006; Smebye & Kirkevold, 2013).

Family carers notice many changes in the person with dementia including changes to the self. Again here there is a contradiction between the person remaining the same and changing. Kaldjian et al. (2010) found that while many family carers saw changes to their loved ones personality and self-identity, the majority also thought that the person with dementia's life still had meaning and purpose. Some carers found that the change in their loved one was profound and saw them as a different person (Gillies & Johnston, 2004). Family carers find such changes emotionally stressful and employ different strategies to manage (MacRae, 2002). Perry and O'Connor (2002) find that spouses of people with dementia support personhood in four ways: maintaining continuity, supporting competencies, protecting from incompetence and having a strategy for managing encounters. Hellstrom (2005) found many examples of how a husband actively supported his wife's personhood by '*doing things together*'. Studies emphasise how there is a fine line between supporting and denying personhood, between protecting dignity and respecting

autonomy (Perry & O'Connor, 2002; Genoe et al., 2010). Smebye and Kirkevold (2013) found that family carer relationships which support personhood were more likely to involve close emotional bonds, characterised by respect, trust and affection. When asked about key qualities of formal carers, family carers identified dignity and respect as the hallmarks of supporting personhood in long-term care (Palmer, 2013).

There is a little bit more research into perceptions of personhood of formal carers. Kurokawa, Yabuwaki, and Kobayashi (2013) found that health care professionals in long-term care, defined personhood according to four factors: attributes such as habit and lifestyle, experience and history, self-efficacy and sense of capacity, and basic attitudes. Hunter et al. (2013) interviewed formal carers to develop a personhood in dementia questionnaire, identifying ten items to define personhood, these relate to biological, psychological, social and moral aspects of personhood. Smebye and Kirkevold (2013) found that formal care relationships which supported personhood were professional in nature, characterised by treating the person with dementia with respect and promoting their agency through a strengths based approach to care. Malloy and Hadjistavropoulos (2004) discuss the theory that formal carers perceptions of personhood in people with dementia has direct implications on how pain is managed, meaning that if personhood is seen as lost, pain is undermanaged. Hunter et al. (2013) were the first to empirically test this, finding that how care providers conceptualise personhood had a direct impact on the care they provide, thus supporting both Kitwood's (1997) and Malloy and Hadjistavropoulos' (2004) theories.

Berenbaum, Tziraki, and Mazuz (2017) used Buron's (2008) model on individual, biologic and sociologic personhood to examine the perceptions of formal carers. They found that formal carers conceptualised people with dementia as having these various levels of personhood and also point to how formal carers identified autonomy as important, with the authors proposing that autonomy should be the focus of providing person-centred care (Berenbaum et al., 2017). Kong, Fang, and Lou (2017) find that relational personhood is important to end of life care practices of staff in nursing homes. While, Gjodsbol, Koch, and Svendsen (2017) discuss how formal carers uphold the personhood and agency of people with advanced dementia through substituting lost functions, essentially carrying out tasks for the person with advanced dementia while also encouraging the person to participate

to the best of their ability. In addition to questions on the personhood of people with dementia, research is now also examining the impact of caring on the personhood and sense of self of those caring for people with dementia, both family carers (Skaalvik, Norberg, et al., 2016; Tuomola et al., 2016) and formal carers (Scales et al., 2017; Cooke, 2018; Kadri et al., 2018).

Interestingly, the literature search found very little on how family and formal carers conceptualise personhood in dementia, but this very conceptualisation has huge implications in how these carers support and care for people with dementia, as emphasised by Malloy and Hadjistavropoulos (2004) and Hunter et al. (2013). Instead, the research has mainly focused on the implementation of interventions to support personhood such as person-centred care models. At times, these models are based on the assumption that family and formal carers believe people with dementia have personhood, without any need for it to be proven.

2.6.2 Interventions to support personhood

Sofronas et al. (2018) found that the majority of research into personhood in dementia focused on moral or relational personhood and interventions to support personhood. While examining such interventions is not the focus of this thesis, a brief reference to such interventions is included here. Caddell and Clare (2011b) systematically reviewed interventions supporting self and identity in people with dementia, finding ten studies which fit the inclusion criteria. At the time, they concluded that interventions to support personhood were in the early stages of development. The interventions they identified included art, music, reminiscence therapies and individualised interventions. Since 2011, a plethora of different interventions have been used in dementia care, not always specifically to support personhood but with aims such as improving well-being and quality of life. Johnston and Narayanasamy (2016) reviewed psychosocial interventions for people with dementia finding that they support personhood and create a legacy. They found 36 articles in total, where the majority of the interventions were either reminiscence, life story work or life review work. Additionally, there were interventions in poetry writing, place therapy, pet therapy, doll therapy, music based interventions and creating personalised profile forms. Reminiscence and life story work was particularly popular. Telling one's life story is found to support personhood as well as affirm relationships with family members and allow people with dementia to

leave a legacy (Savundranayagam, Dilley, & Basting, 2011; Williams et al., 2014). In some cases the interventions intentionally or unintentionally have a dual purpose of developing and supporting the skills of family and formal carers. There are interventions which seek to teach carers to see and support the personhood of the person with dementia, through understanding the life history of the people they care for (Eritz et al., 2015), through communication strategies (Young et al., 2011) and through drama (Kontos et al., 2010). The intervention to support personhood which has been the most prolific in dementia care is person-centred care.

2.6.3 Person-centred care

The promotion and support of personhood is strongly embedded in person-centred care models (Downs, 2013), often, the primary aim of person-centred care is to support personhood (Baldwin et al., 2007; Brooker, 2007; Edvardsson et al., 2008; Kelly, 2010; Hughes & Beatty, 2013; Phinney et al., 2013; Fazio et al., 2018). Person-centred care is based on humanist psychology and the work of Carl Rogers (1961) and Abraham Maslow (Brooker, 2004; Levy-Storms, 2013). It has also been influenced by several other conceptual frameworks such as the social model of disability, new public management, normalisation and citizenship (Wilberforce et al., 2016). Kitwood is credited to introducing it to dementia care (Brooker, 2004; Edvardsson et al., 2008). Providing person-centred care is frequently the focus of health and social care policy, however, similar to the concept of personhood, there is ambiguity around what it is and how to implement it in practice (Brooker, 2004; Edvardsson et al., 2008). Sometimes, other terms are used synonymously with person-centred care such as patient-centred care and individualised care. While, person-centred care focuses on the value of the person, patient-centred care defines the person as a patient, is stigmatising and reduces the humanity of the person (McCormack, 2004 and Goffman, 1968 as cited in Edvardsson et al. (2008). In addition, person-centred care goes beyond traditional notions of individualised care to authentically engaging with the person (McCormack, 2003). Essentially, person-centred care “is founded on the ethics that all human beings are of absolute value and worthy of respect no matter their disability and on a conviction that people with dementia can live fulfilling lives” (Kitwood, 1995 as cited in Epp (2003, p. 15).

Three well-known models of person-centred care in dementia are Kitwood (1997), Brooker (2004) and McCormack and McCance (2006). Kitwood (1997) developed a model of care which focused on supporting the five psychological needs of people with dementia: comfort, identity, attachment, occupation and inclusion. Dementia Care Mapping™ is an observational tool and intervention designed around Kitwood's philosophy of person-centred care (Bradford Dementia Group, 1997). Brooker (2007) built on Kitwood's work to create the VIPS framework. This model, based on the acronym VIPS, focuses on four key elements: valuing the person with dementia, treating people as individuals, taking the perspective of the person with dementia and encouraging the social self. This programme incorporates much of Kitwood's work, in particular the personal enhancers and detractors identified by Kitwood (1997).

In gerontological nursing, more generally, McCormack and McCance (2006) developed a framework for person-centred nursing, supported by prior research (McCormack, 2003, 2004). They outline four key elements to ensuring person-centred outcomes: prerequisites (the attributes of the nurse), the care environment (the context in which care is delivered), person-centred processes (activities of delivering care) and expected outcomes (results of person-centred nursing). Within all three models, there is a strong emphasis on the subjective experience of care, the importance of empathising with the person with dementia by listening to their perspective and attempting to understand their experience. Wilberforce et al. (2016) identify three core similarities across models of person-centred care: understanding the person, empowering the person in decision making and the importance of relationships in care.

Young et al. (2011) explains how person-centred care attempts to include knowledge about the person's personhood into the care process, this includes knowledge about their life history, values, beliefs, preferences and needs. This allows additional strategies for providing person-centred care to be developed including: reminiscence, prioritising well-being over care tasks, personalising the care environment, promoting enjoyable activities and using psychotherapeutic techniques such as validation, holding and facilitation (Epp, 2003; Edvardsson et al., 2008). It is necessary to point out here that often person-centred care is not solely about supporting personhood but has other goals such as treating people with dignity and respect, supporting their autonomy and agency and also promoting

well-being and quality of life. Usually, such aspirations are complimentary but at times there can be conflict between such aspirations, for example, when there is an ethical dilemma for formal carers in balancing autonomy with safety and well-being (Smebye, Kirkevold, & Engedal, 2016).

Person-centred models move away from solely focusing on the biomedical symptoms to focusing on broader psycho-social factors (Wilberforce et al., 2016). Fazio et al. (2018) explain that existing research on person-centred care has many limitations and that more research is required to understand how to measure it. They argue however that a broad definition of person-centred care can be agreed on:

“It becomes clear that providing care based on knowing the person within the context of an interpersonal relationship in a way that supports individualized choice and dignity is difficult to argue against” (Fazio et al., 2018, p. S18).

In practice, the implementation of person-centred care is complex and ensuring personhood is supported is an arduous task: formal carers, like everyone, are a result of the system and society in which they were trained and limited research exists as to whether “person-centred care that respects personhood can be taught” (Palmer, 2013, p. 228). Kelly (2014) suggests using Sabat and Harré’s (1992) definition of selves to allow formal carers to empathetically recognise elements of selfhood that they share in common with the person they are caring for.

2.7 The conceptualisation of personhood in this thesis

Given the depth, breadth, complexity and ambiguity of personhood in dementia it is difficult to do justice to all of its key elements in one study. This thesis examines personhood in dementia in formal care relationships. It includes concepts of the self, self-identity and selfhood in its definition of personhood. It identifies personhood as both an individual and a relational concept. It views personhood as relational in that it is socially constructed within relationships but part of this social construction involves knowing what matters to the person with dementia, and therefore knowing the individual self of the person with dementia. Chapters 3 and 4 of the thesis encompasses all three elements of personhood: the self, relational personhood and embodied selfhood. The latter is largely absent from the empirical study outlined in chapters 5 and 6, mainly because a decision was taken not to engage in the ethnographic work necessary to explore the embodied self in any

great detail, although people do refer indirectly to its constituent elements. In addition, while the thesis acknowledges the wide and varied impacts of the socio-cultural environment on personhood, it is beyond the remit of one thesis to examine that environment in any significant detail. However, subsequent secondary analysis of the interview transcripts would help illuminate what those factors are and what they might mean for stakeholders. These are all limitations of this thesis which will be discussed in more detail at the end of each of the three studies, in Chapter 3, Chapter 4 and Chapter 6.

The aim of this thesis is to reduce some of the ambiguity around the concept of personhood in dementia in relation to formal care provision of services and supports. The work provides an applied and practical perspective of what personhood means to people with dementia, family carers and formal carers and how this can be actualised in formal care relationships. The outputs of the thesis will be useful in several respects. While it is not the aim of the thesis to develop a new theoretical understanding of personhood in dementia, as there are sufficient discussions on this already, it will contribute to existing theory by mapping it on to empirical evidence provided through the evidence synthesis in Chapter 4 and the empirical study in Chapters 5 and 6. The thesis will also contribute to policy by examining how personhood is currently conceptualised within policy-making for people with dementia in Ireland, in Chapter 3, and how future policy can be recalibrated to support the key elements of personhood in dementia in Chapter 7. The findings from the thesis will also be useful in designing health and social care services and supports for people with dementia that respect personhood and support formal carers to translate policy into practice.

2.8 Conclusion

This chapter has provided an overview of theory and practice in personhood in dementia. It has examined how personhood has been historically defined as both metaphysical and moral, primarily along cognitive lines. Personhood in dementia remains a complex and contested concept, comprising the self, relational aspects and embodied selfhood. There are many critiques of personhood, but, along with its actualisation in person-centred care, it continues to be highly influential in dementia care culture and policy. The focus in this thesis is on personhood and its interpretation and manifestations within formal care provision. The next chapter

Chapter 2: Literature review of the theory and practice of personhood in dementia

explores this interpretation in dementia policy in Ireland through a robust and forensic examination of the Irish National Dementia Strategy.

Chapter 3: Personhood, dementia policy and the Irish National Dementia Strategy¹

3.1 Introduction

This chapter examines how personhood in dementia is currently conceptualised in policy-making in Ireland. The chapter begins with a synopsis of dementia policy in Ireland, followed by a content analysis of the Irish National Dementia Strategy and 72 submissions made in the development of the Strategy. These submissions were made by members of the public and interested organisations as part of the consultation process in developing the Strategy. The analysis examines how personhood is conceptualised in these documents, how the Strategy proposes to support personhood in practice and how some of the submissions conceptualise the person with dementia. Essentially, this chapter examines the extent to which personhood is part of the dementia policy narrative in Ireland, as reflected in the use and relevance of the concept in the Strategy and in the submissions.

It is clear that supporting personhood is top of the policy agenda, as the Strategy identifies personhood as one of its two overarching principles, the other being citizenship (Department of Health, 2014). The inclusion of personhood as a principle is representative of a much wider international narrative which has significantly influenced the development of, and movement towards, models of person-centred care in dementia (McCormack et al., 2012). However, there is evidence to show that there is a lack of consistency in how these concepts are translated into policy and practice. For example, Fortinsky and Downs (2014) created a typology of transitions in the dementia journey to examine seven national dementia strategies and found that person-centred care was more evident in early transitions than at later stages of the disease. Colomer and de Vries (2016)

¹ This chapter is based on Hennelly, N., & O'Shea, E. (2019). Personhood, dementia policy and the Irish National Dementia Strategy. *Dementia (London, England)*, 18(5), 1810-1825.

identified similar ambiguities in relation to person-centred care in Irish nursing homes. McCormack et al. (2012) argue that evidence and research into personhood is critical to the application of best practice in person-centred care. However, an absence of clarity with respect to the conceptualisation and actualisation of personhood within policy documents and policy implementation makes it difficult to assess how, and if, person-centred care is enhanced through subsequent practice.

3.2 Dementia policy in Ireland

Historically, dementia care in Ireland has experienced substantial under-funding and under-prioritisation (Cahill, 2010). The current care model is a legacy of institutionalisation, from workhouses for the destitute in the 19th century to large scale county homes for older people up to the 1980's, to current, more enlightened, models of residential care (Timonen & Doyle, 2008). The first tentative signs of a policy shift away from institutionalisation, *The Care of the Aged Report (1968)*, sought to enable more older people to stay in their own homes, but without any plan as to how that might be achieved. This principle was also strongly and more eloquently reflected twenty years later in *The Years Ahead: a Policy for the Elderly (1988)*, which put the emphasis firmly on community-based supports for dependent older people.

At the end of the 1990's, the first dementia specific policy document, *An Action Plan for Dementia* (O'Shea & O'Reilly, 1999), was commissioned by the National Council for Ageing and Older People. This Plan was person-centred in orientation, drawing on Kitwood's (1997) exposition of personhood within dementia as a starting point for new models of care, both in the community and in residential care. While the government's 2001 *Health Strategy* committed to implementing the Plan, this promise was never realised, leaving intact a community care system that was largely impoverished, fragmented, supply-driven and generic (Department of Health and Children, 2001). It is difficult to pinpoint why the commitment was not followed through in a period of rapid economic growth and significant tax-based funding, but dementia never gained traction as an important policy issue. The key policy issue for ageing at that time was the regulation and funding of nursing home care governed by the Nursing Homes Act (1990), which dominated

all other ageing narratives, including key issues like dementia and home care spending.

The failure to implement the Action Plan persisted, despite pressure from various stakeholder groups, until 2011, when there was a commitment given by the incoming government to formulate a National Dementia Strategy. However, given the perilous state of the public finances (Ireland had by that time already entered an IMF/EU austerity bailout), it was accepted by all sides that this would be a *no cost* Strategy, without any additional resources committed to its development or implementation. Help was on the way, however, in the form of an investment in dementia of over €33 million by Atlantic Philanthropies between 2011 and 2016, including direct financial support for the new Strategy (O'Shea & Carney, 2016). Atlantic Philanthropies funded new programmes in dementia throughout the country in areas such as: service transformation; advocacy; and training and education (O'Shea & Carney, 2016). A key aspect of this investment was the development and strengthening of cooperation and collaboration across stakeholders in dementia care in Ireland. This propelled action in the areas of advocacy and policy and, coupled with Atlantic Philanthropies' funding of a research review, *Creating Excellence in Dementia Care* (Cahill et al., 2012), was a driving force in bringing Ireland's first National Dementia Strategy to fruition.

The Strategy (2014) identified five key areas for support: better awareness and understanding; timely diagnosis and intervention; integrated services and supports; training and education; and leadership. The Strategy is nearing the end of its implementation with a total budget of €27.5 million, almost half of which was provided directly by Atlantic Philanthropies on the agreement of matched funding by the government (O'Shea & Carney, 2016). Without Atlantic Philanthropies, it is difficult to see how the Strategy could have been funded, given the absence of public resources in the country at the time.

3.3 Research design and methods

The Strategy was the result of a comprehensive consultation process including the *Creating Excellence in Dementia Care* Report (2012), detailed submissions from stakeholders, a comparative review of international dementia plans, a review of Irish policy contexts, clinician roundtable discussions, workshops for people with dementia, family carers and former family carers and input from an advisory group

(Department of Health, 2014). This chapter concentrates on the content of the detailed submissions from dementia stakeholders in Ireland and on the Strategy itself. The study does not analyse all of the processes involved in the development of the Strategy. Interviews with relevant stakeholders who were involved in the development of the Strategy might have provided further insight into the conceptualisation of personhood within the Strategy, but this was not part of the work.

A total of 73 submissions were made by organisations and individual members of the public to the Department of Health (2012); all but one of these submissions were available for this analysis. Just under half of the submissions (35) are from organisations with the remainder (37) from individuals. Stakeholders were given the option of making a submission using a questionnaire designed specifically by the Department of Health or, alternatively, they could submit an open response of any length. Approximately half of the submissions availed of the questionnaire (Department of Health, 2012).

Content analysis was used to examine both the submissions and the Strategy for the term personhood and personhood-related synonyms (Elo & Kyngas, 2008). The literature review in Chapter 2 generated a list of synonyms for personhood to use in the content analysis (Table 3.1). Autonomy, while frequently referenced in discussions on personhood, is not included in the list of synonyms. There is a tension between assuring individual autonomy and providing person-centred care in dementia (McCormack, 2001). As Pullman (1999) points out, in dementia care, restoring full autonomy is not always possible or realistic.

Table 3.1: Synonyms for personhood

✓ Connection
✓ Dignity
✓ Holistic
✓ Identity
✓ Person-centred
✓ Relationship
✓ Role
✓ Respect
✓ Self
*variations of spellings are included for all synonyms

Content analysis was considered the most suitable method as it allows for a descriptive examination of the phenomenon of interest, in this case personhood, using both inductive and deductive approaches (Elo & Kyngas, 2008). The submissions and Strategy were text searched for personhood and synonyms using NVivo (software version 10 2014, QSR International Pty Ltd). Each individual reference was verified to ensure the context was relevant; for example the word *respect* in the phrase *in respect of* clearly does not have any bearing on personhood in dementia and so would have been excluded in the reference count. The submissions and Strategy were also examined for synonymous phrases, including colloquial terms, which had not been identified in the initial text search. These phrases, while somewhat subjective, were discussed and agreed upon by both my supervisor and me, and were included with the singular synonyms when deemed relevant. Table 3.2 contains sample phrases from the submissions, while Table 3.3 shows sample phrases identified in the Strategy. The content analysis of the Strategy also included a structural analysis, assessing its principles, objectives, priority actions, additional actions and outcomes in relation to personhood.

Table 3.2: Sample synonymous phrases from the submissions

- *wider need of the individual ... to remain involved in their communities.*
- *meaningful doing and engagement in the person's life.*
- *seeing the person as they are.*
- *the spirit remains strong.*
- *we must never assume that the patient 'will not notice'.*
- *the care provider's view of the individual (patient vs. person) colours the entire culture of care.*
- *the regulatory environment should not be permitted to eclipse the view of the end-user.*
- *people, not patients.*
- *unique value of the person.*
- *wishes and comfort of patient and family should be at forefront of decision making.*
- *recognition of the person as a unique individual.*

Table 3.3: Sample synonymous phrases from the Strategy

<ul style="list-style-type: none">• <i>All communications with those with dementia should be as accessible as possible.</i>• <i>It commits to including natural supports (such as family, friends and social interactions) as much as possible.</i>• <i>The Strategy also emphasises the need for a ‘whole community response’ to dementia, with health and social care services as only one part of the package of supports that people with dementia need.</i>• <i>People with dementia should be supported to be cared for in the place of their choice, as far as is possible, including at the end of life.</i>• <i>A timely diagnosis is one that is made and communicated at a time and in a way that best matches the physical, emotional, medical, and other needs of the patient, their families, and carers.</i>

In addition to the content analysis, the 35 organisational submissions were categorised into three distinct theoretical models of dementia; biomedical, biopsychosocial and social (Bond, 2001; Innes & Manthorpe, 2013). We concentrated on the organisational submissions because of a belief that they were more likely to be representative of overall stakeholder paradigms of care than submissions from individual members of the public, which may have been more personal and specific in orientation. We analysed each organisational submission for the language used to describe and position people with dementia and their circumstances both personal and care related. The language used within each submission was the sole criteria for designating which model to place that submission. The organisational submission’s overall focus and priorities were also taken into account. For example, organisational submissions which referred to the person with dementia as a patient requiring health care services and medical attention were labelled as biomedical. Organisational submissions which referenced both biomedical and psycho-social approaches to dementia were labelled as biopsychosocial and organisational submissions which portrayed dementia as primarily a societal concern were labelled as social. The organisational submissions in each model were cross referenced with the original content analysis to determine how many references to personhood and its synonyms could be attributed to each model.

3.4 Results

3.4.1 Content analysis

There are a total of eight direct references to personhood in the organisational and individual submissions made to the Department of Health. The Strategy contains only one direct reference to personhood, albeit as an overarching principle. There are a total of 181 personhood synonyms (singular words or phrases) contained in the organisational and individual submissions and 33 personhood synonyms (singular words or phrases) included in the Strategy. Just under 7% of the total submissions referred directly to personhood, while 61% contained personhood synonyms, either singular words or phrases (Table 3.4). The organisational submissions were more likely to contain references to personhood and its synonyms (66%) than the individual submissions (60%). Some submissions contained multiple references to personhood and its synonyms. For example, one submission contained 25 references to personhood and its synonyms, while seven submissions contained just one or two references.

Table 3.4: References to personhood and synonyms in the submissions

	Number of references in submissions	Percentage of submissions containing references	Number of references in the National Dementia Strategy
Direct reference to Personhood	8	7% (5/72)	1
Personhood Synonyms	181	61% (44/72)	33
Total	189	61% (44/72)	34

Direct references to personhood within the organisational and individual submissions were usually embedded in arguments for the development of more holistic, community-based approaches to the care of people with dementia in

Ireland. For example, personhood is seen as an integral part of the social model of dementia:

“A social and community model of dementia needs to be developed, where dementia is viewed as a social issue, one owned by our community and requiring a community response, and where “personhood” is held at the very core.”

One submission called for the Strategy to ensure that people with dementia are viewed as social beings:

“The Dementia Strategy should focus on the maintenance of personhood, on quality of life, on the preservation of cognitive function, dignity and on promoting any retained ability the individual continues to manifest. Recognition of the person as a unique individual, who belongs in a social world of roles and relationships and who has a biography is required.”

While another contained warning of the effects of ignoring personhood:

“Tom Kitwood, a British Clinical Psychologist, who pioneered the concept of Personhood in dementia care, argued that people living with dementia may be as much disabled in their experiences by public attitudes (malignant social psychology) and environmental psychosocial factors as by the neurological condition itself.”

Ultimately, the direct references to personhood were concerned with the impact of dementia on the social world of the person with dementia, through societal stigma denying their personhood and in particular ignoring their need to be recognised and treated as a social being. This call for a paradigm shift to a social/community model was equally reflected in the synonymous phrases. For example:

“It is important to shift the emphasis from dementia as a physical condition, thereby creating environments for people with dementia/Alzheimer's and their families actively joining in everyday life.”

“One of the strongest messages from the overall consultation was the need for people with dementia to keep living positively and continuing to do what they do. They very much want to remain as active contributors and members of their own communities.”

Some acknowledged that this paradigm shift to a social model of dementia which supports personhood would require key changes to the physical environment and to societal attitudes:

“In other words, the national strategy should seek to normalise the involvement of people with dementia in the everyday life of communities so that they become dementia-friendly, something that will require a systematic approach based on community development principles.”

“Research has shown that the environment can support or hinder social consecutiveness and a sense of self particularly for a person with dementia; hence the approaches to care, connections with families and the local community are paramount.”

The importance of placing the person with dementia in the centre of any strategy, of listening to and responding to their needs and wishes was emphasised:

“We suggest that in the process of developing the strategy, it would be useful to adopt an approach which is consistent with what people have told us they want.”

“A comprehensive set of values and principles must be enshrined into the NDS including social solidarity, social sustainability, active citizenship, respect and putting the person at the centre.”

Table 3.5 shows the structural analysis of the Strategy. Personhood is one of the two overarching principles of the Strategy, alongside citizenship. Within the document, there are eight principles listed, the majority of which (6) contain

references to personhood or its synonyms, including: engagement; representation; communication; and skills-retention.

Table 3.5: References to personhood and synonyms in the Strategy

Sections of the Strategy	References to personhood or its synonyms	Total
Key Principles	6	8
Objectives	10	31
Priority Actions	0	14
Additional Actions	4	21
Outcomes	0	No explicit section assigned to outcomes in the Strategy, although 5 broad references were identified in the objectives and additional actions
Other	14	Refers to references throughout rest of document
Total	34	

Personhood supporting principles include:

“People with dementia should be supported to be cared for in the place of their choice, as far as is possible, including at the end of life” (2014, p.13).

“People with dementia should be supported to retain skills as much as possible” (2014, p.13).

There are 31 objectives dispersed throughout the Strategy, linked to specific themes as follows: awareness; diagnosis; integrated care; training and education; and research and information systems. At least one of the objectives associated with each of these themes has a personhood supporting goal, aggregating to ten in total. Some examples include:

“Sensitive disclosure of a diagnosis and discussion of dementia, taking an individualised and person-centred approach” (2014, p.19).

“The development of educational material for health and social care professionals informed by the experiences of people with dementia and their carers” (2014, p.31).

There are, however, no references to personhood or synonyms within the 14 priority actions outlined in the Strategy, although there are four references associated with 21 additional actions. Of the four references contained in the additional actions, three are concerned with making acute and hospital services more suited to the person with dementia. The fourth refers to capacity and decision making as follows:

“The Health Service Executive will promote an awareness of the Assisted Decision-Making (Capacity) Bill, when enacted, to ensure that people with dementia are supported to participate in all decisions that affect them, according to their will and preference” (2014, p.23).

There is no specific section devoted to outcome measurement or assessment within the Strategy. However, there are five broad references to evaluation under objectives and actions, none of which contain a direct reference to personhood or its synonyms. Certainly, enhancing personhood is not mentioned as a performance indicator or regulatory concern, nor is there any reference to personhood-led measurement. There is a promise to develop performance indicators in the implementation of the Strategy, but no indication as to whether personhood would be part of these indicators.

3.4.2 Dementia care models

The 35 organisational submissions were categorised into one of three models; biomedical, biopsychosocial and social (Bond, 2001; Innes & Manthorpe, 2013).

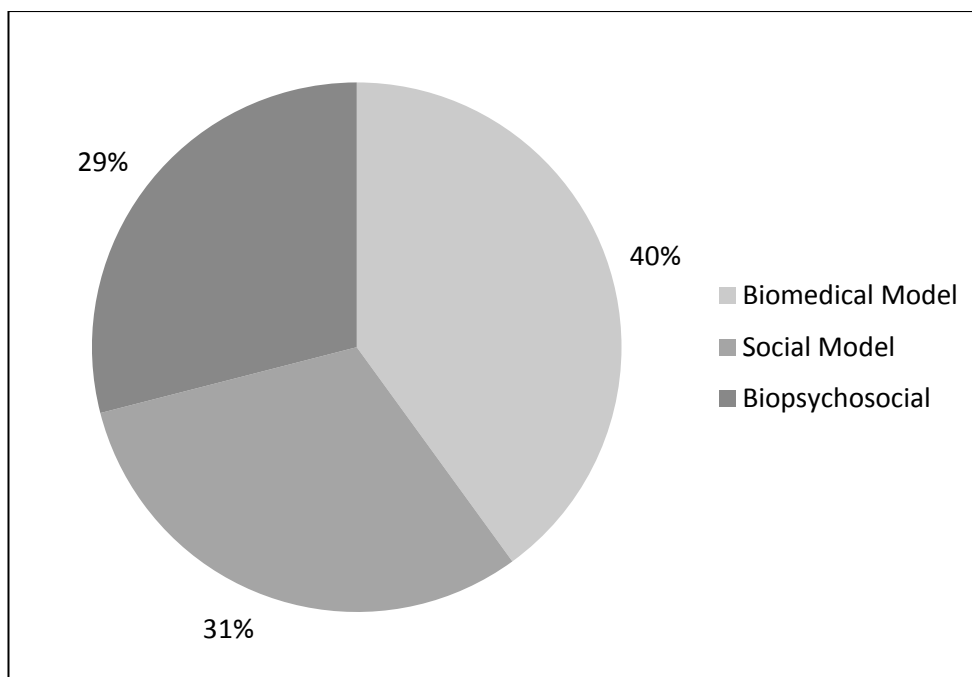


Figure 3.1: Organisational submissions by dementia model

Two fifths of the organisational submissions fit within a biomedical model (Downs et al., 2006), almost a third within a social model (Bond, 2001) and 29% within a biopsychosocial model (Sabat, 2008) (Figure 3.1). Sample phrases from organisational submissions which fit a biomedical model include:

“Minding service where your loved ones will be taken care of.”

“Dementia patients are a very significant group in terms of health service utilisation.”

“A care plan should be designed and agreed using a multi- disciplinary approach with all relevant health professionals. A principal carer nominated by the patient and/or family should be actively involved in the design and implementation of the plan so that it can be tailored to the specific needs of the individual patient.”

Sample phrases from organisational submissions which fit the biopsychosocial model were:

“The resources required to implement meaningful psychosocial approaches supported by professional therapists should be recognised and reflected in the Nursing Homes Support Scheme legislation.”

“We have an opportunity in Ireland to establish an effective template for the early diagnosis of dementia and timely medical and psychosocial interventions that could transform the quality of life for those increasing numbers of people living with dementia.”

“Development of psychosocial processes and the use of such things as music and touch to complement existing medical and neurological interventions.”

Sample phrases from organisational submissions which fit within a social model were:

“Dementia remains a highly neglected area of policy with few dedicated resources and the NDS must recognise this as the starting point with a vision of transformation that supports people with dementia to be placed in the heart of our communities.”

“Supporting people to live at home is not solely about providing community health and social care it also means making dementia everyone’s business.”

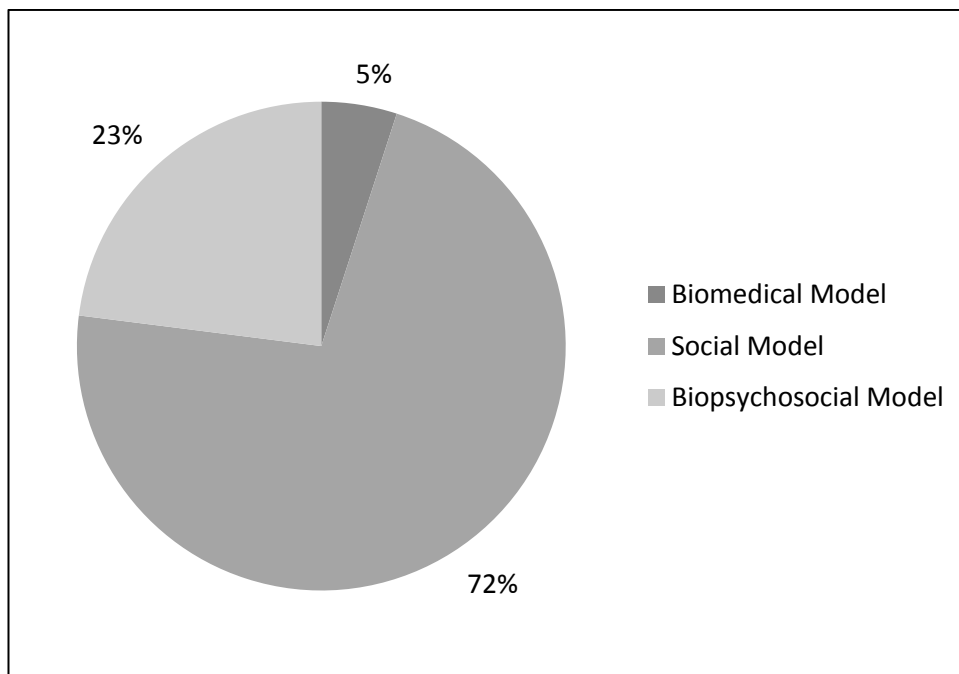


Figure 3.2: References to personhood and its synonyms by models

Figure 3.2 shows the models when cross-referenced with regard to the explicit use

of personhood and its synonyms. There are 128 references to personhood and its various synonyms across the 35 organisational submissions. Twelve organisational submissions contain no reference to personhood or its synonyms. Not surprisingly, only 5% of references to personhood and its synonyms occur within organisational submissions based largely on the biomedical model. Almost three quarters of references (72%) originate within organisational submissions based on a social model, while just under a quarter (23%) relate to the biopsychosocial model. The use of personhood and its synonyms correlates highly with the dementia care model classification system - highest for the social model and lowest for the biomedical model.

3.5 Discussion

Personhood is explicitly referenced as an underlying principle in the Strategy. This is a major breakthrough in the effort to develop a counter-policy frame to the traditional biomedical model that has dominated the dementia landscape in Ireland. One of the objectives of this chapter was to examine the origins of this potentially liberating paradigm shift in the understanding of dementia in the country. Did the inclusion of personhood in the Strategy come about because of pressure from stakeholders in Ireland who wanted a new approach to take hold? References to personhood and its synonyms in the majority of the organisational and individual submissions indicate that stakeholders wanted a change in orientation. Personhood is directly referenced in 7% of these submissions, while synonyms for personhood occur in 61% of submissions. Although, there was variation in the use of personhood and synonyms in those submissions, the use of the concept is noteworthy for its potential influence on the Strategy and as a change agent in dementia care in Ireland. The inclusion of personhood as an overarching principle in the Strategy can, therefore, be directly linked to a stakeholder desire for change, expressed through the submissions.

An additional impetus for the inclusion of personhood as a principle in the Strategy is the significant influence Atlantic Philanthropies had in mobilising and facilitating stakeholder engagement in the policy process in Ireland (O'Shea & Carney, 2016). Atlantic's conceptual model of dementia is firmly rooted in Kitwood's (1997) interpretation of personhood. Through their grant funding, they have supported multiple programmes and projects designed to provide a strong voice and purpose

to people with dementia in Ireland. Their grantees made up the majority of members on the National Dementia Strategy Advisory Group and were instrumental in keeping personhood and person-centred care to the fore when decisions were being made on dominant models in relation to care and supports. The grantees were powerful agents of change at crucial stages in the development of the Strategy in keeping personhood on the policy agenda, even if the final Strategy document was not fully reflective of their efforts (O'Shea & Carney, 2016). Therefore, Atlantic's influence went further than providing money to implement the Strategy, extending to philosophies of care as well, as expressed through their carefully selected grantees.

Succeeding in having personhood included as an overarching principle in the National Dementia Strategy is a necessary but not sufficient condition for changing dementia care in Ireland. An approach to policy built on saying one thing and doing another has been part of the ageing landscape in Ireland for a long time now. In particular, policy documents have consistently pointed to community-based care as being the way forward for dependent older people, while funding continues to be biased towards residential care; funding for residential care is currently twice as much as that provided to community care in Ireland (O'Shea, Keogh, & Cooney, 2019). The attachment to the traditional residential model of care has been impossible to shift thus far, in spite of the community narrative emanating from government circles for the past thirty years.

Similarly, the importance of a strong voice for older people within practice and policy in ageing has been a consistent mantra from government in recent decades, but that voice has become weaker if anything, dominated by a supply-side that continues to influence all of the important decisions in relation to models of care and resource allocation. For example, rights are attached to residential care, but not to home-based care. Moreover, the structure and timing of home care provision are influenced more by the work practices of providers than the needs of people with dementia. Psychosocial supports for dementia are largely absent from community-based care (O'Shea et al., 2016; Keogh et al., *in press*). Public and patient involvement (PPI) in decision-making is only beginning to be taken seriously by policy-makers (Health Research Board, 2016). The portents are not good, therefore, that a new model for dementia will take hold, given the continued

absence of credible transmission mechanisms for change in ageing policy in the country.

Moreover, a careful examination of the Strategy does not fully bear out the principle of personhood at its core. The Strategy lacks a clear conceptualisation of personhood, beyond a statement of principle. Certainly, there are 33 singular or phrase-related personhood synonyms in the Strategy, but there is an absence of detail on how personhood is to be operationalised and realised in practice and in the delivery of care. References to personhood in the Strategy, clearly visible in the principles and objectives, are not always translated into priority actions. There is no road-map, nor any reference to incentives, that might accelerate a shift in the current system and structure of care towards personhood. The Strategy does not provide guidance or guarantees on how services and supports are to be reconfigured in a manner that supports personhood.

Language matters, especially in relation to people with dementia and the expression of their care preferences and care needs. For example, one synonymous reference to personhood within the Strategy reaffirms a previous policy commitment “to including natural supports (such as family, friends and social interactions)” in developing policy for people with dementia. There are two points to be made around the use and influence of language in this case. First, referring to family and friends as natural rather than human supports may change the emphasis on how family and friends are viewed thereby diminishing the humanistic and relationship elements of such supports. Second, there is an implication that the provision of informal care is ‘natural’ and therefore seen as primal by policy-makers. Is it then unnatural to receive support or care from other sources, such as formal care, or that the latter is secondary at best and unnecessary at worst? Ultimately, language reveals how people with dementia, family, friends and health and social care providers are conceptualised and positioned within the Strategy. If policy is to be interpreted and implemented in a manner that enhances personhood then its language must support this rather than undermine it.

The vagueness of the Strategy in relation to planning for personalised care puts a lot of attention and focus on what happens post-publication of the Strategy. There is no doubt that the Strategy is dedicated, at a philosophical level, to systemic changes in dementia over an extended period of time and reflects the views of

stakeholders for a new direction. That includes influencing frontline practice across a variety of care settings. But the Strategy is weak on detail and on identifying the locus of change. The key to ensuring that change actually happens is only referenced in five lines of text under *additional actions* in the final pages of the Strategy. The commitment is to the development of clear and effective management structures that will provide leadership for the implementation of the Strategy, including the development of relevant but unspecified performance indicators. The focus shifts necessarily, therefore, to ex-post implementation strategies to ensure that the conceptualisation and operationalisation of personhood is made explicit and accessible to all those involved in dementia in Ireland. This includes the evaluation and regulatory environment, which can be important for translating the principle of personhood into tangible outcomes for people with dementia and ensuring personhood-led outcome measures. In their study, Fortinsky and Downs (2014) highlight the need for person-centred outcome measures to assess the implementation of national strategies. However, the mid-term review of implementation of the Strategy has little emphasis on person-centred outcomes (Government of Ireland, 2018).

Perhaps the journey towards a new paradigm is not helped by ambiguity among even supportive stakeholders as to the meaning and role of personhood in dementia. People with dementia are conceptualised differently across the submissions. This carries important practical implications, as Malloy and Hadjistavropoulos point out: “a person's ontological position forms the manner in which one perceives the self and others” (2004, p. 149). There is a lack of consistency in regard to a personhood model of care, even within submissions to the Strategy arguing for a new direction in policy. For example one of the personhood-oriented submissions talks about putting the *individual at the centre of service provision*, followed immediately by a reference to a whole system approach that *is patient centred*. The use of the term patient-centred situates the person with dementia as a patient within a biomedical model. The same submission refers to people with dementia as *sufferers* thereby inadvertently but malignantly positioning the person with dementia as a non-person (Kitwood & Bredin, 1992; Sabat & Harré, 1992). This points to the need for education, training and development to ensure that the concept is understood and correctly interpreted as a means of ensuring high quality person-centred care. If it cannot be understood,

then perhaps we need to revert to related and more tangible concepts such as identity, communication, trust, dignity and connectivity.

While there is no clear conceptualisation of personhood across these stakeholders, the majority of the organisational and individual submissions are broadly supportive of the concept, either directly or indirectly. In particular, there is an emphasis on the need for people with dementia to be treated, ultimately, as anyone in society should be treated, with respect, dignity, humanity and empathy. This is reflected in various calls to ensure that people with dementia continue to be included in their community through greater connectivity, social interaction and dementia friendly environments. Considering the level of support for these concepts in the submissions it is surprising that more is not made of them in the Strategy. Personhood could have been articulated better in the various submissions, but this does not explain why similar and related concepts such as identity, communication, respect, dignity and connectivity do not appear in the priority actions or outcomes either. It is clear that stakeholders in Ireland want personhood and its synonyms to be at the core of dementia policy in Ireland, but it remains a puzzle as to why this human dimension of care for people with dementia has not been translated into more measurable action points within the Strategy.

Even if understood, it will still take time for personhood to become central in determining care pathways and interventions for people with dementia in Ireland. While there was strong support for personhood coming from organisational submissions within the social and biopsychosocial models of care, 40% of organisational submissions remain aligned to the biomedical model, which fundamentally views personhood as lost in the person with dementia. Focusing only on the biomedical aspects of dementia narrows the ontological view of the person with dementia and does not result in a model where personhood is core. The biomedical model is proving difficult to dislodge from its position of primacy in the Irish dementia landscape. There is more to be done to ensure that the social model establishes a secure foothold within the policy-making process in Ireland.

3.6 Conclusion

This chapter examined the Irish National Dementia Strategy with respect to one of its overarching principles, personhood. It traced the conceptualisation of personhood within organisational and individual submissions made to the Strategy,

alongside a similar examination of the Strategy itself. There are differences in the levels of engagement with, and understanding of, personhood across these submissions. This reflects divergent ontological positions among stakeholders in how personhood for people with dementia is conceptualised in Ireland. What shines through is the strong support for personhood coming from the organisational submissions within the social and biopsychosocial models of dementia, in contrast to the minimal engagement with personhood in organisational submissions fitting the biomedical model.

The key question is whether the principle of personhood will have any real meaning or influence on the lives of people with dementia in the country. On closer examination of the Strategy, it is clear that personhood does not always permeate the document in a way commensurate with its inclusion as a defining principle. Personhood is not referenced in the priority actions or outcomes of the Strategy. It is vaguely referenced in additional actions, but unconvincingly. There are no clear transmission mechanisms that link concepts to impact or to the regulatory environment, although there is reference to research and information systems. Greater clarity and specificity is needed in the implementation of the Strategy to ensure that personhood and person-centred care take hold across all care settings in Ireland. The concept needs to be simplified and linked to easily understood and measurable concepts such as personalisation, communication and connectivity. It should be possible to regulate for personhood, but only if we have a clear understanding of what it means. So much has been achieved in Ireland and so much good work is currently being done. The next task is to operationalise what the majority of stakeholders want - a personalised system of care that is social in orientation and reflects the preferences and needs of people with dementia in a very human way. While this chapter has examined personhood at the policy and organisational level, the next chapter seeks to explore it at the individual level by reviewing the existing research into personhood in formal care settings from the perspectives of people with dementia.

Chapter 4: Personhood and dementia care: a qualitative evidence synthesis of the perspectives of people with dementia²

4.1 Introduction

Chapter 2 detailed how personhood in dementia is a complex concept including notions of the self, relational personhood and embodied selfhood. This chapter explores this concept further by examining how people with dementia conceptualise personhood in dementia in formal care settings. This involves a systematic review and qualitative evidence synthesis of existing qualitative research. This chapter will provide a deeper insight into the experiences and perceptions of people with dementia and help to develop more clarity around, and understanding of personhood in dementia in formal care settings. The review incorporates detailed methods including: a comprehensive systematic search, screening involving two authors, using CART criteria in the screening process, a quality assessment of the included studies, thematic synthesis and using GRADE CERQual to assess the quality of the review findings. The chapter concludes with a

² This chapter is based on:

Hennelly, N., Cooney, A., Houghton, C., & O'Shea, E. (2019). Personhood and dementia care: a qualitative evidence synthesis of the perspectives of people with dementia. *The Gerontologist*, doi: [10.1093/geront/gnz159](https://doi.org/10.1093/geront/gnz159)

and

Hennelly, N., Cooney, A., Houghton, C., & O'Shea, E. (2018). The experiences and perceptions of personhood for people living with dementia: A qualitative evidence synthesis protocol [version 1; referees: 2 approved]. *HRB Open Res*, 1:18.

discussion on the review findings and limitations of the review. I have carried out this review and synthesis with my supervisor and two other co-authors. The contributions of all four authors are outlined at the end of the chapter.

There are existing syntheses and reviews which have examined different aspects of personhood within dementia, for example: agency (Bosco, Schneider, Coleston-Shields, Jawahar, et al., 2019), the lived experience of dementia (Górska, Forsyth, & Maciver, 2017), living positively with dementia (Wolverson, Clarke, & Moniz-Cook, 2016), relationships in dementia (Eriksen et al., 2016), and couples' shared experiences of dementia (Wadham et al., 2016). Murray and Boyd (2009) have examined disparities in the health care of people with dementia, including the effect on personhood and quality of life. Caddell and Clare's (2010) systematic review is a useful reference point for this synthesis, as they reviewed qualitative and quantitative research into self and identity in dementia. My work extends their analysis by providing the first synthesis of qualitative evidence on personhood (including self and identity), within formal care relationships in different care settings, as articulated and expressed by people with dementia. This review provides direct evidence on how people with dementia view personhood, incorporating their perceptions of the self and self-identity, within formal care relationships in different care settings.

The review has two specific objectives: to describe the experiences and perceptions of personhood for people with dementia who are in receipt of formal care services and supports in different care settings, and to examine the potential implications of this synthesis for practice, regulation and policy in dementia care. The protocol for this review was registered with Prospero (CRD42017076114 (21/11/2017)) and subsequently published in a peer-review journal. In order to carry out this review, I undertook two training courses, one an Introduction to Qualitative Evidence Synthesis in NUI Galway, and the second, a course in Systematic Reviews of Quantitative and Qualitative Evidence in Leuven, Belgium.

4.2 Research design and methods

4.2.1 *Search strategy*

A systematic search was conducted using online databases and citation pearls (Booth, 2016). Nine electronic databases were searched: Scopus, Web of Science,

CINAHL, AgeLine, Sociological Abstracts, PsycINFO, Medline, Embase and Cochrane, using variations of the terms: personhood, dementia, and qualitative (Table 4.1), in November 2017. The search terms and databases were chosen in consultation with an expert librarian. In addition, Google Scholar’s “cited by” option was used to find references which had cited either of two citation pearls: Kitwood and Bredin (1992) and Sabat and Harré (1992). The search ran from 1985 onwards to capture any work that may have been published in the lead-up to 1992, when the concept of personhood in dementia first came to the fore. All records were downloaded using Endnote or Zotero; duplicates were removed in Endnote and remaining records were uploaded into Covidence, a review screening software. The reference lists of the included studies were hand searched.

Table 4.1: Search string

	personhood OR person*hood OR selfhood OR self*hood OR self-identity OR self*identity OR identity OR “sense of self” OR self (Title and abstract)
AND	dementia OR Alzheimer* OR “Lewy Bod*” OR “vascular dementia” OR pick* OR Huntington* OR frontotemporal OR Creutzfeldt-Jakob OR “cognitive impairment”(Title and abstract)
AND	qualitative OR “mixed*method*” OR narrative OR phenomenol* OR ethnograph OR ethnonursing OR ethnological OR questionnaire OR “grounded*theory” OR “case*stud*” OR “action*research” OR “focus*group*” OR thematic OR construction* OR hermeneutic OR heurist* (Title and abstract)

4.2.2 Screening

Title/abstract screening and full-text screening were carried out by two authors independently. Table 4.2 contains the inclusion/exclusion criteria. Titles and abstracts not in English were translated using Google Translate. Similar to the experience of Caddell and Clare (2010) in defining the self for their review, the complexities of defining personhood proved challenging. Many papers did not define personhood which sometimes led to an absence of clarity in relation to both objectives and methodologies, thereby creating difficulty during the screening process. This led the review team to apply the CART criteria to support the screening process (Appendix A). The CART is comprised of four criteria:

completeness, accuracy, relevance and timeliness (Whitaker et al., 2016). Completeness refers to the depth and type of reporting in the article, excluding materials that are incomplete. Accuracy refers to how close the aims/objectives of the study are to the review question. Relevance refers to how relevant the study was in terms of setting, population and phenomenon of interest. Timeliness refers to when a concept or approach became relevant. The latter was not used to exclude studies in this review as a date restriction of 1985 onwards had already been set in the search criteria (Whitaker et al., 2016).

Table 4.2: Inclusion and exclusion criteria

Included	Excluded
Primary research studies reported in peer-reviewed articles.	Non peer-reviewed items including: grey literature, reports and theses Literature reviews and editorials.
Qualitative and mixed method research.	Quantitative research. Studies which collect data qualitatively and analysed it quantitatively.
Study participants are people with any type of dementia. A formal diagnosis of dementia was not necessary. Studies were included once the study author(s) stated that the participants had dementia.	People who do not have dementia including those with mild cognitive impairment, family carers, formal carers, clinicians etc.
Studies examining the experiences and perceptions of personhood for people with dementia which included studies of the self, self-identity, selfhood and sense of self. If studies examined personhood along with another concept in dementia then it must be possible to extract the information specific to personhood in order for the study to be included in the synthesis.	Research on artistic expressions of personhood including interpretation of texts, art or film. Studies which examine interventions to support personhood including for example, reminiscence, person-centred care interventions, self-management interventions etc. Studies which examine other elements of subjective experiences in dementia such as coping, dignity, respect etc.
Studies in different types of care settings including: home care, day care and long-term care settings	Studies in non-care related settings.
Studies from any country and in any language.	

Assessment of methodological limitations

The Critical Appraisal Skills Programme (CASP) Qualitative Checklist was used for quality assessment (CASP, 2018); (Appendix B). The CASP checklist identifies issues to be considered when appraising a qualitative study, including its validity and if the results are of value locally (CASP, 2018). It was not used to exclude studies from the synthesis, because how a study is reported is not necessarily an indication of how the study was conducted (Dixon-Woods et al., 2007). The CASP questions along with other important characteristics of the studies were detailed within NVivo (software version 11 2015, QSR International Pty Ltd) using the Case Classifications option (Houghton et al., 2017). These characteristics, guided by Thomas and Harden (2008) and Noyes et al. (2018), were: author, year, number of participants, type of dementia, other participants, age, number of female participants, number of male participants, methodology, methods, location, setting, where participants lived and aims/objectives (Table 4.3).

4.2.3 Thematic synthesis

RETREAT provides a framework of seven criteria to guide researchers in choosing the appropriate method for a qualitative evidence synthesis. These criteria are: the review question, epistemology, time/timescale, resources, expertise, audience and purpose/type of data (Booth et al., 2018). Given the number of included studies, RETREAT guided us to use thematic synthesis over meta-ethnography to synthesise the data (Thomas & Harden, 2008; Booth et al., 2018). Thematic synthesis involves the systematic coding of data and the generation of descriptive and analytical themes. It moves beyond solely describing qualitative studies to developing new explanations or interpretations of these studies' findings (Barnett-Page & Thomas, 2009). The approach is particularly useful for providing information and guidance for policy and practice (Barnett-Page & Thomas, 2009). The data was synthesised within NVivo directly from the included papers. Thomas and Harden (2008) and Noyes et al. (2018) highlight the difficulty in defining what 'data' is within qualitative research. The data synthesised in this review are direct participant quotes and observations along with authors' findings and observations, meaning that both direct findings from ethnographic studies and themes identified by the authors were included. Authors' discussions and comparisons of findings to other literature were not coded. The coding involved three steps: line by line coding to

develop 'free codes', that were then grouped into descriptive themes and subsequently combined into analytical themes (Thomas & Harden, 2008). The descriptive themes stick closely to the data of the original papers whereas the analytical themes move beyond the raw data and directly address the aims of the review (Thomas & Harden, 2008). Each stage was captured within NVivo for group discussion and a clear audit trail was developed. Following synthesis, key findings were developed to reflect the core findings. The GRADE CERQual tool was used to assess confidence in these key findings (Lewin, Booth, et al., 2018). This tool uses four components for assessing confidence in the findings of qualitative evidence synthesis: methodological limitations, coherence, adequacy of data, and relevance. It then grades the findings according to high, moderate and low confidence (Appendix C).

4.3 Results

The search found 9,150 records for screening (Figure 4.1). Full-text screening identified 58 primary studies suitable for inclusion in the review, 38 were subsequently excluded using the CART criteria (Appendix A). Twenty papers were included in the final synthesis, including one paper not in English for which the paper's authors provided a translation. The included papers involve 179 participants with dementia across five countries, Canada, Japan, Sweden, the United Kingdom and the United States of America. At least 98 participants were female and 70 were male (one study did not report gender details). The age of participants ranged from 49-97 years. The studies took place across a variety of care settings: long-term care facilities, a psychogeriatric day hospital, a memory clinic, day care centres and participants' own homes (Table 4.3).

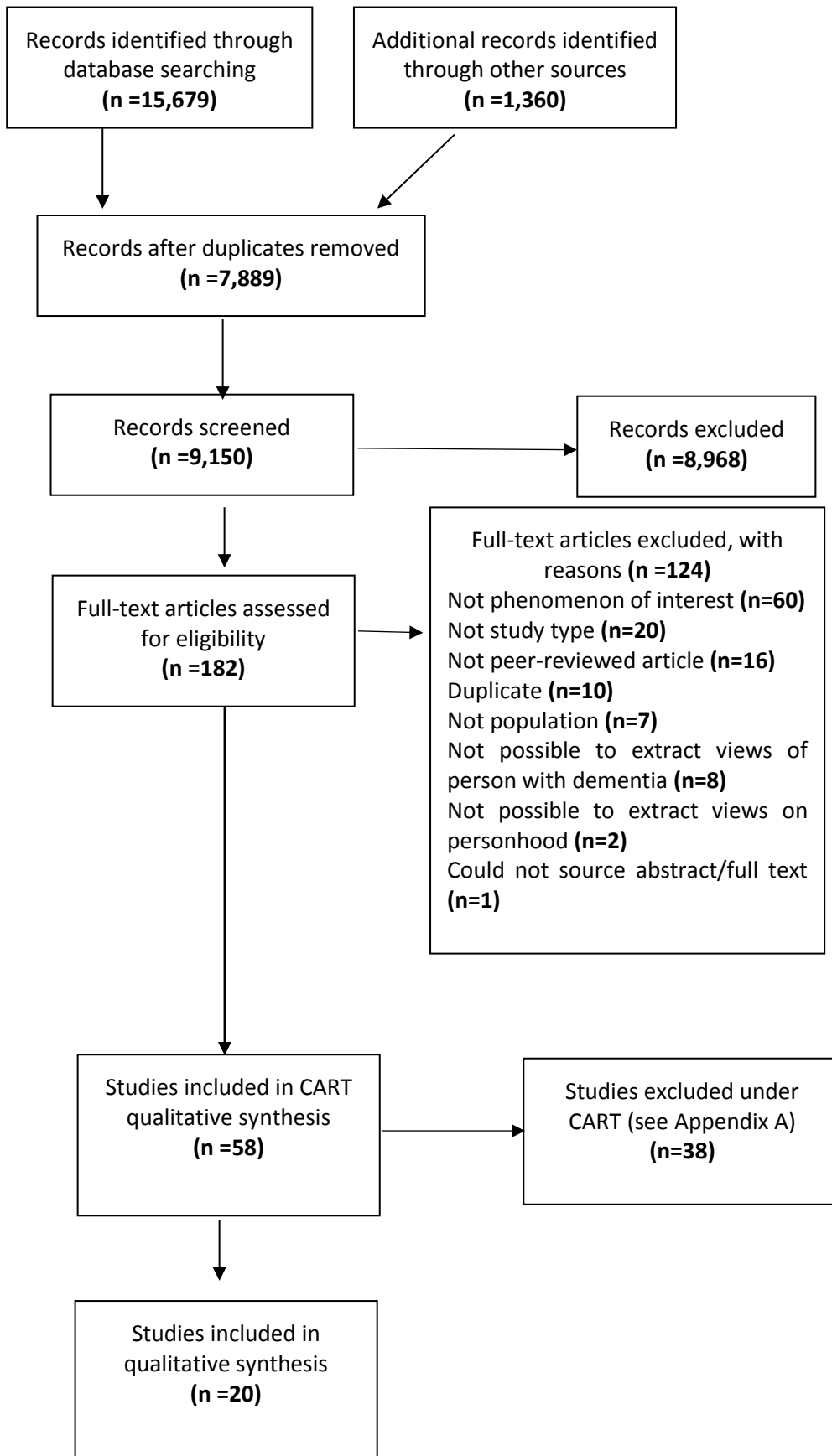


Figure 4.1: PRISMA (2009) flow diagram

Table 4.3: Included studies' characteristics

Author(s), year,	Country	Study aim	Design and methods	No.	Type of dementia	Setting
Anbäcken, Minemoto, and Fujii 2015	Japan	The purpose and scope of this article is to picture and analyse expressions of identity and self in the daily life of residents at a group home for older persons with dementia in Japan.	Ethnographic approach involving observation (n=19) and interviews (n=6)	19	Mix of dementias	Long-term care facility
Batra et al. 2016	USA	This study was designed to assess whether the narratives of self are similar in people with AD and others without cognitive impairment.	Qualitative approach using semi-structured interviews	7	AD	Residential dementia care facility
Beard 2004	USA	This study examined the impact of being diagnosed with early AD on identity construction.	Grounded theory approach involving interviews, focus groups and observation	13	ESAD	Mix: support group, diagnostic setting, community
Borley and Hardy 2017	UK	The aim of this study is to explore the lived experience of becoming cared for and the impact this has on the identity and sense of self of women with Alzheimer's disease.	Interpretative phenomenology using semi-structured interviews	8	AD	Community
Hung and Chaudhury 2011	Canada	This paper explores the concept of personhood in dining experiences of residents with dementia living in long-term care facilities.	Ethnographic approach and examination of policy documents	20	Mix of dementias	Dining room
Kontos 2012	Canada	This paper argues for an expansion of the discourse on sociability in dementia to include embodied selfhood as a source of interactive practices.	Ethnographic approach using observation	13	Mix of dementias	Long-term care facility dementia specific floor

Table 4.3: Continued

Author(s), year,	Country	Study aim	Design and methods	No.	Type of dementia	Setting
Kontos 2004	Canada	This theoretical framework of embodiment informs the analysis reported in this paper of the findings of an ethnographic study of selfhood in Alzheimer's disease in a long-term care facility in Canada.	Ethnographic approach using observation	13	Mix of dementias	Long-term care facility dementia specific floor
Li & Orleans 2002	USA	The purpose of this article is to examine the behaviors of Alzheimer's patients as they convey conceptions of self through their communication and interaction and to explore the ways these patients respond to their immediate environment signifying some attachment of personal subjectivity to the social world.	Grounded theory approach using observation and interviews with caregivers	4	AD	Residential dementia care facility
Lloyd, Kalsy, & Gatherer 2007	UK	The aim of this research was to explore the perspectives and subjective experiences of individuals with Down syndrome living with dementia.	Interpretative phenomenology using semi-structured interviews	6	Dementia and Intellectual disability	Long-term care facility
Mills 1997	UK	The apparent relationship between types of memory and emotion in dementia is significant and worthy of further investigation. A research project was, therefore, designed to examine these phenomena in more depth.	Case-study approach	8	Mix of dementias	Psychogeriatric day hospital
Nowell, Thornton, & Simpson 2013	UK	This study aimed to understand personhood by exploring the subjective experiences of those with dementia.	Interpretative phenomenology using semi-structured interviews	7	Mix of dementias	Ward setting

Table 4.3: Continued

Author(s), year,	Country	Study aim	Design and methods	No.	Type of dementia	Setting
Sabat & Harré 1992	USA	The loss of self in Alzheimer's Disease is examined from a social constructionist view of the nature of the self.	Case-study approach, interactions and observations	3	AD	Day care center
Sabat & Collins 1999	USA	The paper explores in detail the case of an AD sufferer and attempt to provide specific empirical evidence, derived from her discourse in the social setting of a day care center, for the existence of indicators of relative wellbeing, manifestations of selfhood, and thus the existence of complex cognitive functions that remain intact despite deficits.	Case-study, interactions and observations	1	AD	Day care center
Sabat et al. 1999	USA	The articles uses a case study approach to examine relations between AD sufferers and the non-afflicted, focusing on the strategies used by the former to maintain their sense of self-worth.	Case-study, interactions and observations	4	AD	Day care center or own homes
Saunders 1998	USA	This article describes the ways in which older dementia patients use memory-related accounts to socially construct their identity during a visit to the memory clinic.	Discursive analysis of transcripts of neuropsychological examinations	17	Mix of dementias	Memory Clinic
Shenk et al. 2002	USA	This paper contributes to the understanding of the continuity of self-identity in dementia as portrayed in life story, as well as the implications of such continuity for the care of the person with dementia.	Narrative life story using interviews	1	Dementia	Residential care facility (supported independent living)
Shenk, Min-Xia, & Zhi-Jun, 2008	USA	The article examines how people with Alzheimer's disease maintain their identity and sense of self as evidenced in their conversation over time.	Narrative life story using interviews	2	Dementia	Residential care facility (supported independent living)

Table 4.3: Continued

Author(s), year,	Country	Study aim	Design and methods	No.	Type of dementia	Setting
Surr 2006	UK	This study aimed to provide empirical evidence to examine the relevance of a socio-biographical theory of self to people with dementia living in residential care.	Narrative life story using interviews	14	Mix of dementias	Long-term care facilities (4)
Tolhurst & Weicht 2017	UK	This article draws upon qualitative research that included joint interviews with 14 men with dementia and their carers. The analytical focus is on the perspectives of the men with dementia and the strategies with which they respond to the condition.	Narrative analysis using semi-structured interviews	14	Mix of dementias	At home
Westius, Kallenberg, & Norberg 2010	Sweden	The aim of this study is to elucidate the role of the view of life of people with Alzheimer's in framing their sense of identity.	Phenomenological hermeneutic method using narrative life story interviews	21	AD	Day care center or own homes

Three analytical themes were identified in the data: living with change, maintaining sense of self and managing care arrangements (Table 4.4).

Table 4.4: Analytical themes

Analytical themes	Sub-themes
1. Living with change	Life Changes Adapting to the diagnosis
2. Maintaining sense of self	Important relationships Knowing who I am Continuity of self
3. Managing care arrangements	Environmental changes Adapting to environmental changes Relationships in the care setting

4.3.1 Theme 1: Living with change

Theme 1 refers to the changes people with dementia experience because of dementia, and how they manage and adapt to these changes, reflecting a similar theme identified by Górska et al. (2017). It contains two subthemes: life changes and adapting to the diagnosis.

4.3.1.1 Life changes

Many participants experienced changes because of dementia including changes to day-to-day living, and new experiences brought about by memory loss. Participants spoke about becoming aware of memory problems (Saunders, 1998; Beard, 2004). In one study, a participant described feeling things were just not right (Beard, 2004). There were also references to the experience of forgetting things (Sabat & Harré, 1992; Mills, 1997; Saunders, 1998; Lloyd, Kalsy, & Gatherer, 2007).

“They tell me and I keep forget, yeah. Yeah, erm they told me Julie, I forgot the name, Julie. I can’t think, yeah” (Lloyd et al., 2007, p. 75).

Participants experienced a loss of role when no longer able to do the things they used to do (Sabat & Harré, 1992; Mills, 1997; Sabat et al., 1999; Surr, 2006; Lloyd

et al., 2007; Westius, Kallenberg, & Norberg, 2010; Batra et al., 2016; Borley & Hardy, 2017). For example, Phyllis spoke about no longer being able to do things and how this affected her role as a woman.

“Phyllis: It’s just that you’re not a woman anymore because you’re not doing the things you should be doing” (Borley & Hardy, 2017, p. 1019).

Some grieved the loss associated with physical decline (Li & Orleans, 2002; Lloyd et al., 2007); others experienced difficulty narrating self as previous powers waned (Mills, 1997; Batra et al., 2016). Participants recognised changes in self because of dementia (Nowell et al., 2013), and spoke about the effect of changing roles on identity (Lloyd et al., 2007; Nowell et al., 2013; Anbäcken, Minemoto, & Fujii, 2015).

*“How can I put the two together? I am the same but I am different”
(Nowell et al., 2013, p. 402).*

Participants experienced negative feelings around having dementia and the changes it brought, including anger, devastation, confusion, feeling distressed and feeling frustrated (Sabat & Harré, 1992; Mills, 1997; Saunders, 1998; Sabat & Collins, 1999; Sabat et al., 1999; Beard, 2004; Lloyd et al., 2007; Kontos, 2012; Nowell et al., 2013; Anbäcken et al., 2015; Borley & Hardy, 2017).

“When I first found out what was my diagnosis I couldn’t believe it... it was like something’s wrong with me and it was really.. . really sad. ... It was nasty, I was nasty” (Beard, 2004, p. 421).

However, some people reported positive feelings, including contentment, seeing a positive side to having dementia and taking it day by day (Mills, 1997; Beard, 2004; Westius et al., 2010; Anbäcken et al., 2015; Batra et al., 2016; Borley & Hardy, 2017; Tolhurst & Weicht, 2017). Mrs. T expressed contentment with her life:

“[Are] you are happy about your life?’ she affirmed, ‘Yes, even now, actually” (Westius et al., 2010, p. 1271).

4.3.1.2 *Adapting to the diagnosis*

Participants engaged in a continuum of strategies to adjust to the changes brought about by dementia. Participants talked about accepting or partially accepting their diagnosis and/or symptoms of dementia (Mills, 1997; Saunders, 1998; Sabat et al., 1999; Beard, 2004; Lloyd et al., 2007; Shenk, Min-Xia, & Zhi-Jun, 2008; Nowell et al., 2013; Anbäcken et al., 2015; Borley & Hardy, 2017; Tolhurst & Weicht, 2017).

“And I know certain things, I know like memory loss, and this happens all the time with me, but I said, ‘Well, that’s probably part of Alzheimer’s”

(Beard, 2004, p. 423).

Some participants used denial as a way of managing dementia including: not thinking about it, blaming it on getting older, or claiming not to have memory problems (Mills, 1997; Saunders, 1998; Beard, 2004; Lloyd et al., 2007; Shenk et al., 2008; Nowell et al., 2013; Anbäcken et al., 2015; Borley & Hardy, 2017; Tolhurst & Weicht, 2017).

“I don’t think there is anything wrong with me. I can’t understand why I am here. That’s my problem. Physically, I feel pretty good. (Ken)” (Nowell et al., 2013, p. 400).

et al., 2013, p. 400).

Other participants used humour as a strategy to manage change (Mills, 1997; Saunders, 1998; Sabat & Collins, 1999; Beard, 2004; Shenk et al., 2008; Tolhurst et al., 2014; Anbäcken et al., 2015; Borley & Hardy, 2017; Tolhurst & Weicht, 2017).

“Is not that awful, it’s just that my brain is off (cough) a key (laughs)” (Saunders,

1998, p. 74).

Many attempted to take back control by hiding, masking or minimising the difficulties they experienced (Sabat & Harré, 1992; Mills, 1997; Saunders, 1998; Sabat & Collins, 1999; Sabat et al., 1999; Lloyd et al., 2007; Shenk et al., 2008; Tolhurst & Weicht, 2017).

“To be honest with you, I hide it from - you know - all of the people I see. They don’t know what’s wrong with me, I’m sure, but –” (Shenk et al., 2008, p. 8).

Others attempted to take back control by defending their agency or fighting back (Mills, 1997; Westius et al., 2010; Nowell et al., 2013; Tolhurst & Weicht, 2017), by focusing on what they could do (Saunders, 1998; Sabat et al., 1999; Beard, 2004; Lloyd et al., 2007; Borley & Hardy, 2017; Tolhurst & Weicht, 2017), or by staying active or maintaining roles (Sabat et al., 1999; Li & Orleans, 2002; Beard, 2004; Lloyd et al., 2007; Tolhurst & Weicht, 2017).

“I felt it's up to me to try and do what I can do. And listen to what they have to tell me” (Tolhurst & Weicht, 2017, p. 32).

Participants sought to tailor their skills, to manage their new cognitive difficulties (Sabat & Collins, 1999; Sabat et al., 1999; Beard, 2004; Lloyd et al., 2007), this included sometimes lowering expectations following a diagnosis (Lloyd et al., 2007). Participants discussed their decision and experience of telling others about diagnosis (Tolhurst & Weicht, 2017), sometimes finding that being open about their diagnosis was empowering (Beard, 2004), or resulted in their being treated with kindness and compassion (Beard, 2004; Westius et al., 2010). Dealing with the diagnosis was easier if there was support from other people and lines of communication remained open and strong (Beard, 2004; Lloyd et al., 2007; Westius et al., 2010; Nowell et al., 2013).

4.3.2 Theme 2: Maintaining sense of self

This theme focuses on what people with dementia do to preserve and maintain the self through: important relationships, knowing who I am and continuity of self.

4.3.2.1 Important relationships

Family and friendships were frequently referenced as a very important part of the self. Childhood relationships and experiences, and social and occupational roles throughout life, contributed to the development of a sense of self. Participants spoke about their childhood, referencing their parents, siblings and grandparents (Mills, 1997; Saunders, 1998; Shenk et al., 2008; Westius et al., 2010; Nowell et al., 2013), describing both good relationships/experiences (Shenk et al., 2002; Shenk et al., 2008; Westius et al., 2010; Nowell et al., 2013; Batra et al., 2016; Borley & Hardy, 2017) and bad relationships/experiences (Mills, 1997; Sabat & Collins, 1999; Lloyd et al., 2007; Westius et al., 2010; Hung & Chaudhury, 2011; Nowell et al., 2013;

Anbäcken et al., 2015; Batra et al., 2016).

“...and I washed clothes and helped momma cook and clean the house and stuff like that. I was the oldest child and I had sisters and brothers that I helped with” (Batra et al., 2016, p. 1270).

Family relationships were important (Mills, 1997; Li & Orleans, 2002; Shenk et al., 2002; Surr, 2006; Lloyd et al., 2007; Shenk et al., 2008; Westius et al., 2010; Nowell et al., 2013; Anbäcken et al., 2015), as well as participants' changing role within the family (Sabat & Harré, 1992; Surr, 2006; Anbäcken et al., 2015; Borley & Hardy, 2017).

“Although she could not talk fluently, Grace was still a loving, caring, and proud mother” ... “she kept touching her daughter Joan's short sleeve and asking repeatedly, “Are you cold?” (Li & Orleans, 2002, p. 235).

“Don't hardly know how much your kids mean to you 'til your daddy- 'til their daddy's gone” (Shenk et al., 2008, p. 13).

People with dementia discussed not wanting to burden family (Sabat & Harré, 1992) and the importance of giving their family carer a break (Tolhurst & Weicht, 2017). Participants mentioned their spouses (Mills, 1997; Saunders, 1998; Shenk et al., 2002; Shenk et al., 2008; Hung & Chaudhury, 2011; Anbäcken et al., 2015; Batra et al., 2016; Borley & Hardy, 2017), good qualities they had (Sabat & Harré, 1992; Mills, 1997; Westius et al., 2010; Batra et al., 2016), their spouses' occupations (Shenk et al., 2002; Batra et al., 2016) and the effect of dementia on the spousal relationship (Borley & Hardy, 2017). Participants also emphasised the importance of friendship (Surr, 2006; Batra et al., 2016) and peer support (Beard, 2004).

People with dementia spoke about relationships in general, about the value and enjoyment they got out of interacting with others (Mills, 1997; Lloyd et al., 2007; Westius et al., 2010; Batra et al., 2016; Borley & Hardy, 2017). Participants described the impact people had on their life (Batra et al., 2016), including the importance of love (Mills, 1997; Li & Orleans, 2002; Shenk et al., 2002; Surr, 2006; Lloyd et al., 2007; Shenk et al., 2008; Hung & Chaudhury, 2011; Anbäcken et al., 2015; Borley & Hardy, 2017), caring for one another (Sabat & Harré, 1992; Mills, 1997; Shenk et al., 2002; Surr, 2006; Shenk et al., 2008; Westius et al., 2010; Tolhurst & Weicht, 2017) and sexuality (Batra et al., 2016; Borley & Hardy, 2017).

They mentioned bereavement and other losses they had experienced (Mills, 1997; Sabat & Collins, 1999; Shenk et al., 2002; Surr, 2006; Lloyd et al., 2007; Shenk et al., 2008; Anbäcken et al., 2015; Batra et al., 2016).

“...one time he did it and down he went on the floor, and a couple of the men from the ... thing went to help him up and he was dead. ... That’s why I’m living here now. Mm. Miss him terribly, you know” (Surr, 2006, p. 1727).

*“LH: Margaret, what do you like or dislike about eating here?
Margaret: I’m speaking for myself. I don’t know about the others. Uh, to me, love is very important to us, as human. I think there is something lost in today’s world”* (Hung & Chaudhury, 2011, p. 12).

4.3.2.2 *Knowing who I am*

Participants had clear and defined understandings of who they were, their role identity, their likes, dislikes and self-image. They described what was important to them, and the social and occupational roles they played. Participants referenced different elements of their self-image such as; appearance, beliefs, spirituality, values, cultural norms, education and gendered roles (Sabat & Harré, 1992; Mills, 1997; Li & Orleans, 2002; Shenk et al., 2002; Kontos, 2004; Surr, 2006; Shenk et al., 2008; Westius et al., 2010; Anbäcken et al., 2015; Batra et al., 2016; Tolhurst & Weicht, 2017).

“I belong to the happy people. If I saw a sad person ... I went over there [to him or her] and tried to make it better. ... I was light-hearted. ... I liked to sing” (Westius et al., 2010, p. 1267).

Participants highlighted the importance of past roles and childhood on the self (Saunders, 1998; Sabat et al., 1999; Li & Orleans, 2002; Lloyd et al., 2007; Shenk et al., 2008; Westius et al., 2010; Nowell et al., 2013; Anbäcken et al., 2015; Tolhurst & Weicht, 2017). Participants identified the different roles they played such as being a helpful daughter, fulfilling a domestic role, and being a religious person (Sabat et al., 1999; Surr, 2006; Lloyd et al., 2007; Shenk et al., 2008; Nowell et al., 2013; Batra et al., 2016; Borley & Hardy, 2017; Tolhurst & Weicht, 2017). They also

recognised their own strengths such as self-respect and, generally, were clear about who they were (Sabat & Harré, 1992; Mills, 1997; Saunders, 1998; Sabat & Collins, 1999; Sabat et al., 1999; Li & Orleans, 2002; Kontos, 2004; Shenk et al., 2008; Westius et al., 2010; Anbäcken et al., 2015; Tolhurst & Weicht, 2017). A participant in Mills (1997) study sees themselves as a good person:

“ My great problem is I’m too gentle...I personally feel that I’m...I’m a bit too good...I’m not in the habit of getting in trouble with any...not even the police or nothing...I was...To be truthful, I was a little angel! I shouldn’t say that really but I was! To myself!” (Mills, 1997, p. 693).

The effect of negative life experiences on the self were also outlined (Mills, 1997; Westius et al., 2010). Occupation was referenced frequently by participants, and was strongly linked to and part of the self. Participants referenced previous jobs and what they enjoyed about them (Sabat & Harré, 1992; Mills, 1997; Saunders, 1998; Sabat et al., 1999; Li & Orleans, 2002; Shenk et al., 2002; Surr, 2006; Lloyd et al., 2007; Westius et al., 2010; Hung & Chaudhury, 2011; Nowell et al., 2013; Anbäcken et al., 2015; Batra et al., 2016; Borley & Hardy, 2017; Tolhurst & Weicht, 2017). There were references to gendered occupational roles and how some felt it was their duty to carry out these roles (Sabat et al., 1999; Shenk et al., 2002; Surr, 2006; Lloyd et al., 2007; Westius et al., 2010; Anbäcken et al., 2015; Borley & Hardy, 2017; Tolhurst & Weicht, 2017). Participants talked about activities, their likes and hobbies including; cars, colour, dance, fashion, food, knitting, music, nature and television (Sabat & Harré, 1992; Sabat et al., 1999; Li & Orleans, 2002; Beard, 2004; Kontos, 2004; Lloyd et al., 2007; Hung & Chaudhury, 2011; Kontos, 2012; Batra et al., 2016; Borley & Hardy, 2017).

“I don’t think we should let the Alzheimer’s eat us up. If you like to play checkers, play them!” (Beard, 2004, p. 424).

Some mentioned the importance of having and keeping a sense of purpose (Mills, 1997; Sabat et al., 1999; Li & Orleans, 2002; Lloyd et al., 2007; Westius et al., 2010; Anbäcken et al., 2015).

“Peter: Don’t have jobs. Always trying to help something though” (Lloyd et al., 2007, p. 72).

4.3.2.3 *Continuity of self*

Some participants were able to engage with those around them to project their sense of self out into the world. Participants used different strategies to maintain the self and create a sense of continuity. Participants expressed the self through the use of personal pronouns, such as I and me, and through non-verbal communication, portraying embodied selfhood (Sabat & Harré, 1992; Mills, 1997; Sabat & Collins, 1999; Beard, 2004; Kontos, 2004; Shenk et al., 2008; Batra et al., 2016). There were many examples of people with dementia narrating self through life story conversations (Sabat & Harré, 1992; Mills, 1997; Li & Orleans, 2002; Surr, 2006; Westius et al., 2010; Anbäcken et al., 2015; Tolhurst & Weicht, 2017).

Participants responded to encroachments on the self through different proactive strategies and attempts to maintain continuity of the self. These included managing their image to preserve their identity, communicating through metaphor, being a member of a group and asserting self (Sabat & Harré, 1992; Mills, 1997; Saunders, 1998; Sabat & Collins, 1999; Sabat et al., 1999; Li & Orleans, 2002; Beard, 2004; Surr, 2006; Lloyd et al., 2007; Westius et al., 2010; Nowell et al., 2013; Tolhurst & Weicht, 2017).

“Respondents devised systems to minimize those things that might ‘expose’ them, like cooking, driving, and being at social events or in unfamiliar surroundings” (Beard, 2004, p. 424).

“She’s looking after me and she’s always going to look after me, so I have to help her as well don’t I. (Oliver)” (Tolhurst & Weicht, 2017, p. 33).

Participants asserted the self in how they chose to engage in activities, occupational and social roles. For example, many participants engaged in caring and supportive roles within the care settings as a strategy to stay occupied and to find purpose (Sabat & Harré, 1992; Sabat et al., 1999; Li & Orleans, 2002; Kontos, 2004; Surr, 2006; Lloyd et al., 2007; Westius et al., 2010; Kontos, 2012; Anbäcken et al., 2015; Tolhurst & Weicht, 2017).

“Her ‘job’ was essentially to be the ‘life of the party’ at the day care center” ... “that she cheered them up with her songs and jokes (‘I got a

million of 'em!')" (Sabat et al., 1999, p. 21).

"And so then I decided to go to the gym, because when people know I go to the gym, they've got more idea as to what the situation is. I could go out and say "Oh well I've joined the gym now". It was a means of conversation, and not just saying, "By the way do you know that I'm a nutter?" (Timothy)" (Tolhurst & Weicht, 2017, p. 32).

Some participants attempted to stay engaged but not necessarily active (Sabat et al., 1999; Li & Orleans, 2002; Kontos, 2004; Lloyd et al., 2007; Hung & Chaudhury, 2011), while some felt they did not have enough activity in their lives (Sabat et al., 1999; Li & Orleans, 2002; Lloyd et al., 2007; Batra et al., 2016; Borley & Hardy, 2017). Other participants choose not to do things (Sabat & Harré, 1992; Sabat et al., 1999; Li & Orleans, 2002; Lloyd et al., 2007; Borley & Hardy, 2017) and some were passive about getting involved (Lloyd et al., 2007; Westius et al., 2010; Nowell et al., 2013). Several experienced a decline in activity (Sabat & Harré, 1992; Lloyd et al., 2007; Tolhurst & Weicht, 2017) and others reflected on having to give up driving (Mills, 1997; Borley & Hardy, 2017).

4.3.3 *Theme 3: Managing care arrangements*

Formal care is an important part of the life of many people with dementia, resulting in new and sometimes challenging experiences, as well as different types of relationships. This theme looks at the changes associated with formal care arrangements and provision.

4.3.3.1 *Environmental changes*

Environmental changes refer to changes to place experienced when the person with dementia could no longer live at home, necessitating transfer to new care settings, both short-term and long-term. Loss of autonomy was experienced by some participants in their own homes and in day care settings (Mills, 1997; Sabat et al., 1999; Borley & Hardy, 2017), however, loss of autonomy was even more prevalent in long-term care settings, where residents were expected to adhere to the settings' rules and may have no choice but to endure the regime (Beard, 2004; Lloyd et al., 2007; Hung & Chaudhury, 2011; Nowell et al., 2013; Anbäcken et al., 2015; Batra et al., 2016). One participant referenced that they *"ought to tie me*

down” in relation to wandering (Beard, 2004, p. 424), while another participant felt trapped in the setting:

“When you are kind of trapped in a situation where your presence elsewhere isn’t possible you have to take what’s available and deal with it” (Nowell et al., 2013, p. 401).

One participant living at home with her husband felt like a prisoner:

“He doesn’t like me to drive, so I can’t... I can’t see what I’ve got to look forward to....I’m not happy; it’s like being in a prison really, just going out when he goes” (Borley & Hardy, 2017, p. 1019).

Another study referenced how participants adapted to mealtimes with others in long-stay care settings (Kontos, 2012). Barriers to adjusting to the long-stay care environment included residents being constantly rushed and difficulties with the design of the physical environment (Hung & Chaudhury, 2011). Participants sometimes used non-verbal communication to show that they had been institutionalised into new care settings (Li & Orleans, 2002; Nowell et al., 2013). Negative feelings attached to the residential settings included: anger, feeling abandoned, feeling like an outsider, feeling bored, confused, disrespected, frustrated, and lonely (Mills, 1997; Sabat et al., 1999; Li & Orleans, 2002; Surr, 2006; Lloyd et al., 2007; Shenk et al., 2008; Hung & Chaudhury, 2011; Nowell et al., 2013; Anbäcken et al., 2015; Tolhurst & Weicht, 2017). The following exchange reveals how angry one person with dementia was about being kept in a secure ward in a psychogeriatric day hospital:

“Int. And you feel angry? MR. I do! Very! Very! MR.NNNN!can’t can’t can’t do d told. I I I not not not said! I’ve never seen la seen er...and anything else! And that’s what’s onononmymymybad head! [MR sounded frustrated and angry]” (Mills, 1997, p. 690).

In one long-term care setting, a participant thought the *“place is not fit for humans to live”* (Hung & Chaudhury, 2011, p. 10), and many reported that would have preferred to live in their own homes (Surr, 2006; Lloyd et al., 2007; Hung & Chaudhury, 2011). However, there were also examples of people being content with the long-term care setting (Kontos, 2004; Shenk et al., 2008; Anbäcken et al.,

2015) as well as day care and home settings (Westius et al., 2010; Tolhurst & Weicht, 2017), this included feeling connected and important in the setting (Sabat & Harré, 1992; Sabat et al., 1999; Nowell et al., 2013). One participant was content with her life in a long-term care setting:

“Now I am renting a room here and am thankful for that. I can do what I like” (Anbäcken et al., 2015, p. 72).

4.3.3.2 *Adapting to environmental changes*

Participants highlighted difficulties adapting to long-term care settings such as making friends and feeling trapped (Sabat & Harré, 1992; Sabat et al., 1999; Surr, 2006; Shenk et al., 2008; Nowell et al., 2013; Anbäcken et al., 2015). Some highlighted the importance of working out the new system of care and learning the rules in the new setting (Sabat et al., 1999; Lloyd et al., 2007; Nowell et al., 2013).

“Participants described adjusting both their expectations and feelings about the system to fit the system, rather than the reverse being true” (Nowell et al., 2013, p. 399).

“Yet Alice minimized this by describing her own negative response to it as ‘being naughty’, indicating both infantilization of herself and the belief that she should have simply accepted the situation without complaint” (Lloyd et al., 2007, p. 78).

Many attempted to maintain independence within the new settings, be it long-term care (Li & Orleans, 2002; Beard, 2004; Lloyd et al., 2007; Anbäcken et al., 2015) or community settings (Sabat et al., 1999; Borley & Hardy, 2017).

“But Katherine and Grace required pushing, and most of the time Grace would not come. She enjoyed sitting where she was and left whenever she wanted” (Li & Orleans, 2002, p. 236).

4.3.3.3 *Relationships in the care settings*

This subtheme examines the different relationships participants had in various care

settings, particularly long-term care facilities. These interactions involved people with dementia's efforts to maintain social connectedness with others, to be part of a social group, to create friendships and to enjoy life. Some participants in care settings sought purpose through fulfilling lifelong social roles. Participants sought to interact with other care recipients, through engaging in social etiquette, adopting different social identities and roles, seeking company, developing a romantic relationship, seeking approval from others and connecting with other care recipients, including taking care of them (Mills, 1997; Sabat & Collins, 1999; Sabat et al., 1999; Li & Orleans, 2002; Kontos, 2004; Surr, 2006; Lloyd et al., 2007; Kontos, 2012; Nowell et al., 2013; Anbäcken et al., 2015; Tolhurst & Weicht, 2017). Li and Orleans (2002) describe a situation in which the participants adhered to social etiquette:

"Marion hit the ball too hard, and it flew the opposite direction into the chest of the lady on the other side. Katherine said immediately: "We are sorry to hit you over there"" (Li & Orleans, 2002, p. 234).

Participants acknowledged friendships, fun and humour with other care recipients (Mills, 1997; Sabat et al., 1999; Li & Orleans, 2002; Kontos, 2004; Surr, 2006; Shenk et al., 2008; Kontos, 2012; Anbäcken et al., 2015; Tolhurst & Weicht, 2017). Participants sought to interact through non-verbal communication, some of which was culturally specific (Sabat & Harré, 1992; Sabat & Collins, 1999; Sabat et al., 1999; Kontos, 2004, 2012; Anbäcken et al., 2015). Participants continued to maintain the ability to communicate with others (Sabat & Collins, 1999; Sabat et al., 1999; Li & Orleans, 2002; Kontos, 2004; Anbäcken et al., 2015).

"Dora reached over and placed her hand gently on top of the resident's forearm. Holding her hand there, she sang Tumbalayka, a Yiddish lullaby" (Kontos, 2004, p. 834).

There were negative aspects to some relationships: with participants being annoyed by other care recipients, having difficulty adjusting to living with others, feeling shame around others, being frustrated by others, and finding a lack of empathy from others (Sabat & Collins, 1999; Sabat et al., 1999; Li & Orleans, 2002; Kontos, 2004; Surr, 2006; Lloyd et al., 2007; Shenk et al., 2008; Hung & Chaudhury, 2011; Kontos, 2012; Nowell et al., 2013). Some participants' efforts to interact with others failed entirely and they experienced social isolation (Sabat & Harré, 1992;

Sabat et al., 1999; Li & Orleans, 2002; Surr, 2006; Shenk et al., 2008; Hung & Chaudhury, 2011; Nowell et al., 2013; Anbäcken et al., 2015).

“Keeping the peace was the main priority for staff, and this often resulted in lack of validation for the self-Ethel was asserting. She became more and more socially isolated and her difficult relationship with staff was reflected in Ethel’s interviews, where she spoke at times of being powerless and ignored in the care setting” (Surr, 2006, p. 1725).

Participants adhered to social etiquette with formal carers (Kontos, 2004; Hung & Chaudhury, 2011; Kontos, 2012), and to the social construction of roles (Sabat & Harré, 1992). The importance of social interaction with formal carers was outlined (Sabat et al., 1999; Lloyd et al., 2007; Hung & Chaudhury, 2011). There were examples of participants connecting with formal carers, seeking their approval and having their preferences respected (Sabat & Collins, 1999; Sabat et al., 1999; Li & Orleans, 2002; Surr, 2006; Lloyd et al., 2007; Hung & Chaudhury, 2011). These experiences resulted in participants feeling respected, validated, and supported (Saunders, 1998; Sabat et al., 1999; Hung & Chaudhury, 2011; Anbäcken et al., 2015), clearly demonstrating what supporting personhood looks like in formal care:

“She [a community-based health professional] asks ‘how’s things been, how are you doing?’ And then she’ll get her book out and see what I can remember. I enjoy her company because she is so friendly” (Tolhurst & Weicht, 2017, p. 34).

Participants also experienced negative emotions from interacting with formal carers, including feeling confused, disrespected, frustrated, ignored, lonely, upset and worthless (Saunders, 1998; Sabat & Collins, 1999; Lloyd et al., 2007; Shenk et al., 2008; Hung & Chaudhury, 2011; Nowell et al., 2013; Anbäcken et al., 2015), leaving no doubt as to how formal care can sometimes impact negatively on the personhood of the person with dementia. There were differences in power differentials in care relationships (Sabat & Harré, 1992; Saunders, 1998), as well as reduced autonomy (Hung & Chaudhury, 2011). Sometimes the absence of sufficient staff contributed to negative experiences (Kontos, 2012).

4.4 Discussion

This evidence synthesis has addressed a gap in the existing research by describing the experiences and perceptions of personhood for people with dementia in relation to formal care, in different care settings. It is the first study that has synthesised personhood, selfhood and self-identity as a combined concept. The synthesis found that people with dementia are actively engaged in maintaining their sense of self, described elsewhere as self-maintaining or self-adjusting strategies (Clare, 2003; Caddell & Clare, 2011a; Wolverson et al., 2016). The results show, with high confidence (based on the GRADE CERQual analysis), that relationships were hugely important to participants in this process, supporting evidence from other studies on the importance of familial roles and social interactions, to the self (Harris & Keady, 2009; Boyle, 2017). The self is particularly vulnerable to erosion without the support and cooperation of those around the person with dementia (Sabat, 2002; Eriksen et al., 2016). There was high confidence in findings that people with dementia also maintained the self through occupational and social roles. Engaging in such roles was important to participants, with many referencing past and current roles when discussing self. Findings elsewhere reflect a similar understanding of the importance of meaningful roles in reaffirming sense of self (Harris & Keady, 2009; Hellstrom et al., 2015; Lam & Keller, 2015).

The synthesis also found, with high confidence, that participants experienced a loss of autonomy and feelings of being trapped and imprisoned, particularly in residential care settings. McCormack (2004) refers to the importance of 'being in place' and the role of person-centred care in supporting ageing in place, while Bosco, Schneider, Coleston-Shields, and Orrell (2019) point to the role that the physical care environment can play in supporting personhood. At the very least, the care environment should not cause the person with dementia to experience an erosion of their autonomy, independence and dignity, nor should it exacerbate changes to the self (Cahill, 2018).

The findings are important for informing practice in relation to dementia care, particularly in relation to how the health and social care system should best respond to the changes arising from the diagnosis itself and to changes in care needs and care settings over time (Eriksen et al., 2016; Górska et al., 2017). Supporting people with dementia to live with these changes is an important role of

formal care, helping them to maintain essential elements of personhood, such as independence, autonomy and agency. While families are likely to be the mainstay for supporting the self, formal carers also have a role to play in this regard, through their interactions, exchanges and deliberations with the person with dementia. Practice must, therefore, support and encourage self-enhancing relationships within formal care provision to empower and enable people with dementia to maintain and sustain personhood. Formal care must also acknowledge the importance of lifelong roles and support people with dementia to continue to engage in such roles. Regulatory instruments that incorporate: education, training, standard-setting and outcome assessment will be required to ensure that personhood is incorporated within routine care (Kane, 2001). Additionally, there are differences across care settings in how personhood is conceptualised and supported, highlighting the need for further research on setting-specific issues and interventions.

Care structures in many countries are currently designed around the needs of providers and not the individual needs of people with dementia (O'Shea et al., 2017). Risk averse, paternalistic models designed to keep the person 'safe' without taking into account the individuals' preferences and their need for autonomy are very restrictive for people with dementia (Stephan et al., 2018). However, as Malloy and Hadjistavropoulos (2004) point out, it is not easy or uncomplicated to ensure that care is person-centred, as everyone in the care structure, is influenced by the system and society in which they live. The conceptual view of a formal carer has of people with advanced dementia affects the care they give them (Hughes, 2001; Malloy & Hadjistavropoulos, 2004). Currently, that view is strongly risk averse, paternalistic, and largely institutional in orientation (Smebye et al., 2016), as evidenced in how people with dementia sometimes felt trapped and lacking autonomy in this synthesis. Reframing public policy towards a more personhood oriented provision is, therefore, not likely to be easy in the face of professional, cultural and resource barriers, but it is a necessary condition for real change to occur in the lives of people with dementia (O'Shea et al., 2016).

There is evidence that respect, autonomy, personalised care and enhanced communication skills among formal carers can singularly, and in combination, make an important contribution to personhood within dementia care. This synthesis also reveals that people with dementia understand personhood and can identify its constituent parts. The task now is to ensure that practitioners and policy-makers

deliver the necessary practical changes to make personhood a reality for more people with dementia.

4.5 Declaration of contribution of authors

NH was primarily responsible for the initial idea and received support for the design of the study from AC, CH and EOS. Screening was primarily undertaken by NH, AC and EOS. CART was conducted by NH with support and agreement from AC, CH and EOS. CASP was carried out by NH. The synthesis was carried out by NH with support and agreement from AC, CH and EOS. GRADE CERQual was carried out by NH with support and peer debriefing from CH. All authors contributed to the synthesis findings and discussion.

4.6 Limitations

This review synthesises studies which used different methodologies and conceptualisations of personhood and the self, a point made by Caddell and Clare (2010) in their review. The review did not attempt to address these differences, but instead synthesised all relevant qualitative research, irrespective of theoretical stance or methodology. The quality of the included studies varied. However, using GRADE CERQual to examine the confidence in the findings provided reassurance in relation to the quality of the evidence. Overall, the review findings were mainly of high and moderate confidence, with only two of low confidence. The low confidence findings do not inform the discussion or conclusions, but remain in the findings to provide transparency, and prompt the need for more primary research (Lewin, Bohren, et al., 2018). Due to the large number of relevant studies, it was not feasible to include non peer-reviewed work. Clearly, other forms of information, such as autobiographies, blogs, poetry etc. created by people with dementia, could have provided an ever richer understanding of the lived experience of dementia and personhood. A final limitation is that the review does not incorporate cultural or gender considerations into the synthesis. However, this could be explored in future research through sub-group analysis of the synthesis findings.

4.7 Conclusion

This chapter has synthesised the existing qualitative evidence on personhood in formal care relationships from the perspectives of people with dementia. It finds that people with dementia experience many changes because of dementia and from their subsequent engagement with the health and social care system. They use different strategies to protect and maintain personhood, very often seeking to come to terms with the disease through reflection, as well as through engagement and interaction with others. This review is useful for informing person-centred care models on what matters in relation to personhood and sense of self. Keeping people with dementia connected to others and to their sense of place, however fractured that might be, is important; so too is empowering people to continue to engage in lifelong occupational and social roles. The evidence from this synthesis has shown that seeking out and recognising the person within formal care relationships can have strong positive effects for people with dementia, enabling them to connect with themselves and others, through an enhanced personhood. This is an important message for practitioners and policy-makers. The next two chapters move on to explore the lived experience of personhood of all three groups in the care triad, people with dementia, family carers and formal carers.

Chapter 5: Methodology and methods of the empirical study

5.1 Introduction

This chapter describes the philosophical underpinnings and methods used for the empirical study. The latter explores the perspectives and experiences of personhood of people with dementia, family carers and formal carers within formal care relationships in Ireland. This chapter details the research methodology, research design, research procedures, ethical considerations, data analysis and quality assurance used in this study.

5.2 Research methodology

Research methodology is: “a general approach to studying a research topic. It establishes how one will go about studying any phenomenon” (Silverman, 1993, p. 2). This section details the ontological and epistemological underpinnings of this study.

5.2.1 *Ontology and epistemology*

Ontology is concerned with the nature of reality or how we view knowledge (Creswell, 2014). There are two main ontological positions, objectivism and constructionism (also called constructivism) (Bryman, 2012). Objectivism argues that social phenomena are independent of social actors, and that social phenomena are beyond the reach or influence of social actors (Bryman, 2012). The phenomenon being examined is *not* influenced by the world around it. Constructionism holds an opposing view positing that social phenomena are “continually being accomplished by social actors” (Bryman, 2012, p. 33). So the phenomenon of interest *is* influenced by the world around it. It theorises that the nature of truth is subjective and the result is co-constructed in the relationship between researcher and participant. For example, Sabat and Harré (1992) use the constructionist theory of the self in their work. They posit how, in particular, the Self 3 is co-constructed with those around the person with dementia.

Epistemology is the study of what is considered or accepted as knowledge (Bryman, 2012). There are many different epistemologies and there are differences amongst

authors in how they are described. Positivism views knowledge as being objective and therefore measured objectively (Bryman, 2012). For phenomena that are not easy to objectively measure, for example human emotions or behaviours, science should still attempt to measure them objectively or conclude that they may not be worth measuring. Essentially, positivism supports using natural science methods in the social sciences. The predominant epistemology of the traditional medical model in dementia is positivist in its orientation, one where the person can be objectively assessed and measured.

The opposite of positivism is naturalism which does not accept that every reality and truth can be measured directly. Instead, it theorises that all reality is viewed through that individual's lens of experience, expectations and knowledge (Rubin & Rubin, 2011). Interpretivism, which is a type of naturalism, views knowledge as subjective, that requires "the scientist to grasp the subjective meaning of social action" (Bryman, 2012, p. 30). The main difference between a positivist approach and an interpretivist approach is that the former aims to explain human behaviour while the latter attempts to understand human behaviour. Interpretivism is influenced by hermeneutics, phenomenology and symbolic interactionism (Bryman, 2012). The empirical study in this thesis is theoretically based within a constructivist ontology where reality is viewed as a construct created in co-operation with the social world around it and an interpretative epistemology where knowledge is viewed as subjective and interpreted through the experiences of participants. This theoretical framework is most suited to addressing the third research objective of this thesis (as outlined in Chapter 1): *To identify the core elements, defining natures and fundamental meanings of personhood in dementia as experienced and practiced by people with dementia, their family carers and formal carers in Ireland in different settings.*

Considering the realities involved in carrying out research in the field, particularly with vulnerable and hard to reach groups, this study, while remaining loyal to its theoretical base, takes a flexible and practical approach to the research design and methods. A qualitative methodology was viewed as the most suitable approach to access the experiences and perceptions of the three participant groups: people with dementia, family carers and formal carers. Creswell (1994) outlines the four most frequently used qualitative designs as ethnographies, grounded theory, case studies and phenomenological studies. This study takes a phenomenological approach using interpretative phenomenological analysis (IPA). The key aim of IPA

is to examine how people make sense of their experiences (Pietkiewicz & Smith, 2014). This involves exploring in detail the participant's view of the subject matter being investigated (Smith, Jarman, & Osborn, 1999). IPA is particularly suited to this research question due to its phenomenological base with its focus on the participants' personal experiences and perceptions and its interpretative stance crucial to gaining an 'insider's perspective' on personhood in dementia (Conrad (1987) as cited in Smith et al. (1999), allowing the researcher to make sense of the experiences of participants through interpretation (Smith & Osborn, 2003). IPA is rooted in, and heavily influenced, by phenomenology, hermeneutics and idiography and is particularly well suited as a methodological approach to understanding the experiences of people with dementia, family carers and formal carers.

5.2.2 Phenomenology

Phenomenology is defined as: "an attempt to bring philosophy back from abstract metaphysical speculation wrapped up in pseudo-problems, in order to come in contact with the matters themselves, with concrete living experience" (Moran, 2000, p. xiii). Essentially, it is concerned with how people understand the world around them and how the researcher ought to put aside their own preconceptions when examining that person's 'lived world' (Bryman, 2012, p. 30). Smith, Flowers, and Larkin (2009) identify the four most significant phenomenological philosophers as: Husserl (1927), Heidegger (1962/1927), Merleau-Ponty (1962) and Sartre (1956/1943). Husserl was concerned with understanding how we might accurately come to know our own experiences and argued that it was better to examine that experience in the context of how it had occurred (Husserl (1962) as cited in Smith et al. (2009). Heidegger contributed to phenomenology by examining our experience of 'being' in the world. He theorised that this experience is 'in relation to' the world around us including our relation to other people calling this 'intersubjectivity' (Heidegger (1962/1927) as cited in Smith et al. (2009). The concept of 'intersubjectivity' supports the use of multiple perspective designs (Larkin, Shaw, & Flowers, 2019). Merleau-Ponty examined the embodied nature of being. He posited that while we can attempt to understand and have empathy with someone else's experience, we can never truly experience it as every person comes from their own embodied position in the world (Merleau-Ponty (1962) as cited in Smith et al. (2009). Sartre like Heidegger, emphasised that we are involved in projects in the world, meaning that our experiences are dependent on our

relationships, (or lack of) with other people (Sartre (1956/1943) as cited in Smith et al. (2009). Essentially, phenomenological studies aim to fully understand a given phenomenon and to do so believe that it should be studied as closely as possible to the context in which it occurs (Giorgi & Giorgi, 2003). Therefore it is important to seek out participants who have first-hand experience of the phenomenon of interest in order to capture closely the context in which the phenomenon is experienced, and how the phenomenon is experienced (Giorgi & Giorgi, 2003).

A second significant theoretical influence on IPA is symbolic interactionism (Smith, Flowers, & Osborn, 1997; Smith & Osborn, 2003). It posits that as well as the experience itself, the meaning that people assign to an experience should be of central importance to the researcher and that such meanings can only be arrived at through interpretation (Smith et al., 1997). In the last two decades, research in dementia is focusing more on the lived experience of people with dementia. This is reflected in the fact that philosophical conceptualisations of person-centred care models are based on a phenomenological view of dementia (Edvardsson et al., 2008), and increasingly many studies of the lived experience in dementia use phenomenological approaches, including IPA (Lloyd et al., 2007; Nowell et al., 2013; Borley & Hardy, 2017). Ultimately, phenomenology is concerned with examining the lived experience, allowing that experience to be communicated in its preferred terms rather than being defined by a pre-existing set of criteria. This means that phenomenology is defined within IPA as an interpretative process (Smith et al., 2009).

5.2.3 *Hermeneutics*

Hermeneutics is a theory of interpretation (Bryman, 2012). It has developed over many hundreds of years from a theory of how to interpret biblical texts to interpretation of all types of documents and texts (Smith et al., 2009). Hermeneutics facilitates an understanding of the meaning of text and narrative from the perspective of the original author, while acknowledging the role of the analyst in the interpretation (Bryman, 2012). Hermeneutics attempts to examine different aspects of interpretation, including how the analyst interprets and if the original intentions of the author can be correctly interpreted (Smith et al., 2009). Schleiermacher defined two elements of hermeneutics as the grammatical and the psychological interpretation of a given text (Schleiermacher (1998) as cited in Smith et al. (2009). The first involves examining the text itself and the second the author

of the text. Hermeneutics differs from other forms of qualitative psychology, in that it attempts to understand the meaning of the language used by the author, both explicit and implicit, and, as such, can provide the analyst with insight beyond what the author has formally written (Smith et al., 2009). Phenomenology examines the meaning people ascribe to an experience, while hermeneutics examines the meanings of text. Not surprisingly, at times, the two concepts have become blurred (Smith et al., 1997); for example, some authors use a phenomenological hermeneutical method for interpreting the lived experience (Lindseth & Norberg, 2004; Swall et al., 2017).

Within hermeneutics, the concept of reflexivity has also come up for discussion. Heidegger questioned the feasibility of 'bracketing' all of the researchers preconceptions to one side before embarking on an analysis, arguing that the researcher may not be even able to consciously describe those preconceptions prior to analysis (Heidegger (1962/1927) as cited in Smith et al. (2009)). Gadamer elaborated on Heidegger's work arguing that the phenomenon being examined can influence the interpretation which can influence the preconceptions of the analyst which can in turn influence the interpretation (Gadamer (1990/1960) as cited in Smith et al. (2009)). There are two important terms in hermeneutics, the hermeneutic circle and the concept of double hermeneutics. The hermeneutic circle is what Ricoeur refers to as "the reciprocity between the *text*-interpretation and *self*-interpretation" (1991, p. 303). It conceptualises interpretation as iterative, where interpretation moves from 'the part' to 'the whole' and then back again (Smith et al., 2009). The implications of this for IPA is that analysis is not conducted solely in a step by step process moving from one level to the next, but rather it is iterative throughout the analysis (Smith et al., 2009). Double hermeneutics refers to two stages of interpretation whereby the participant interprets their experience and this in turn is interpreted by the analyst (Smith & Osborn, 2003). IPA "combines an empathic hermeneutics with a questioning hermeneutics" (Smith & Osborn, 2003, p. 51). In practice this means both attempting to understand the text by empathising with the participant's point of view and asking questions of the text to examine if there are other interpretations that even the participant is unaware of (Smith & Osborn, 2003).

5.2.4 *Idiography*

Idiography focuses on the particular, the antonym for nomothetics, a term in psychology concerned with the whole (Smith et al., 2009). IPA is idiographic as it is concerned with examining the understandings and perceptions of a particular group rather than making generalisations at a population level (Smith & Osborn, 2003). While it does not rule out making general claims, it goes about it differently to other schools within psychology. An idiographic approach involves examining and analysing particular examples to begin with and slowly moving up to more general claims (Smith et al. (1995) as cited in Smith and Osborn (2003). This idiographic focus requires IPA to be detailed and in-depth, meaning that IPA studies tend to have small sample sizes allowing researchers to conduct in-depth interviews and analysis on a particular group. However, IPA is not solely consigned to the case level, as its analytical methods allow one to move from the case level to more general statements, without losing the ability to retrieve statements at the case level (Smith et al., 2009). One challenge in multiple perspective IPA is maintaining the idiographic focus as the sample size increases (Smith et al., 2009).

5.2.5 *Selecting the IPA methodology*

Several different methodological approaches were contemplated for use in this study, in particular, discourse analysis and grounded theory. Similar to IPA, discourse analysis also interprets text but it is different in its “perception of the status of cognition” (Smith et al., 1999, p. 219). Discourse analysis examines what is said, but it does not map this onto what the participant may think or believe. IPA acknowledges that the participants’ thoughts are not solely accessed through the interview transcripts, but additionally through analysing what the participant says and what this implies about their meaning making (Smith et al., 1999). IPA is “interested in cognition in the sense of cognition as a complex, nuanced process of sense and meaning-making” and sees cognition as “dilemmatic, affective and embodied” (Smith et al., 2009, p. 191). In other words it examines *what* participants say and *how* they say it. For participants with dementia, examining *how* the participant says what they say is significant, particularly in the context of limited verbal communication from some participants.

Grounded theory is viewed as the approach closest to IPA. Grounded theory seeks to generate a theory on the given phenomenon, whereas, IPA seeks to develop an

understanding of the lived experience of a phenomenon of interest (Smith et al., 2009). As grounded theory focuses on developing theory at an explanatory level it requires a larger sample, while IPA examines the lived experiences of a smaller number of participants, focusing on the convergences and divergences of these accounts (Smith et al., 2009). IPA was viewed as more appropriate than grounded theory, for this study, as the aim of the research was to explore the perspectives and lived experiences of the three groups in relation to personhood, rather than generating a theory of personhood in dementia. In deciding which approach to choose, I consulted with other researchers who had conducted PhD research in dementia at NUI Galway, using grounded theory (Hunter, 2014) and IPA (Dempsey, 2019). I also attended a qualitative research summer school in Dublin City University, in May 2016, where Prof. Paul Flowers gave a one day workshop on “An Introduction to Interpretative Phenomenological Analysis”. This workshop reinforced my view that IPA was the best approach to address the research questions in this study. The workshop also provided an opportunity to gain practice and feedback on both interviewing skills and data analysis for IPA. Additionally, it provided training on research design, including developing research instruments aligned with an IPA approach.

5.3 Research design

To answer the research question, a multiple perspective qualitative research design was chosen. This design involves one off semi-structured interviews with all participants.

5.3.1 Interviews

Interviews are frequently used in studies where more in-depth information is required to elicit opinions, views and experiences from participants (Denscombe, 1998; Creswell, 2014). Face to face interviews have several advantages including providing valuable insights, requiring limited equipment, being flexible and relatively easy to set up (Denscombe, 1998). However, they can be time consuming and the reliability of the process has been questioned, such as how the researcher’s presence may bias responses (Denscombe, 1998; Creswell, 2014). This study uses a semi-structured interview design to provide the flexibility required to explore a concept as complex as personhood (Denscombe, 1998). Semi-structured interviews were chosen over unstructured interviews as they are particularly useful for participants, such as people with dementia, who may find it difficult to talk at length

unprompted. There is also concern about the impact the interviewer may have on the interview. This is particularly relevant when the subject matter is sensitive, such as interviews about personal health (Denscombe, 1998). While there is very little I could do to change how participants might perceive me during the interview, I tried to be passive, neutral and non-judgemental throughout, as advised by Denscombe (1998).

5.3.2 *Multiple perspective design*

In order to understand personhood within formal care, this study gathers the perspectives and experiences of three distinct groups, people with dementia, family carers and formal carers. This approach is appropriate in health care research when attempting to examine the similarities and differences in the perceptions of different groups, such as patients, family members and formal carers (Kendall et al., 2009). For older people, including people with dementia, health and social care provision tends to form a triadic relationship which includes the family carer (Fortinsky, 2001; Quinn et al., 2012) and therefore this study includes family carers. In this study, formal carers refers to a range of paid professionals providing care to people with dementia. As evidenced in other studies, there can be many different health and social care professionals involved in the care of the person with dementia both contemporaneously and over the course of the disease (Adams & Gardiner, 2005). For example, Kadri et al. (2018) interviewed a range of formal carers working within nursing homes such as care assistants, managers and nurses, while Jansen et al. (2009) interviewed a range of formal carers based in the community such as nurses, social workers, home care aides etc.

Traditionally, IPA involves using homogenous samples where the focus of the study is on the lived experience of one particular group (Larkin et al., 2019). However, “the exploration of one phenomenon from multi perspectives can help the IPA analyst to develop a more detailed and multifaceted account of that phenomenon” (Smith et al., 2009, p. 52). Additionally, multiple perspective design is useful in cases where some research participants experience difficulty verbalising their perspectives and so gathering multiple perspectives can be very informative (Larkin et al., 2019). Multiple perspective IPA is a relatively new addition to IPA. To date multiple perspective IPA has been mainly used in dyad studies (Clare, 2002; Robinson, Clare, & Evans, 2005; Patterson, Hollins Martin, & Karatzias, 2019) and in studies interested in eliciting responses from multiple participant groups (Rostill-

Brookes et al., 2011; Quinn et al., 2012; Borg Xuereb, Shaw, & Lane, 2016; Schmidt et al., 2018).

5.3.3 Sampling strategies and sample size

Purposive sampling was chosen as the best method for identifying participants for this study. Purposive sampling is a non-probability form of sampling, where the researcher is not seeking participants at random, but has a sampling strategy (Bryman, 2012). Essentially, this means that participants are 'handpicked' and selected as the most appropriate people to provide insight into the given phenomenon (Denscombe, 2014). Additionally, purposive sampling is required for studies using IPA (Smith et al., 2009). People with dementia and their family carers were recruited as dyads for this study. However, it was necessary to be pragmatic about sample selection, so, if for example a participant with dementia was willing to participate but their family carer did not wish to be interviewed then the person with dementia was interviewed without interviewing the family carer and vice versa. Similar to other IPA studies (Borg Xuereb et al., 2016; Patterson et al., 2019), the formal carers interviewed for this study did not need to care directly for the person with dementia, i.e. the study is not focusing on the nature of care triads. There were several reasons for this decision including: preserving anonymity, maintaining the integrity of the care relationship, the practicalities of finding care triads and the potential for widening the formal care network beyond immediate dyad participants. This means that the study selected a range of formal carers to gain a wider perspective on their experiences of personhood within formal care provision. While they are all formal carers they engage in different roles and provide different types of care and support. This was also important in answering the main research question in this thesis, which centres on formal care provision as a whole and not on one particular element or type of formal care. Initially, a sample size of 15 participants per group was targeted, a total of 45 participants. The final sample size includes 31 participants, 8 people with dementia, 8 family carers and 15 formal carers, and is detailed in the results in Chapter 6.

5.3.4 Research participants

People with dementia often feel frustrated and inadequate when not asked for their views on their condition and related health and social care needs (Hunt, 2010). It is therefore very important for people with dementia to be included in research

such as this, exploring the nature of their condition and formal responses to it among those providing care and support (Moore & Hollett, 2003; Hughes & Romero, 2015). The inclusion and exclusion criteria for the different participant groups are as follows:

People with dementia

An official diagnosis of dementia from a memory clinic/geriatrician/health care professional was needed for inclusion in this study (similar to Anbäcken et al. (2015). Participant's memory was not directly assessed prior to interview using diagnostic tools, as this information was not required for the purposes of this study and may have an adverse effect on the person with dementia's dignity and self-respect (Krohne, Slettebø, & Bergland, 2011). However, it was possible to subjectively gauge the stages of dementia the participant was experiencing through the interview itself (Gennip et al., 2016). The study was not restricted by setting, so people with dementia could be living in different settings, for example, living in the community, living in the community and accessing day care services and living in long-term care facilities. There were no age restrictions on participants with dementia. People with dementia could engage in the study, whether their family carer agreed to participate or not.

Family carers

The family carers were defined as an individual providing unpaid care to a person with dementia on a regular basis either now or in the past (if the person was living in long-term care). They were not required to be living with the person with dementia, nor did they have to be the sole family carer. If a family carer wanted to participate and the person with dementia didn't they were allowed to participate. Family carers needed to be 18 years of age or older to engage with the study.

Formal carers

Formal carers referred to anyone who provided paid professional care to people with dementia. They could also be called formal care providers or health care professionals. However, none were involved directly in triad relationships with the person with dementia and/or their family carer. In order to capture the experiences of personhood for people with dementia living at home and in nursing homes, formal carers who provide care to either (or both) groups of people with dementia were included. For this reason, the study focuses on a range of formal carers rather than solely one 'type' of formal carer, including nurses, general practitioners,

nursing home care assistants, care managers and home care assistants. All of these providers must have had experience of working with people with dementia on a regular basis. There was no requirement in relation to years of experience working with people with dementia.

5.3.5 Using dyads in IPA

The intention of the study was to undertake face to face individual interviews, whereby the participant could speak freely, thereby allowing the researcher to gain a deeper understanding of the individuals' lived experience and the ensuing care process. However, it was anticipated that in certain circumstances the person with dementia may prefer to be interviewed together with the family carer, as was the experience of Kendall et al. (2009). Using dyads adds additional complexity to understanding the subjective experience of the individuals involved as the relationship between the dyads may influence, and sometimes constrain, what the participants are willing to discuss in front of each other (Robinson et al., 2005). However, it can also be advantageous when the dyads are able to prompt each other during interviews (Kendall et al., 2009), or when the person with dementia has difficulty communicating (Pratt, 2002). Tolhurst et al. (2017) are critical of the lack of analysis of interactions within dyadic interviews, pointing out that while interviews may take place in a dyad, analysis is normally carried out at the individual rather than the interactional level, thereby missing out on important information regarding how the dyad relates to each other. In this study however, the interactional aspect of personhood is not examined at the dyad level. Instead, the concept of personhood is acknowledged as a relational concept through the adoption of a multiple perspective approach. The study seeks to gain a broad understanding of personhood within formal care relationships and not a micro level understanding of personhood within individual formal care relationships. Therefore the formal carers in this study are not related to nor provide care to the dyad. Equally, the study does not examine the dyadic relationship between the family carer and the person with dementia. Advice on how to manage dyad interviews was sourced from previous studies (Forbat, 2003; Hellström et al., 2005; Genoe et al., 2010; Merrick, 2012).

5.3.6 Limitations of research design and IPA

IPA has been used extensively in dementia research (Pearce et al., 2002; Clare, 2003; Quinn et al., 2008; Caddell & Clare, 2011a; Nowell et al., 2013; Stokes, Combes, & Stokes, 2014; Bergman et al., 2016; Johnson, 2016). One potential limitation of using IPA with people with dementia is that it relies solely on the participant's ability to articulate their thoughts, experiences and feelings on the given phenomenon. People with dementia experience varied degrees of difficulty with verbal communication. However, as already discussed above, IPA's focus on cognition allows the analyst to critically examine the use of language in several ways, including linguistics, ultimately creating a detailed set of data on which to interpret the lived experience of the participant. An additional limitation is that IPA does not focus on non-verbal communication, thereby missing potentially useful and rich expressions of a participant's thoughts and experiences. Given the research on embodied selfhood in dementia this is a limitation of this study. Another potential criticism of the design of this study is the lack of homogeneity within the formal carers group. Other studies using multiple perspective IPA have used more homogenous groups of formal carers, for example Rostill-Brookes et al. (2011) interviewed only social care workers. This study defines formal carers as people who are paid professional carers who work with people with dementia and therefore includes a variety of formal carers. This is similar to how Schmidt et al. defined health care professionals, as anyone who was directly involved in providing care such as: "caregivers, managers, physicians, social service workers, pastoral care, volunteers or domestic help" (2018, p. 659).

5.4 Research procedures

The research procedures outline the steps that were taken to carry out the research study.

5.4.1 *Accessibility*

Given the research topic, it was important that the entire research process including recruitment, consent, interview and follow up was designed to be respectful of personhood and person-centred (Dewing, 2002; Cowdell, 2006). This ethos guided the design of the research procedures and the entire research process. Decisions about where the interviews were conducted was left to the participant, meaning that they could be conducted in their own homes or in another setting of their choosing. This was to ensure that the participants felt comfortable and relaxed during the interview. Ideally, interviews with people with

dementia took place in their own homes as it is familiar to the person with dementia and a “protective setting for their identity” (Nygård, 2006; Hellström et al., 2007, p. 9). If interviews were conducted outside the home great care was taken to make sure that they were held in comfortable, warm and quiet locations avoiding excessive noise. The interviews with family carers and formal carers could also take part in a location of their choosing such as their home, their place of work or at the Centre for Economic and Social Research on Dementia in Galway. All interviews were audio recorded, with the permission of the participants.

5.4.2 Research instruments

Participant information sheets were designed for each group, using guidelines from the NUI Galway Research Ethics Committee (Appendix F-K). A second more accessible information sheet, as well as an accessible consent form was drafted using the Dementia Engagement and Empowerment Project (DEEP) guidelines (DEEP, 2013). After due consideration, it was decided to use the term memory problems instead of dementia in the participant information sheets for the person with dementia and the family carer. This was done to avoid upsetting potential participants, some of whom may have been unaware of their formal diagnosis. During recruitment and interview stage, the decision to refer directly to the dementia diagnosis was taken on cue from the family carer and the person with dementia (Bartlett, Milne, & Croucher, 2019). During the pilot interviews, the participant information sheets and consent forms were checked for understanding and suitability. The interview guides were influenced by the literature review of personhood in dementia. Questions centred on topics such as the participants’ conceptualisation of personhood, autonomy, flexibility, choice, relationships, communication, dignity and respect. The guide was informed by advice on designing guides for use in IPA studies, for example, the first question of all guides was an open-ended one to encourage the participant to talk at length and allow them to settle into the interview (Smith et al., 2009). There were three interview guides, one for each participant group (Appendix L-N). People with dementia were asked about their own personhood, while family and formal carers were asked about their perception of personhood in dementia. In addition, questions for the person with dementia tended to focus on feelings and experiences rather than cognitive capacities or answers requiring episodic memory (Small & Perry, 2005; Heggstad, Nortvedt, & Slettebø, 2013). The guides also contained prompts and probes to encourage the participant to expand on a given point.

5.4.3 Recruitment

One difficulty in involving people with dementia in research is gaining access to potential participants. Gatekeepers were used in this study to recruit people with dementia. This included non-governmental organisations, health service providers, private nursing homes, private home care agencies and family members. Appendix E is a sample recruitment letter which was sent to gatekeepers. Using gatekeepers means there is a risk that they will cherry pick participants (Bartlett & Martin, 2002), and also that participants will feel obliged to participate (Hellström et al., 2007). Wherever possible recruitment was conducted face-to-face, as this has been found to be more effective (Bartlett et al., 2019). However, it was not restricted to face-to-face recruitment, as phone and email was also used. The main strategy for recruitment was ensuring that people with dementia were residing in different settings and that formal carers from a range of professional roles were recruited.

5.4.4 Pilot interviews

How the interview is conducted is critical to the research process and to producing rich and detailed accounts of the lived experience of dementia (Smith, 2011), therefore it was important to gain practice in conducting interviews and develop interview skills. Pilot interviews were carried out with seven participants, three people with dementia, two family carers and two formal carers. These were conducted to test the reliability and feasibility of the research instruments. One finding from the pilots was that there were too many questions on the interview guides, particularly the guide for formal carers, and so the interview guides were edited. Another observation from the pilot interviews was that the family carer sometimes wanted to do their interview in the presence of the person with dementia. This was mainly down to practical issues such as not wanting to leave the person with dementia on their own. This may have affected the information the family carer provided because they were aware of the person with dementia in the room.

There were difficulties, sometimes, when the family carer spoke about the person with dementia in the third person in their presence, thereby denying their personhood, which was the antithesis of the research itself (Cowdell, 2006). This was a difficult issue to navigate. It often happened for the very best motives, for example when the carer expressed a desire to sit in on the interview with the

person with dementia, to support them emotionally and practically, through helping them to remember things.

Another important learning for me was the need to be specific about the inclusion criteria when recruiting participants. For one of the pilots, the person with dementia had moderate to severe dementia and had significant difficulty in communicating verbally. While, I had emphasised the nature of the study to the family carer, they had wanted to participate and also wanted the person with dementia to do likewise. Unfortunately, even after consenting, the participant with dementia was unable to take a full part in the interview process.

The experience of conducting pilot interviews was invaluable as it emphasised for me the flexibility required to carry out these interviews. I learned the importance of being very familiar with the interview guide and being able to rephrase questions in many different ways depending on the needs of the person with dementia. I needed to be able to respond to the unexpected, and realise that the interview would not always flow in a linear fashion in which all of the questions would be answered precisely and specifically. Personhood itself was essentially the reason why the interviews with the participants would never be precisely the same.

5.4.5 Communication

Several factors were considered when setting up the interviews to support communication during the consultation process, particularly among people with dementia. A key goal, prior to and at the start of the interview, was to develop a good rapport and relationship with the participants (Smith et al., 2009; Bartlett et al., 2019), what Pietkiewicz and Smith (2014, p. 10) refer to as a 'warm-up' discussion to help reduce or diminish any apprehension on the part of the research participant. Tappen et al. (1997) encourage expression of feeling through speaking with participants as equals, finding common ground and sharing a little of oneself. Denscombe (2014) advises being attentive, using prompts and probes and being non-judgemental. IPA provides additional guidance for interviews, including being comfortable with and allowing silence and also being aware of body language and non-verbal cues (Pietkiewicz & Smith, 2014). I was acutely aware of not patronising the participants or using infantilising or stigmatising language, which, unsurprisingly, has been shown to have a negative impact on the person with dementia (Herman & Williams, 2009; Novek & Wilkinson, 2019). This had to be balanced with phrasing and rephrasing questions if a participant did not

understand. I was careful not to use pronouns but rather to name the person. I was also cognisant of the length of sentences used, avoiding complex ones, but instead using several shorter sentences, making sure that repetition was exact and slowing the pace of speech (Weirather, 2010). The use of checks ensured I understood participants correctly, supporting consistency within the interview and at times across interviews (Rubin & Rubin, 2011), without leading the participant in any particular direction with the probes used (Whiting, 2008). The interviews were very much context and person dependent. I had to be adept at changing my approach and technique to each interview and individual, and be flexible and adaptable in this approach during the interview. If a particular theme was important to the participant, I would encourage the participant to continue by summarising what the participant had said (Tappen et al., 1997); this was also a useful method when checking to see if I had understood the participant correctly, what Sabat (2001) refers to as in-direct repair. A major risk while carrying out interviews was to ensure they did not turn into a counselling session, which is a balance between having empathy, while still continuing to have boundaries in the research relationship. I also had to resist providing reassurances to participants when I did not know what the outcome would be (Ashton, 2014).

The use of visual cues has been found to be important to encouraging person-centred communication (Williams et al., 2011). Therefore, in preparation for the interviews I engaged in several different types of training. I undertook training in Dementia Care Mapping™ (Bradford Dementia Group, 1997) at the University of Bradford. Dementia care mapping is a tool used to monitor and implement person-centred care for people with dementia in different care settings. This training was useful in observing and interpreting non-verbal communication. I also received communication skills advice from a speech and language therapist, advice on active listening from a psychotherapist and I attended several masterclasses in relation to qualitative research with people with dementia. All of this training was important given the fact that while I had a lot of experience working with older people, I had very little experience of working closely with people with dementia.

5.4.6 Observation and reflection

During the study, observation and reflective notes were taken. Prior to the interview I reflected on my expectations for that interview. Immediately after each interview, detailed observation notes were taken using a template as a guide

(Appendix D). These notes allow for the contextualisation of the audio recording and served as an additional method for validating the interview data. Post interview, I also reflected on my experience of conducting the interview and what I thought my influence on the interview had been (Appendix D). This step was of significance in acknowledging the influence of me as the interviewer and was helpful in developing my interview skills as I reflected on my weaknesses and strengths post interview (Whiting, 2008). Both the observation and reflexive notes provided important context to the transcribed interview data, ensuring the reliability of the data through data triangulation. I also engaged in reflective dialogue with my supervisor post interviews as well as engaging in reflection while analysing the interview transcripts.

5.5 Ethical considerations

5.5.1 *Ethical approval*

Ethical approval for this research was sought and approved from the National University of Ireland Galway, Research Ethics Committee (University Ethics Reference: 18-Jan-06). This section examines the main ethical considerations of consent, confidentiality and anonymity, and ethical protocols.

5.5.2 *Consent*

The issue of consent is always important, however, it is particularly so when carrying out research with individuals with diminished capacity. The National Bioethics Advisory Commission (1998) state that it is ethically unacceptable to presume that people with some decision making deficit cannot be assisted to achieve a level of functioning that would allow them to give valid consent. McCormack (2002) also questions the traditional outlook on informed consent and its appropriateness with people with dementia. The direct involvement of people with dementia in exploring the nature and form of personhood is central to this study and participation requires their consent and on-going assent. Procedures were in place (e.g. gatekeeper recruitment, informed consent and protection of identity) that helped to ensure that the vulnerability of people with dementia was minimised. The process of obtaining consent was negotiated on an individual basis. Prior to seeking consent, all participants including the person with dementia, were informed about the study and asked if they would like to participate. Participants had multiple opportunities to decline participation or withdraw, for example, when

approached by the gatekeeper, when contacted by the researcher, and then at any time during the study. This minimised any pressure the participant may have felt to participate, particularly, if they were receiving services from the gatekeepers, what Hellström et al. (2007) refer to as withstanding powerful others. In the vast majority of cases, the participant information sheet was provided in advance of the interview, as well as on the day of the interview. Where possible, the person with dementia and the family carers completed the consent forms together. The American Geriatrics Society (1996) recommend the involvement of trusted family members in decisions regarding participation in research, as they will be most familiar with the participants value system and will have the best interests of the research participant to the fore. All participants were given time to review and discuss the participant information sheet with the interviewer or, in the case of the person with dementia, another trusted individual in private, before providing consent. In cases where the person with dementia indicated they wanted to participate but could not provide written consent, the person with dementia's guardian was asked to give formal written consent, consent by proxy, on behalf of the research participant (Good, 2001). In all cases, active assent was continually sought during the interviews, by checking if the participant was happy to continue (Good, 2001; Saks, Dunn, & Palmer, 2006). I was sensitive to verbal and non-verbal cues that could be interpreted as signals of distress resulting from participation in the study (Bartlett & Martin, 2002). I followed the Revised Partnership of Consent Protocol (Batchelor-Aselage et al., 2014), which builds on previous guidelines regarding consent and assent for people with dementia participating in research (Slaughter et al., 2007), see Appendix O.

5.5.3 Confidentiality and anonymity

All of the participants' information was kept confidentially. Signed consent forms were stored in a locked facility within the CESRD. All audio data was destroyed during write up. A participant number was assigned to each transcript and all identifying data was removed from the transcript on transcription. Given the multiple perspective design, there is a risk that participants may be able to recognise the quotes of their dyad from within the study, what Larkin et al. (2019, p. 189) refer to as 'internal anonymity'. For this reason the relationship between the dyad is not included in the results section nor any other information that would allow participants in the dyad to identify each other. Guidelines provided by Ummel

and Achille (2016) were followed to ensure anonymity in reporting results, including reporting data at the group level, rather than the individual level.

5.5.4 *Protocols*

A key concern with carrying out any research is that no harm is done to the participants. One cannot rule out that face-to-face interviews or discussions could potentially cause distress to participants, particularly interviews dealing with personhood, caregiver burden and dementia care. Participants were made aware that the interview could be terminated at any time if they felt uncomfortable with the discussion and a protocol was drawn up for dealing with distressed participants (Appendix P). This included a list of contact telephone numbers for organisations and agencies involved in providing support for people with dementia and family carers, for example, the Alzheimer Society of Ireland and the Senior Help Line. Researcher safety is also important when conducting research and particularly so when research is being conducted in the community including in peoples' private homes and in their places of work. A researcher safety protocol was adhered to, to ensure researcher safety during the field work stage of the study (Appendix Q). The protocol included communicating with my supervisor or a contact at the centre before starting and after completing each interview. Additionally, doing more than two interviews per day was avoided if possible, to reduce researcher burnout (Smith et al., 2009).

5.6 Data analysis

IPA provides a detailed guide to carrying out analysis, however this is not intended to be definitive but rather that IPA should have a "healthy flexibility in matters of analytic development" (Smith et al., 2009, p. 79; Pietkiewicz & Smith, 2014). When analysing data using IPA the focus is on the participants' efforts to understand their experiences (Smith et al., 2009), meaning that the analyst tries to "totally immerse themselves in the data or in other words, try to step into the participants' shoes as far as possible" (Pietkiewicz & Smith, 2014, p. 11). Analysis of a multiple perspective IPA study brings additional complexity (Larkin et al., 2019). In this study, the transcripts were analysed in three different groups, firstly the accounts of people with dementia, then the family carers and finally the formal carers. As advised by

Smith et al. (2009), I started with the richest account in each group (this tended to be the longest interview). A traditional IPA study examines the entire transcript and clusters themes for each transcript (case) before moving on to the next transcript (Pietkiewicz & Smith, 2014). However in this study, I coded all of the interviews for each group and clustered the themes at the group level, not at the individual level, as was advised for larger sample sizes (Smith et al., 2009). Once all of the three groups were analysed, I synthesised the three groups examining their accounts for convergence, divergence and conflicts.

5.6.1 Transcribing

IPA requires a semantic transcription of the interview, ensuring that all words uttered, and sounds (e.g. laughing, sighing etc.) by participants are recorded (Smith et al., 2009). All of the transcriptions with people with dementia were transcribed by me. The interviews with family carers and formal carers were transcribed by a professional transcription service. I listened back through all of these recordings correcting and editing transcripts to ensure that they were verbatim.

5.6.2 Individual level: Reading, rereading and making notes

The interviews were analysed initially in Microsoft Word and then in NVivo (version 11 2015, QSR International Pty Ltd). A Word document was created, with one table divided into three. The original transcript was placed in the centre, the column to the right contained the exploratory comments and the emergent themes were noted in the left-hand column. The initial analysis involved listening to the interview again while reading and rereading the transcript (step 1) and taking notes (step 2) (Smith et al., 2009). Pietkiewicz and Smith (2014) recommend relistening to the audio to allow the analyst to immerse themselves in the data. In some cases, during step 2 the transcript was listened to again to provide context to what was being discussed and the tone in which it was discussed. This was particularly important if what the participant had said wasn't clear. Along with the audio, I reread the reflective notes and the observation notes to recall the context and feel of the interview. Step 2 involved noting the exploratory comments which include descriptive, linguistic and conceptual comments. The descriptive comments were noted first; on subsequent reads the linguistic and conceptual comments were noted. The descriptive comments related to what participants said about the things that mattered to them such as: "relationships, processes, places, events, values and

principles of their lived world” (Smith et al., 2009, p. 83). Linguistic comments examined the use of language such as repetition or metaphors. Conceptual comments included questioning the data, (linking back to the concept of questioning hermeneutics), by asked the following questions: “What was the person trying to achieve here? Is there something leaking out there that wasn’t intended? Do I have a sense of something going on here that maybe the participants themselves are less aware of?” (Smith & Osborn, 2003, p. 51). In analysing attention was paid to the potential for social identities (including gender and ethnic identities) to influence how the participants spoke and their interactions with the interviewer (Pope & Ripich, 2005). During this stage I wrote comments on personal reflexivity on how I might impact on the analysis (Pietkiewicz & Smith, 2014). It was very important at this stage, and throughout the analysis to ensure that the analysis continued to focus directly on the research question (Larkin et al., 2019), which was the relationship between personhood and formal care.

5.6.3 Individual level: Emergent themes

On subsequent runs through the transcript, emergent themes were identified and noted on the left hand margin. These developed from the exploratory themes but were more concise and abstract (Pietkiewicz & Smith, 2014). The emergent themes were checked against the original transcript (in the centre of the document), to ensure that the emergent themes appeared in the original transcript, avoiding any researcher bias (Smith et al., 1999). The process of developing emergent themes was iterative moving from the whole transcript to a specific quote, and back to the whole, engaging in the hermeneutic circle (Smith et al., 2009). Once all of the transcript was analysed for emergent themes it was left aside and the next transcript was analysed.

5.6.4 Group level: Developing relationships and clustering themes

For larger sample sizes, Smith et al. (2009) recommend searching for connections across emergent themes at the group level. So instead of clustering themes for each transcript individually, I re-examined all of the coded transcripts for the group, looking for connections and relationships between the emergent themes and clustered themes for that group (Smith et al., 1999). This was very much a cyclical process. For example, if a new theme appeared in subsequent transcripts these themes were searched for in previous transcripts, to make sure they hadn’t been

overlooked (Smith et al., 1999). The Word documents were converted into Adobe PDF files and uploaded onto NVivo. The themes were clustered within NVivo. These themes were supported by directly coding the relevant piece of transcript, leaving a clear audit trail from transcript to theme.

5.6.5 *Multiple perspective analysis*

Once all of the three groups had been analysed separately, and clustered themes developed for each group, a merging of the three groups was conducted, what Larkin et al. (2019) call a mini meta-synthesis. Using Larkin et al.'s (2019) advice, the analysis looked for:

1. Consensus: participants from different groups expressing the same concerns
2. Conflict of perspectives: Disagreement between the different groups
3. Reciprocity of concepts: Participants talking about the same concept from different perspectives
4. Paths of meaning: Shared experiences with divergent meanings

This was a complex and complicated process. It involved merging similar themes together and renaming some themes. I used some additional tools in NVivo to support this process such as colour coding each of the groups to make them easily identifiable. While all of the transcripts were coded for all clustered themes it was not practical to merge all of these in the multiple perspective analysis. For this next stage, only those themes that were present in 30% or more of the transcripts in a given group were synthesised, meaning that all of the groups were given equal weighting in the analysis (Smith et al., 2009). This was of particular importance as there were twice as many formal carers than people with dementia or family carers, so it ensured equal representation of themes in the synthesised data. This applied per group but it did not require that other groups also referred to the same theme, so for example, certain themes that appeared in some groups did not appear in other groups, but if this occurrence was over 30% they were included in the findings. Research elsewhere has used differing figures for deciding prevalence, for example Dickson, Knussen, and Flowers (2007) presented themes that had appeared in at least half of the transcripts, justifying this in order to “promote an idiographic perspective, but at the same time to counterbalance that perspective with more generic accounts across the transcripts” (Dickson et al., 2007, p. 855).

5.6.6 Write up

The aim of writing up a study using IPA is to provide “a full narrative account which is comprehensible, systematic and persuasive” to the reader (Smith et al., 2009, p. 109). Again the writing up was iterative whereby I wrote from the NVivo analysis moving backwards and forwards, reconfiguring and reconceptualised themes. “Good IPA like any good qualitative work requires careful writing and usually considerable drafting and re-drafting” (Smith et al., 2009, p. 182). This was carried out in consultation with my supervisor, who provided support throughout the analysis, but particularly at the write up stage. Given the hermeneutic foundations of IPA it is important that the reader can understand the researchers’ interpretation of the meaning making of the participants (Smith et al., 2009). This can be best illustrated by supporting interpretations with quotes from participants (Pietkiewicz & Smith, 2014). The goal of writing up was to demonstrate how the “multiple perspectives *relate to* [emphasis in original] one another and to reflect upon how those differences can co-exist” (Larkin et al., 2019, p. 192). The write up should also portray the interpretative nature of IPA and be tentative and nuanced in its expressions (Smith et al., 2009). For smaller IPA studies, it is expected that quotes from each participant for every theme are included (Smith et al, 2009), however for larger studies, such as this one, this is not feasible. Instead, I have selected appropriate quotes to illustrate each theme, and attempt to draw on the accounts of all participants as evenly as possible (Smith et al., 2009).

5.7 Quality in qualitative research

Extensive discussion exists on how to evaluate quality in qualitative research, with questions centred on what criteria should be applied, who should apply it and when it should be applied (Smith, 2011); and how terms such as objectivity, reliability and validity apply to qualitative research compared to quantitative research (Silverman, 1993; Denscombe, 1998; Smith et al., 2009). This section examines the quality in this study in relation to validity; which includes discussions on sensitivity to context, commitment and rigour, transparency and coherence, impact and importance, and researcher bias and reflexivity.

5.7.1 Validity

Validity in qualitative research refers to examining the accuracy of the findings of the research, by checking if the data and the methods used to obtain the data are

'right', if the data is a true representation of the truth and if it answers the research question (Denscombe, 1998; Creswell & Creswell, 2018). This can be done by undergoing several checking procedures including: data triangulation, verifying data with research participants, using rich data to illustrate the findings, being open about researcher bias and reflexivity, presenting negative information, spending a long time in the field of study, using peer debriefing or using an external auditor (Creswell, 2014). Smith et al. (2009) suggest using Yardley's (2000) four principles for assessing quality in IPA studies: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Using both Creswell's (2014) and Smith et al.'s (2009) definitions I will illustrate the validity of this study.

5.7.1.1 Sensitivity to context

This study was sensitive to context. Firstly, the choice of IPA as a research approach demonstrates the need to be sensitive to context by closely engaging with the idiographic (Smith et al., 2009). For me, engaging with existing literature on personhood, as well as with stakeholders in the field of dementia research, created significant awareness and understanding of the context people with dementia, family carers and formal carers find themselves in, in relation to formal care provision. I think this was vitally important in designing, setting up and carrying out the interviews to ensure that they were conducted in a sensitive and ethical manner, making sure I empathised with the participants' lived experience. I did so through attentive listening, being flexible in my approach, developing a rapport and making sure that the participant felt comfortable and at ease. This sensitivity continued through the analysis, ensuring that I returned at all times to the idiographic nature of the analysis and the task of understanding the meaning making of each individual participant.

5.7.1.2 Commitment and rigour

The second of Yardley's principles is commitment and rigour (Yardley (2000) as cited in Smith et al. (2009). Commitment refers to how committed the researcher is to the research study, demonstrated for example, by how attentive I was to the participants needs and overlaps with sensitivity to context in this regard. Rigour is about how thorough the study is. For example, the interviews were conducted carefully and thoroughly and probes were used skilfully and consistently within and across the interviews. Methods suggested by Creswell (2014) also fall within commitment and rigour such as data triangulation and verifying data. While there was only one main source of data, the interview transcript, the observation notes

and reflective notes provided context and allowed for some data triangulation. Within dyads, both the person with dementia and family carer at times spoke about the same issue from different perspectives, validating each other's perspectives. During the interviews, I verified data from the participants by repeating what they had said back to them. However, I did not return to participants with transcripts of the interviews for validation as did not consider this appropriate for participants who may have difficulty reading, or trouble remembering the interview. Nor did I return to verify the findings of the study with the participants, due to time constraints.

5.7.1.3 Transparency and coherence

The third of Yardley's principles is transparency and coherence (Yardley's (2000) as cited in Smith et al. (2009). In particular it is important to focus here on how the study is written up, so that it is transparent to the reader that all stages of the research were conducted with quality in mind. Creswell (2014) suggests using rich data to illustrate findings and presenting negative findings. Smith et al. (2009) propose to read and reread the study, trying to take a first time reader's perspective of the work to ensure that it is coherent. My supervisor provided support to me to ensure that the methods and findings are well structured, coherent and not contradictory. Negative findings are reported alongside all of the findings. During the interview process I conducted peer debriefing with my supervisor; this was useful in reflecting on how the interviews had gone and what the learnings were from the interviews. Yin posits that one way of portraying validity and transparency is filing the data in such a way that it is easy for another person to audit (Yin (1989) as cited in Smith et al. (2009). I have done so in this study by containing everything within one NVivo file allowing a visible audit trail, from all of the analysed transcripts to the final set of themes. There are folders of nodes for the clustered themes at the group level and the multiple perspective themes. Coded nodes for the three main findings are contained in Appendix R. During the analysis my supervisor provided support and audited the analysis through examining the development of codes, clustered themes and multiple perspective themes.

5.7.1.4 Impact and importance

The final of Yardley's principles is impact and importance (Yardley's (2000) as cited in Smith et al. (2009). It is concerned with how the research tells the reader something interesting, important or useful, ultimately addressing how the research fills a gap in the literature and is novel. This is the first piece of research using IPA

to examine personhood in dementia formal care, using a multiple perspective design. In particular, there is very limited research into the views of all three groups in the care triad on personhood. There is also limited research into this topic in Ireland and given the importance of the principle of personhood in Irish dementia policy, this work will be useful and informative to future policy and practice development in relation to recalibrating formal care provision to focus on and support personhood in dementia.

5.7.1.5 *Researcher bias and reflexivity*

One important consideration in ensuring quality in qualitative research is researcher reflexivity. Creswell defines reflexivity as how:

“The inquirer reflects about how their role in the study and their personal background, culture, and experiences hold potential for shaping their interpretations, such as the themes they advance and the meaning they ascribe to the data” (Creswell, 2014, p. 186).

In particular, Husserl’s work has supported researchers to understand the importance of reflection in the research process (Husserl (1927) as cited in Smith et al. (2009). As discussed above under Hermeneutics, IPA moves away from Husserl’s emphasis of ‘bracketing’ of such preconceptions, acknowledging the difficulty in truly being able to bracket off all preconceptions:

“Heidegger’s complex and dynamic notion of fore-understanding helps us see a more enlivened form of bracketing as both a cyclical process and as something which can only be partially achieved” (Smith et al., 2009, p. 25).

This means that the emphasis on bracketing off or describing the researchers’ role prior to analysis is not as strongly emphasised in IPA as it is in other qualitative research methods such as grounded theory. While IPA acknowledges that it is not possible to bracket off all preconceptions, I did engage in reflection during the analysis. Throughout the interviews and subsequent analysis, I kept a constant check on my interpretation of the participant’s meaning making. So for example, I was very cognisant of how who I am may influence what I saw or what I looked for. I was very aware of how this might influence how I made meaning from participant interviews, and for a topic such as personhood, how I could inadvertently influence the analysis by focusing on elements that resonated with me to the detriment of

other possible meanings. This was a complex task, requiring constant reflection. At the end of the initial analysis of a transcript I would write down a short summary of who I thought the participant was and also what elements of them I most identified with. I did this because I wanted to make certain that I was not displacing or transposing these qualities onto the participants themselves when they weren't there. One concern is that I was analysing the situation from my perspective rather than the family carer's perspective and this was particularly difficult in situations where there was conflict between the family carer and the person with dementia. When analysing dyads, Ummel and Achille (2016) emphasise the need to be reflexive and aware that the researcher remains impartial about the relationship and does not 'take sides' in the dyad.

5.8 Conclusion

This chapter has discussed the methods of the empirical study. These include the research methodology, the research design, the research procedures, ethical considerations, data analysis and ensuring quality in qualitative research. As can be seen the methods used in this study, involve a certain degree of complexity including both the interviewing of participants who could be considered vulnerable, and have difficulty communicating. In addition, using multiple perspective IPA is a relatively new and multifaceted design. The next chapter details the results of this study.

Chapter 6: Understanding personhood in formal care: The perspectives and experiences of people with dementia, family carers and formal carers

6.1 Introduction

This chapter presents the findings of the empirical study detailed in Chapter 5, the aim of which is to examine the application, practice and perception of personhood within formal care relationships in Ireland. This chapter provides details of the interview data. To give the reader a sense of what that data is like, it provides the author's interpretations of the data and an argument for what the data and its interpretation all mean (Smith et al., 2009). The results are divided into three main themes: the conceptualisation of personhood; barriers to supporting personhood and personhood in the formal care process. As a whole, these themes represent what the groups think of personhood, what barriers prevent personhood from being put into practice and how personhood is put into practice. The themes are strongly interrelated and interdependent. Each theme outlines the views of the three groups, where they contain consensus, how this consensus relates across the groups, differences between these groups, how these differences co-exist and possible reasons for these differences (Larkin et al., 2019). Appendix R presents the nodes for each of the three main themes. In interpreting the results it is useful to remember that the participants with dementia and family carers predominantly spoke about the personal rather than the abstract. Formal carers tended to speak in the abstract, referring to anecdotes about individuals to illustrate their points.

6.2 Results

In total, 31 people participated in this study, 8 people with dementia, 8 family carers and 15 formal carers. One of the interviews was a dyad interview therefore there were 30 interviews in total. Originally, 45 participants were targeted,

however, given the choice of IPA as the research approach and the complexities of recruiting a hard to reach population group this target was reduced. The interviews took place in a variety of locations across Ireland, including peoples' own homes, formal carers' places of work and the offices of the Centre for Economic and Social Research on Dementia at NUI Galway. As already detailed in Chapter 5, recruitment took place via gatekeepers. The duration of the interviews varied between thirty minutes and two hours. The resulting data provides a rich and detailed account of the practice, perceptions and experiences of these three groups in relation to personhood in dementia and formal care. In the quotes contained in this chapter, the acronym *pwd* refers to person with dementia, *fc* refers to family carer and *fcp* refers to formal carer.

6.2.1 *People with dementia*

All eight participants have some form of dementia, some are in the early stages of dementia and others are in moderate stages. Five of the participants are female and three male ranging in age from 58 to 84. For anonymity reasons, individual level data will not be provided. Six of the participants are living at home and two in a nursing home. They have wide and varied experiences of receiving formal care, in the form of health and social care services and supports. Table 6.1 details their pseudonyms.

Table 6.1: Participants with dementia characteristics

Name	Gender
Patrick	Male
Thomas	Male
Julia	Female
Christine	Female
Nuala	Female
Robert	Male
Maeve	Female
Maura	Female

6.2.2 Family carers

Eight family carers participated in the study, six of whom are family carers to the people with dementia who participated. Five are female and three male. The nature of the relationship between the family carer and the person with dementia varied, including being spouses, children, siblings and extended family. For anonymity reasons, the exact relationships will not be disclosed. The family carers vary in age with some being of working age and others retired. Four of the family carers identify as a secondary carer, meaning that another relative was or had been the primary carer for the person with dementia, the remaining carers are primary carers. Three of the carers are living with the person with dementia. Table 6.2 outlines their pseudonyms.

Table 6.2: Family carers' characteristics

Name	Carer
Michael	Primary family carer
Noreen	Primary family carer
James	Primary family carer
Andrea	Secondary family carer
Emily	Secondary family carer
Johnathon	Primary family carer
Cynthia	Secondary family carer
Louise	Secondary family carer

6.2.3 *Formal carers*

In total, 15 formal carers participated in this study, eleven females and four males. The professional qualification and setting they currently work in is detailed in Table 6.3. They have varied years of experience from a couple of years to a long career of providing care to people with dementia. Due to their different professions, the context and nature of the contact they have with people with dementia varied.

Table 6.3: Formal carers' characteristics

Name	Profession	Setting	Degree of contact with people with dementia
Phil	Geriatrician	Acute setting and memory clinic	High
Barbara	Nurse	Community and memory clinic	High
Claire	Clinical Psychologist	Community and long-stay setting	Medium
Terry	Psychiatric Nurse	Community and long-stay setting	Medium
Elaine	Nurse	Community and memory clinic	High
Geraldine	Social care practitioner	Long-stay setting	High
Harry	Nurse	Long-stay setting	High
Ita	Care assistant	Community	High
Jackie	Care assistant	Community	High
Karen	Care assistant	Community	Medium
Laura	Home help manager	Community	Low
Pauline	Care assistant	Community	Medium
Ronan	GP	Community	Low
Shane	Nursing home assistant	Long-stay setting	High
Trudy	Nursing home assistant	Long-stay setting	High

6.3 Theme 1: The conceptualisation of personhood

This first theme examines how personhood is viewed and understood across the three groups. It is divided into two subthemes; expressions of self and interpreting changes to personhood. There is significant consensus across the groups on the former, but not on the latter.

6.3.1 *Expressions of self*

All three groups define people with dementia, as having interests, preferences and traits, having lifecourse experience and being social. In addition, participants with dementia and family carers refer to familial relationships and people with dementia, in particular, refer to their relationship with place and environment.

6.3.1.1 *Interests, preferences and traits*

Participants with dementia express who they are through discussing their traits, interests and preferences. Some participants describe themselves as active, as a good person and as conscious of their appearance. They are certain of their preferences and hobbies, from enjoying hillwalking to hating yoghurt. Julia, who had difficulty communicating verbally, was very clear about her likes and the degree to which she liked or loved them:

“I: So did you like dancing?”

P: I loved dancing”

“I: And do you like clothes and jewellery yourself?”

P: I love clothes and jewellery”

(Julia, pwd).

As part of the discussion on hobbies, half of the participants with dementia refer to their love of the outdoors and how much they enjoy being outside and in nature. Christine is emphatic about her love for the outdoors:

“I love nature, I love being out (chuckle) I'm not skilled at any particular sport or anything like that but I love being outdoors and that's what really makes me happy being out even on a wet day, being outdoors”

(Christine, pwd).

Family carers also emphasise the person with dementia's different personality

traits and interests. Family carers describe the person with dementia in different ways, including traits such as being active, conscious of appearance and popular. They describe many other traits, individual to each person with dementia, and too lengthy to report. Ultimately, family carers describe the person with dementia like any other person, as someone with strengths, flaws and characteristics that make them who they are.

In turn, formal carers spoke in the abstract, strongly prioritising the importance of knowing the person, their preferences, likes and dislikes to providing formal care. All but one formal carer referred to how important it is to know peoples' preferences. Jackie emphasises the significance of knowing the person's likes and dislikes:

“Oh it’s everything, it’s everything, it really is, it’s so important because it kind of, it gives you, I wouldn’t say power because power would be the worst word to use, but it gives you an insight into that person, how, you know, what that person likes” (Jackie, fcp).

Additionally, the majority of formal carers reference supporting hobbies as an important part of formal care, representing how they view the person with dementia as someone with interests and passions. Trudy describes how they support peoples' hobbies in the care setting she works in:

“And kind of encouraging like hobbies they did have when they were younger. Like some of the ladies, they might like knitting and sewing and stuff, so we do our best am to kind of have that sort of stuff. And there’s another guy here and he makes, he was like a basket maker. And they got a guy in to make those baskets that you put turf in and stuff” (Trudy, fcp).

While all groups identify interests, preferences and attributes as part of personhood, formal carers in particular emphasis how important knowing preferences is to providing formal care.

6.3.1.2 Lifecourse experience

Almost all of the participants with dementia conceptualise themselves through their experiences across the life course, how those contribute to who they are now

and what that means for their personhood. For example, participants with dementia talked about past and current occupations and roles and how these contribute to who they are. While some participants in later stages of dementia had difficulty recounting their life story they were able to construct it when supported by a family member and in one case a life storybook. At times, participants with dementia surprised family members with what they recalled. For some participants with dementia, knowing that they had worked hard gave them a continued sense of purpose that helped them get through difficult times. Maeve talks about how reminiscing on her lifecourse experiences provides comfort to her:

“Wherever I lived I was always involved and I think it has really helped sustain me in the difficult times now that when I sometimes pick up a photograph or something that I had from long ago or somebody reminds me of something in my past life that I had forgotten about and it brings me some great joy you know to know that I you know delivered on something” (Maeve, pwd).

Family carers spoke about the life experiences of the person with dementia, mostly in the context of loss and bereavement but also in the context of occupational roles the person with dementia had played during their life. Louise conceptualises her father through his military background:

“He was very routine orientated my Dad, he was in the military and then he went from the military and then he grew up in a military background anyhow, his father was in the army, and then he was in the army and then Dad ended up working in the fire and security in [place name]. So kind of military again like” (Louise, fc).

From the perspective of formal carers knowing the life story of the person with dementia is not only viewed as part of who they are but as significant in providing formal care. Over half of the formal carers refer to lifecourse experience. Karen explains how she discovered her client’s love of dancing:

“I suppose for instance, my client that does the dancing, the reason we found that, she was talking about when she was a child and she used to do Irish dancing and she loved dancing, and then she told me one day that some music came on and she was dancing around her apartment” (Karen, fcp).

A minority of the formal carers also point to the importance of reminiscing with

people with dementia to continue to support a sense of self through recalling their life story. For the formal carers, having knowledge about life experience as well as preferences is key to understanding who the person with dementia is.

6.3.1.3 *The social self*

All three groups conceptualise the person with dementia as a social being, one whose well-being depends on social interaction, meeting and engaging with others. All participants with dementia refer to the social self, emphasising the importance of social connections, enjoying social activities, keeping up with local news, getting out and about and a feeling of belonging. Thomas describes a care setting he attends through social interaction:

“I: And what do you do in there?”

P: I go in and talk to people yea, that lad and that lad and the other one and the other one and this one and have the dinner and hang around and sing a song”

(Thomas, pwd).

The social self is equally reflected in the accounts of family carers who emphasise the importance of social interaction and getting out and about. Louise describes her father as a social being:

“Ok. And even if he’s watching television there is one or two other dementia people beside him, there’ll be a carer, and that’s all he wants, he wants company.

He just wants company”

(Louise, fc).

Formal carers echo these views on the social self by emphasising the need for formal care to be structured around social interaction and getting out and about. Ita explains how getting out and talking to people provided comfort to one of her clients:

“When she deteriorated, we’d go out in the wheelchair when she wasn’t able to walk and that and it just got her out and she’d see people or have a conversation with people that she thought she knew but didn’t, and they’d be looking at me and they’d be just smiling. But it just relaxed, and then when we got back to the house then, she was more relaxed” (Ita, fcp).

6.3.1.4 Family

Nearly all participants with dementia spoke about family, defining themselves through their relationships to family members and at times friends. Maura emphasises how very important family are to her:

“Well the family was very important to me like, very important to me in my life like was very important the family like you know yea” (Maura, pwd).

Family is a significant aspect of the self and impacts on the self. For the most part, family had a positive influence for participants with dementia, however, at times, elements of familial relationships were rejected by the participant as something they didn't enjoy or identify with and could be a source of anxiety or stress. For Christine, family were also a source of tension or anxiety:

“On good terms with the people that matter to me in my life within my family and my circle of friends and ah there's certain people I've had to kind of withdraw from in my life as well for health reasons” (Christine, pwd).

Family carers are less likely to talk about what family means to the person with dementia, however, given the focus of the discussion on formal care, this is not surprising. However, family carers spoke at length about their own relationship with the person with dementia and how this was influenced by dementia. The family carers expressed a whole range of emotions and experiences in their relationships from trials and conflict with the person with dementia to trusting loving relationships. These are explored in the second theme on barriers to supporting personhood. Similarly, formal carers reference family in relation to their own relationships with family carers, however there was minimal reference to it in the context of personhood, besides two formal carers who spoke about the person with dementia as being part of a couple.

6.3.1.5 Relationship with place and environment

The majority of participants with dementia reference the importance of place and environment to the expression of personhood. Thomas had lived in the same place all of his life and defined his personhood through this:

*“I: The first question is just could you tell me a little about yourself about your life?
P: Well sure I was reared, born and reared here [place name]” (Thomas, pwd).*

Barbara, refers to the connection between place, environment and personhood, conceptualising it as part of the self:

“I don’t think there’s one particular thing but I think sense of identity is probably another question but I think sense of identity is about like, that thing about who you are, where you come from, maybe a bit about what you did, although I don’t know in the future will that make much sense to us, what we did and that sense of belonging that you belong wherever you are, that you belong to somewhere, yea, so that’s my vague answer to that question (chuckle)” (Barbara, fcp).

In addition, place is discussed in relation to the provision of services and what participants think the best type of service to support personhood is. This is reflected by Maura, who prefers attending the local day care centre as she knows everyone there:

“Well I like the local one of course because I’m used to it you see you know and I’m living and I like that cause I, used to it and I’d know the people and I’m used to it kind of thing” (Maura, pwd).

Family carers did not reference place and environment. In conclusion, all three groups define sense of self as having interests, preferences and attributes, lifecourse experience and the social self. Participants with dementia and family carers emphasise the importance and impact of familial relationships on the self. The majority of people with dementia and a minority of formal carers referred to the relationship with place and environment.

6.3.2 Interpreting changes to personhood

While there is general consensus on expressions of self, there is less agreement on interpreting changes to personhood. The participants with dementia tended to have a clear view of their own personhood, while both family carers and formal carers have difficulty interpreting changes to personhood, resulting in contradictory and ambiguous views of personhood.

6.3.2.1 Participants with dementia’s view of personhood

Participants with dementia convey personhood through talking about who they

are, expressing who they are through communication, being certain of the self, being aware of their memory problems and seeing themselves as normal. During the interviews, participants with dementia did not directly address whether they have personhood or what that might mean. Maeve and Nuala, talk about and describe themselves as people, and as 'normal' and 'average', like everyone else:

"I think that it is about me as a person and it's about my voice and it's about what I want" (Maeve, pwd).

"Yea I'm just an average person, an average person, I like things to be done properly and tastefully and am honestly and everything would be done honestly"
(Nuala, pwd).

Throughout the interviews, all of the participants with dementia were actively engaged in expressing and asserting the self. They used humour and self-depreciation to do so, showing how they were certain of themselves. Robert, a person with moderate to advanced dementia, expressed his sense of humour when talking about the birds outside his window:

"..but he's am one of umpteen flying out of here and I don't mean they're flying off to New York or anything (chuckle)" (Robert, pwd).

There was no indication that any of the participants with dementia thought they were less of a person or did not have personhood due to dementia. While some were aware of their memory loss and expressed self-doubt at their own abilities, for example, referring to themselves as stupid, this did not automatically undermine their ability to retain a sense of preserved self. Maeve talks about the experience of rediscovering the self after diagnosis:

"I have chosen a path that has kept me well for the last seven years and the path took me almost the first one of those seven to after my diagnosis of Alzheimer's to find out that I could do something again that I could be of use to the community that I could be of use to more important of all to myself to my own personhood that I was a person and that person was still there" (Maeve, pwd).

Participants with dementia spoke about how they were accepting new limits with

some trying to just get on with life, some were concerned about their family carer and some were trying to cope with anxiety. Some did, however, express uncertainty around their future self and what might happen as the disease progresses, in particular in relation to care services. The relative certainty around the conceptualisation of the self, expressed by people with dementia finds support in the views articulated by family carers and formal carers.

6.3.2.2 Personhood as unchanged

There is significantly more ambiguity among family carers and formal carers in understanding and interpreting changes associated with dementia, and what this means for personhood. They see the person with dementia as both changed and unchanged. When the person is viewed as unchanged, this is presented in a positive light implying that their personhood remains intact, that the person with dementia is *'still there'*. Some family carers mention that it is important to accept the person with dementia as they are and have a normalised conceptualisation of that person. Louise, a family carer, speaks about how her father continues to be a friendly person:

"I suppose the one thing that's still there, he is very friendly, he always was that was his personality. He would be outgoing and friendly and thankfully that never changed, he would always be happy to see anybody coming, he will try and engage as much as he can" (Louise, fc).

Michael talks about his frustration and struggle with his mother when she does not engage in conversation, but how she, as the person with dementia, assures him that she is present:

"Funny enough she would she came out with something to me there a while ago and you know I'd you know, it's not all plain sailing. As I said, the issues are with me and the the the outbursts come from me, obviously (chuckle). And she did say you do know I'd say because I'd get mad, I said you can talk to me, I'd like for you to talk to me and have a conversation ... And she said to me that you do know she said, I'm always aware that you're there" (Michael, fc).

Equally, some formal carers visualise personhood as unchanged, seeing the person with dementia as still being the same person. Terry, a formal carer, emphasises that people with dementia remain 'people':

"Even if you have a dementia you're still a person and you can still learn, you can still appreciate what's going on and you shouldn't be just kind of put into a corner and spoken about rather than spoken to, though that seems to be, the involvement of the patients is paramount I think" (Terry, fcp).

Formal carers also conceptualise the person with dementia as a human being, consulting them on their views, seeing them as smart and as part of a couple. The majority of the formal carers refer to how everyone is different and that this uniqueness is at the core of every person, including people with dementia. This conceptualisation then proliferates every aspect of care from the formal carers' perspective as it requires constant flexibility and ability to personalise care to each individual. Karen, a formal carer, talks about her approach to personalising care:

"Once that is done it's person to person, everyone's different like so the care is going to be different. So I suppose if one person loves nature and loves being out of doors then we're going to try and do that and go to pretty places with flowers" (Karen, fcp).

The majority of the formal carers refer to taking the person with dementia's perspective in relation to care practices. For example, they imagine what it would feel like if they themselves had dementia and apply this to what they would prefer in a given situation. This ability to empathise and reflect on the experience of the person with dementia is indicative of how they viewed personhood as the same for all people. Trudy conceptualises people with dementia as the same as everyone else:

"Because there's a few residents here and if they hear anyone at the door they get really panicky and everything, because that's what most people would be like (chuckle)" (Trudy, fcp).

6.3.2.3 Personhood as changing

Family carers and formal carers also refer to changes in the person with dementia. When the person with dementia is viewed as different or changed, this is conceptualised as a negative occurrence. Family carers and formal carers often perceive the person with dementia as lost, as being a problem, being in their own

world, becoming child-like over time, not being the person they once were, being unstable, passive and changing. For some family carers there is sometimes a contradiction between who the person was and who they have become in the eyes of the family carers. The majority of the family carers conceptualise the person with dementia as a child:

“Right but it's his typical way of and he says he doesn't like something you have to question yourself why, it's like a child” (Noreen, fc).

Family carers also reference how others had given up on the person with dementia and put them on the *'scrapheap of society'*. Ultimately, these nihilistic views of the person with dementia represent the meaning that family carers make from the perceived changes in their loved one and the perception of others in relation to those changes.

Some formal carers reference how personhood has changed for people with dementia under their care. That change can result in problems within the care relationship. Formal carers see some people with dementia as sometimes creating and causing stress in the care environment due to their behaviour, while others are framed as *'easier'* to handle. Terry compares the behaviour of a husband and wife who developed dementia:

“They both have developed dementia, the husband is very accepting of it, will go to a nursing home, the wife, says she has nothing wrong with her, demanding to be at home and creating havoc” (Terry, fcp).

Interestingly, several formal carers self-checked some of their more negative conceptualisations, correcting things that they said. Whether this was because they didn't believe what they were saying or because they wanted to appear more politically correct to the interviewer is unknown. Karen corrected herself when talking about people with dementia:

“They everyone has maybe they're suffering or that's a really bad word to use” (Karen, fcp).

Shane eloquently epitomises the difficulty formal carers experience in conceptualising personhood. He assumes that personhood remains even though at times he sees it as lost:

“I don’t think you can ever assume that somebody is just not there and not taking in what you’re saying, I think it’s much safer to just assume that they’re taking in everything even though they aren’t but you know better off assuming that they are” (Shane, fcp).

Family carers are more likely to have negative conceptualisations of the person with dementia such as infantilization and seeing them as unstable, formal carers are more likely to externalise this, moving the focus away from the person with dementia and towards the dementia itself. In this way, the dementia is seen as the problem, not the person. Ita talks about her strategy for dealing with this:

“And I said, look, that’s fine. I says, all that goes over our head. I says, we don’t take it personally you know. Because he might tell you to off, you know? And I said look, I won’t take it personally. You know, I says, because she says that is just his illness” (Ita, fcp).

Overall, formal carers are more likely than family carers to conceptualise personhood as unchanged. While all family carers refer to both how personhood remained the same and had also changed, they placed a much stronger emphasis on how personhood had changed and struggled to interpret the meaning of this change to personhood. This may reflect the fact that family carers spend much more time with the person with dementia than formal carers and can identify ongoing changes in day to day expressions of personhood. However, it may also be due to the fact that formal carers are more likely to receive dementia specific training, helping to reduce stigma and counteract nihilistic views of personhood in dementia.

6.4 Theme 2: Barriers to supporting personhood

This theme centres on why at times formal care relationships don’t support personhood and the meaning made of such experiences by the three groups. This theme is divided into two subthemes: interpersonal barriers and structural barriers.

6.4.1 Interpersonal barriers

Interpersonal barriers are difficulties experienced in the formal care relationship due to the actions of individual members of the care triad. Two main difficulties are identified by participants, conflict and a lack of understanding of dementia.

6.4.1.1 Conflict

At times, relations with both family and people with dementia are perceived as barriers by formal carers. The majority of formal carers cite family as a barrier to supporting personhood, often this is in relation to conflict between what family think is important and what formal carers view as important. Jackie describes her experience of family members placing unreasonable demands on her as a home care worker:

“Sometimes family, family sometimes can be the worst because you might get a text oh I want you to Hoover this room, I want you to Hoover that room, you know, and I’m there oh here, hang on a minute, you know, I’ve got one hour, your mum needs to be showered, she needs to be fed, she needs her medication and she needs a little bit of outside company as well, you know” (Jackie, fcp).

The quote above typifies how family carers may look for flexibility from the formal carer while the formal carer seeks to prioritise the needs of the person with dementia, given the limited time available. For the majority of the formal carers, the person with dementia themselves was also conceptualised as a barrier. Formal carers experience difficulty dealing with agitated behaviour or with abuse, including racism. Some formal carers attempted to deal with such behaviour by externalising dementia, separating the dementia from the person. Ita talks about how she deals with abuse:

*“I: Yea, because that can be difficult I’d imagine sometimes. For you?
P: Oh yea, oh yea, sometimes, yea. Some of them you kind of think, ah here now, I’m not here to do this you know. I don’t get paid enough or this isn’t my job to be sitting here and taking all this abuse, you know? Now, unless it actually becomes too bad you know. The verbal abuse, if it’s not them, you can accept it. I mean, to the family I says, we can take that. That kind of abuse, within reason, you know from them because you know it’s not what they were. It’s something that’s come with the dementia” (Ita, fcp).*

Just under half of people with dementia and family carers cited conflict as a

barrier to supporting personhood, so perceived issues and tensions in the care relationship were also reflected by other parties in the care triad. For example, Louise explains her frustration in trying to access services from the local health service but how also she didn't want to complain as the service provider had all the power in the relationship:

“Yea cause they have the power of pushing the hours you see, so you know, you can't afford to be too crappy to them either you know, like, to be fit to go in and. I mean, I went in I don't know how many times and it is literally just down the road and they never called in even though we had flagged it and flagged it and flagged it... They actually have the power of the giving and the taking really. You know? Especially the giving anyway, I don't know about the taking” (Louise, fc).

When discussing consistency in the care relationship, a minority of participants, refer to how a change of personnel is desirable if there is tension or conflict. Noreen explains that change can be good if there are communication difficulties with the formal carer:

“You see sometimes it's good that shifting around because if you don't get on with someone that there is just like it's not that you don't like each other it's just you can't talk” (Noreen, fc).

While Christine reflects on how some formal carers are easier to get on with and that a change of carers can be good if a person doesn't feel at ease around a formal carer:

“I suppose like sometimes variety is nice sometimes personalities might be a little bit different whatever you know so am one or two people maybe stand out as being kind of easier to be easier for me to feel at ease with in my surroundings”
(Christine, pwd).

6.4.1.2 Lack of understanding of dementia

A lack of understanding of dementia is also cited as an interpersonal barrier. Formal carers reference how families don't always understand dementia, which may lead to poor communication within households, making the formal carers' job more difficult and the potential for conflict higher. Pauline reflects on the need for more education and training for family:

"Families don't always understand what's, am, have more education, maybe, for families, as regards dementia... I have seen how families would get frustrated with the person" (Pauline, fcp)

Formal carers reference a lack of training in their own profession as a barrier to supporting personhood, citing many different elements to this. In particular, formal carers refer to poor communication. They experience difficulty communicating with the person with dementia, for example if the person with dementia has difficulty speaking, hearing difficulties or language barriers. A minority of formal carers also refer to the effect of labelling on the communicative process. Shane reflects on the need for more formal carers to be specifically trained in dementia:

"I think the ideal scenario would be having more people who are specifically trained to deal with dementia and that's not what you get in nursing homes"
(Shane, fcp).

Formal carers talk about the need to change the culture of care within dementia settings, but also talk about resistance to change and to training from some formal carers.

The need for more training for formal carers is reflected in family carers' accounts, who experience significant difficulty getting a diagnosis citing issues around not being taken seriously and ageist attitudes towards dementia. Family carers found that formal carers were tiptoeing around the diagnosis or not telling the family carer what was going on. Louise, a family carer, felt 'fobbed off' by her father's GP:

"The GP he had attended all his life really fobbed us off ... and the GP basically was saying, 'sure he's 80 or 80 whatever and sure what do you expect'" (Louise, fc).

For family carers this lack of communication was frustrating. Family carers also talk about poor communication in general from formal carers, both with the person with dementia, with the family carer and between the formal carers themselves, all leading to poorer care. This poor communication was linked by some family carers to a lack of understanding of dementia. Michael describes what he sees as bad communication from formal carers:

"It's a little bit, I suppose, a failing in probably, as in the book by the cover theory, ah well, you know, there's no point in talking to her, isn't it? So, again I suppose you'd describe that as bad communication" (Michael, fc).

6.4.2 Structural barriers

Nearly all of the participants reference structural barriers to the development of personhood ideals. These are external factors which impact negatively on personhood and are related to how formal care provision is structured and delivered in Ireland. These include: issues around choice, flexibility, consistency, autonomy and other system barriers.

6.4.2.1 Choice

There are some dilemmas and constraints, particularly amongst formal carers, in providing choice. These centre on balancing risk and choice, need and choice and priority-setting within dementia care. People with dementia had mixed experiences on receiving choice and mixed views of choice depending on their experience of it. Maura, although not certain of the finer details of her relationship with her GP, was confident that he respected her and gave her choice:

“He probably would yea I'd say he would yea I'd say he would he'd give you a choice like you know yea yea he would ah he's fair enough like everyway like kind of thing you know yea yea hm” (Maura, pwd).

However, Maeve was very upset by the complete lack of any choice or even provision of services and supports:

“We haven't been able to get support and that has been that has been very very very upsetting for me am (voice wavers) but at the end of the day we just have to live with it you know” (Maeve, pwd).

For some participants with dementia, choice was very important while for others it wasn't. Instead, they were passive about choice, conceptualising it as an impossibility and so by consequence something there was no point aspiring to. Patrick and his family carer James use humour to portray this:

“Patrick (pwd): No, there wasn't, never really, any choice given or

I: Ok. And would you like to have a choice?

Patrick: Sure ah it makes very little difference

I: Ok yea.

Patrick: Like that it'd be ..

*James (fc): What couple of choices could you or have would be the question
(chuckle)”*

The experiences of limited choice are equally reflected in the accounts of family carers. Some family carers felt forced to accept services their loved one didn't want as they were afraid they wouldn't get any other services. Emily talks about accepting care that she knew her father didn't want:

“But because we were all trying to get on with our lives, we needed this although we knew it wasn't what he wanted” (Emily, fc).

Similarly to participants with dementia, family carers conceptualise both the person with dementia and themselves as passive in the formal care process primarily because they felt there was no choice available to them. James doesn't remember being provided any choice by the health and social care system:

“I don't think there was anything about it only they said they were sending out somebody, that's all I think” (James, fc).

For people with dementia and family carers choice is predominantly defined in relation to the provision of services in the aggregate and in binary form - services or no services. In contrast, formal carers are more likely to conceptualise choice within the care relationship in a more nuanced way, emphasising the personalised nature of care delivery. That said, the majority of formal carers conceptualise choice as limited; choice as a possibility rather than a certainty. Sometimes choice conflicts with risk to the person with dementia and other care recipients and therefore has to be constrained. Other times, the budget constraint does not allow choice to be provided to the person with dementia. At the same time, formal carers emphasise the significance of choice. Claire refers to how it is important to provide choice to the person with dementia, even within limited choice sets:

“I: How important do you think it is that people get flexibility and choice in relation to services?”

P: I think it's extremely important, yea I think it's extremely important where possible. And even where not possible, I think it's really important to find choices within the limited choices, you know, to allow people at least have the perception that they have some control over, you know, what's happening to them in terms of care” (Claire, fcp).

The majority of formal carers refer to risk as one of the main limitations to choice. Laura explains how choice is limited if other factors, such as hygiene, are impacted:

“But choices, like I often choice, like every day there’s choices isn’t there? Like we’d have clients and they don’t want to have a shower and that’s ok, we can’t force them, but if it goes more than a week or, you know, if they begin to smell, you do have to kind of take control then, you know?” (Laura, fcp).

Elaine refers to how perception of risk and hence provision of choice varied between care settings. She was happy to support people to walk around in a day care setting even though there was a falls risk, having worked in both settings, however, Elaine felt that this choice would be removed if a person went into a long-term care setting:

“But the minute they come into a long-term care they’re on a chair alarm and they can’t walk. That choice, I think, you know, that’s where people lose a choice”
(Elaine, fcp).

Due to these perceptions of risk, three formal carers saw choice as impossible in a long-term care setting. Harry was frustrated at not being able to provide more choice:

“So I mean if you’re used to having choices, and you have to, to be able to give them choices, but unfortunately it’s not always possible. Am that’s one thing I do find frustrating about the job, because you, you know they need a lot, we need to be able to give them a lot more choices than we are currently able to give them”
(Harry, fcp).

6.4.2.2 Flexibility

A concept which goes hand in hand with choice is that of flexibility. Fewer participants with dementia refer to flexibility compared to choice, but those that do think it is important and give examples of how they benefitted from flexibility in service provision. Family carers are more likely to talk about flexibility than people with dementia. Some family carers highlight the importance of flexibility, and how a lack of flexibility means that the person with dementia misses out on accessing services and also that this lack of flexibility does not support the needs of the family

carer. Louise refers to her parents' experience of home help, where her father was living with dementia and her mother was his primary carer:

“And ah you know, once his mobility came back he could dress himself and all of that. So, I think her needs changed for the help that she needed with him, he needed less hands, she needed home help in the home which the person she had would not do any of that” (Louise, fc).

Fewer formal carers identify flexibility as important compared to choice. However, over a third of formal carers mention how more flexibility in relation to services and supports is required for people with dementia. Laura, a home care manager, explains how important flexibility is when providing care to a person with dementia:

“But with people with dementia, like they mightn't be getting up until eleven o'clock or they might be getting up at eight o'clock or you know, you do have to be very flexible, you know? And again half hours, you can forget about it, because you can't be rushing somebody with dementia. You know so if you've somebody going into, if you have a carer going into a client for half an hour, they are going to be rushing, you know? They are going to be under pressure for time. So I think you do have to be flexible. I think things are just that bit slower. I think it's different for somebody who doesn't have dementia, you know?” (Laura, fcp).

Ronan explains that before you can talk about flexibility you have to address availability, which is sometimes limited and often non-existent.

*“I: Do you think people get any flexibility or choice in services at the moment?
P: Very little. Very little, ok. I mean it's a matter of either what they're eligible for or what they can afford versus availability, which is often the great limiting factor as well”* (Ronan, fcp).

6.4.2.3 Consistency

Coupled with choice and flexibility, the issue of consistency of care personnel is also discussed by participants. The majority of participants with dementia reflected on how their experience of care to date has been a mixed bag, having both good and bad care experiences. Some people with dementia would prefer a common

approach to dealing with the disease, particularly in relation to the psychosocial elements of care. Maeve reflects on her experience of inconsistency in how she is communicated with:

“How we're communicated to when we're in the environment we're in within a hospital environment or within a doctors environment am that is all down to the person that is dealing with you ah and it is a mixed bag because some doctors will be very understanding and be kind some more of them will get you in and get you out ok” (Maeve, pwd).

There is a stronger emphasis on consistency from family carers, with all of them referring to the benefits of having the same person delivering care, thereby allowing a relationship to evolve with the person with dementia over time. Half of the family carers directly refer to the importance of consistency in formal care provision with some referencing that too many changes of personnel is detrimental to the person with dementia. Jonathon reflects on his loved one's experience of inconsistency in formal care:

“She didn't like them coming into her house, and that was basically it, and then they were changing, there might be one girl one day and a different girl another day and that threw her off altogether I think. If she got used to the one person I think it would have been way better for anyone if they got to know her”
(Johnathon, fc).

A third of the formal carers cite the consistency of the care itself as more important than who delivers the care:

“Yea, yea. I don't know, I think we're all attracted to different parts of people and consistency is important but it's more the consistency of the information”
(Barbara, fcp).

As already referenced in the subtheme conflict, several of the participants mention how, at times, change can be beneficial if there are tensions in the formal care relationship. For all three groups consistency is framed within the dynamics of the care relationship and how well the care relationship works depends in some part on the compatibility of the formal carer and the person with dementia. If this is working then consistency is important, if this is not working then sometimes change

is necessary and desirable.

6.4.2.4 *Autonomy*

The concept of autonomy is almost exclusively discussed by formal carers. While not synonymous with choice, autonomy is closely tied to discussions around choice, limits to choice and risk. The majority of formal carers touch on autonomy in some way referring to how it is important to respect autonomy but that again it was a balancing act with risk. Phil explains how finding this balance is difficult:

“But I think it’s am hard to kind of, I suppose get that balance between being a carer, being paternalistic and also acknowledging the autonomy of the person in front of you” (Phil, fcp).

A few of the formal carers describe themselves as risk taking but limited by a risk averse society, including regulation, which denies people with dementia the right to take a risk. Elaine expresses frustration at why older people are not allowed to take risks:

“And why when you’re 82 can’t you do stuff? Because it’s a risk. You know, I think HIQA have to change all that too, people have to be allowed you know do, we say this in the training all the time but like, when are we going to be stopped from making foolish decisions? I can make a foolish decision you know?” (Elaine, fcp).

Two formal carers reference the impact of a loss of independence or autonomy, for example no longer driving, and the impact these events have on the individual. Elaine reflects on a discussion with a person with dementia and how it occurred to her that being in the long-term care setting was not the choice of the person with dementia but that they had no choice at all and so had to try to accept their situation:

“I actually started putting down the answers and one of the questions was, ‘Would you recommend this place?’ And someone said, ‘Yea, Yea I would, it’s a very good place, it’s very clean’ but one of the questions, ‘Yea I would’ but I used to kind of draw it out a bit further, ‘Are you good?’ and they’d say, ‘Yea, but it’s the last place I’d want them to end up’. Now, that was nothing got to do with that hospital, they didn’t want to be there themselves either. Yea, if you had to go into a nursing home this is where you could go, this is a good nursing home but they’re

not asking the questions, if you had a choice would you be here? And you see, people don't want to ask that question because then they might say, 'Well, you know'" (Elaine, fcp).

A minority of participants with dementia refer to how the care provided to them and the setting were authoritarian, reflecting that fact that they did not feel they had control in the care relationship, lacking autonomy and contributing to issues around control and power imbalances. Nuala talked about her experience of a care setting she attends, one in which she did not feel she had autonomy or could do things for herself but rather felt that she needed to defer such decisions to 'someone in charge':

"I: Do you think you're allowed to do things for yourself when you're down there?

P: I wouldn't think so no no way .. I'd be limited in what I could ask for

I: Ok

P: Sure the last thing I think of anyhow is myself

I: So if you wanted to do something yea you wouldn't?

P: Go to the head person whoever and get permission" (Nuala, pwd).

6.4.2.5 Other system barriers

The majority of participants reference other types of system barriers such as time constraints, being understaffed and feeling obliged to accept care. The majority of family carers reference time as a barrier. They believe that formal carers are too busy and do not have sufficient time to support personhood. Only one participant with dementia references time, referring to how busy care staff are. One family carer describes care as being 'hit and run', while another attributes the lack of time to insufficient staffing. Emily sees formal carers as constantly rushing:

"Yea that they listen to their needs, that they're adhered to, you know, to repeat myself about the care services, I think a lot of it is am they're rushing to the next job, emm and they're not really they don't really, a lot of them don't really care, you know, I think they're just all rushing, rushing, rushing am I can't really say an awful lot more about it" (Emily, fc).

Similar to family carers, the majority of formal carers identify time constraints as a barrier. Formal carers feel rushed when providing care to the person with dementia and see time pressure as a constraint to really being able to connect and engage with the person. Shane is frustrated by these time constraints:

“I think the one thing that matters most is the that they probably never get enough of is just time and you know as much one-to-one you know relating as possible and it's just you know sometimes it's one of the more frustrating aspects of the job and it's just not possible to do that an awful lot of the time” (Shane, fcp).

Hand in hand with the issue of time constraints. A minority of formal carers refer to understaffing as an issue. Geraldine explains how understaffing impinges on the ability to provide more personalised care:

“I feel that resources though impinge on that. Am you know, maybe not on that scenario because that would be something that's provided. But I guess I'm trying to think of an example of am I guess resources in the sense that as much as we can personalise somebody's care, am sometimes resources just I guess staffing levels is kind of what I'm thinking of” (Geraldine, fcp).

Two participants with dementia felt they had no choice but to accept whatever care they could get. Thomas felt that he was attending a day care service too frequently and did not want to be there, but felt obliged to attend:

“I: Ok, so you go in a couple of days in the week?”

P: Yea yea but sure I have to for who or what (inaud) anyway

I: You have to sorry?

P: Put up with what I'm at” (Thomas, pwd).

The majority of family carers reference how the person they cared for sometimes did not want a particular service, for example, home help or day care, but that they ended up receiving the care anyway. Sometimes, family carers colluded in the provision of unwanted care to the person with dementia. A minority of formal carers explain that the provision of unwanted care to the person with dementia is due to poor communication and lack of choice generally. Some formal carers hoped that care had moved on from this model, seeing newer models as empowering rather than disempowering.

6.5 Theme 3: Personhood in the formal care process

This theme focuses on elements that support personhood in formal care relationships: communication skills for personhood-enhancing care and traits of personhood-enhancing care. Often the responses by formal carers, and family carers to a lesser extent, are tempered by stage of dementia, so, for example, certain qualities and communication skills became more important when a person had more advanced dementia.

6.5.1 *Communication skills for personhood-enhancing care*

Good communication skills are identified as important for personhood-enhancing care. However, there isn't a strong degree of consensus on what 'good' means. It is not the case that there is strong evidence of conflict among the three groups of respondents, but rather there is weak consensus, with participants in each group citing a wide range of requirements. However, all of the groups refer to the need for communication to be easy, clear, simple and include humour, citing the content and speed of delivery of the language used. Formal carers are much more likely to focus in on the specifics of communicating with the person with dementia and emphasise additional skills such as being at the person's level, taking time and listening to the person. Formal carers also refer to their skill of balancing different elements of the care relationship.

All of the groups refer to the need for communication to be easy, clear and simple. Half of the participants with dementia talk about how they find communication with some formal carers easy. Maura finds it easy to speak with people who provide care to her:

"I: Do you find it easy to talk with people?"

P: On the whole I do yea yea I usually talk away I might talk too much sometimes (laughter)" (Maura, pwd).

This is not always the case but rather that some formal carers are easy to communicate with and others aren't. Some family carers reference the importance of clear communication, including the speed and content of the language used and the significance of connecting with the person with dementia. Noreen identifies the

importance of using language to make a connection with the person with dementia:

“The language, the the speed of information, yea and if, sometimes it helps when you make a connection with the person first, to talk and like where are you from eh hobbies or anything do you have dogs, do you have horses, what do you like, what do you used to do, where did you live, did you go and travel and all of that. It's bringing down, he's relaxed and talks more freely” (Noreen, fc).

A third of the formal carers highlight the significance of communication being simple and clear. Additionally, they mention the importance of non-verbal communication both theirs and that of the person with dementia. Karen explains how if you know a person well you can read their body language and you don't always have to rely on verbal communication:

“So that you don't always have to have good verbal communication with the person, you already know you know what if you obviously tell by their body language if they're uncomfortable with something, that you know change it” (Karen, fcp).

The majority of formal carers focus in on more specific aspects of effective communication with the person with dementia. Nearly all of the formal carers emphasise the need to be at the person's level, to sit with and maintain eye contact with the person with dementia when communicating. Elaine emphasises the importance of taking your time and connecting through communication:

“Why can't we just make it more sociable, there's nothing wrong with having a cup of tea when you're assisting someone to eat, it'll slow you down. That is stuff I have learned, sitting down, making eye contact and actually listening to the person, you know?” (Elaine, fcp).

A minority of family carers also refer to how taking time is as important as getting the care task completed. One of the main purposes of taking time is to ensure that formal carers are listening to the person with dementia. Maeve identifies being listened to as key to respect, dignity and good communication:

“I: Thinking about what things like respect or dignity would look like to you in

those relationships?

P: Well I think first of all dignity and respect is about listening to us listening to what listening to what I need ok that's that's the first" (Maeve, pwd).

Half of the family carers mention the importance of humour in communication. Their emphasis is stronger than the other two groups, a minority of whom also reference humour. While participants with dementia did not specifically reference humour as a desired communication skill, all of the participants expressed humour during their interviews. A third of the formal carers reference humour as an important skill when communicating, including things like having fun with the person. Humour links closely with the trait of friendliness outlined in the next subtheme. Harry talks about how he enjoys having fun with people he provides care to:

"One of the lads used to, a resident, he used to take the piss out of me here, 'Model them again for me, them jumpers. Which ones you want me to put on?' He says 'I don't give a shite what I put on.' you know? (chuckle) I was here showing him 'Which one do you want?' and he said 'Try and hold that one up. Hold that one up again. Hold the other one up again.' That's what I like like, a bit of banter with them, you get to build up your trust" (Harry, fcp).

Communication is very important to avoid or defuse conflict between formal carers and people with dementia. All of the formal carers spoke about various communication skills to resolve tense situations such as going out of their way to avoid upsetting the person with dementia, avoiding conflict and not taking things personally. They may also take a step back from a situation if it becomes tense and 'go with the person', for example, agreeing with the person with dementia or metaphorically going with the person and their current reality when it is not accurate. Laura explains her strategy if a person she cares for becomes upset:

"Calm and initiative and sometimes you just have to give a client space and come back to them then afterwards and try and, you know, if you're trying to get somebody ready for bed at night and they don't want to get ready for bed, you go 'Well that's grand' and you go away and you put the kettle on, make a cup of tea and then come back and then they might be ready, you know? So nothing happens, it's kind of on their terms. You kind of have to go with the flow Niamh, you know?" (Laura, fcp).

In this act to find balance, the majority of formal carers talk about persuading the person with dementia to do certain things. Persuading the person ranges from encouraging the person to engage in an activity to deceiving the person with dementia. Ita talks about how she would bring a client for a drive to their childhood home and pretend to knock on the door:

“Go in and ask them does someone live here’. So, I’d get out of the car and go for a walk. I wouldn’t go knocking on the door. And then come back into the car and I’d say ‘No’. I’d say, ‘They used to, but they moved away years ago’. ‘Oh right, oh ok then. We’d better just head back home again now’. But she was happy. She was relaxed because it was she thought she had made contact with her past, you know?” (Ita, fcp).

The act to find balance was not solely limited to communication, formal carers also tried to balance all elements of care to suit the support required by the person with dementia relating to the type and stage of dementia. They also had to balance care according to personhood needs, who the person is and how that influences the care they provide. Therefore the majority of formal carers also reference personalising care tasks and balancing activities to ensure that it was right for the person with dementia. They refer to how care will always be different as every person is different. Barbara explains how it is important to personalise the task, (making sure the person has food), to include their wider social and psychological needs:

“Whereas but the end goal is still the same, the person still has food in their press but it’s so important that the process is actually supportive of the person, so if the if the support network is flexible then somebody can be taken shopping, you know where they go out and they experience a whole social period of time in the day, you know where they’re actually walking into the supermarket, the smells and the sounds and the you don’t get that if your shopping is delivered to your door, you know” (Barbara, fcp).

However, half of the formal carers then refer to how personal care is prioritised over other types of care, that once personal care is complete then other care may be attended to if time permits. Claire expands on this emphasising that some formal carers struggle to see how the person’s needs and personhood can be supported

simultaneously:

“There’s a lot of needs, a lot of these people, you know, a lot of our clients can’t do very much for themselves at all so they’re requiring a lot of input. Am but it’s, I suppose it’s about how do you, how can you honour personhood and take their blood pressure or whatever it is” (Claire, fcp).

In conclusion, good communication skills are seen as crucial to supporting personhood in the formal care process. The next subtheme outlines traits of personhood-enhancing care in practice.

6.5.2 Traits of personhood-enhancing care

All three groups reach consensus on some qualities or traits of personhood-enhancing care. There are some differences in emphasis among the three groups as they examine the formal care relationship from different perspectives. Traits found to be important to supporting personhood include: competency and friendliness, respect, honesty and trust, knowing the person, empowerment and sense of security. While there are no significant conflicts among the groups, there are some qualities that are emphasised more strongly by one group than another.

6.5.2.1 Competency and friendliness

All of the participants with dementia were content with some aspects of the care they received. One participant was particularly happy with the care, feeling that criticism of health care providers is unfair and down to a lack of resources. Many of the participants with dementia describe the carers as nice and good conveying competency and friendliness. For participants with dementia, competency also includes concepts such as reliability and availability. Some participants with dementia, including Thomas, specifically refer to how the competence of the care staff was important to them:

“I: Is there anything that’s very important to you about any of the health care that you get?”

P: Well there’s not much I can think of but I’d like to be looked after in a sense you know” (Thomas, pwd).

Family carers place a strong emphasis on competency and refer to how some

formal carers were amazing and had done everything in their power to support the person with dementia and their family. This includes how the formal carers had listened to the family carer and the person with dementia. The experience of family carers relates as much to their own relationship with the formal carer as it did to the perceived relationship between the person with dementia and the formal carer. Family carers conceptualise some of the formal carers' competencies as being intuitive and innate. For example, Michael refers to how one formal carer had a 'good way' about her:

"She had a very good way. I mean if you could have handpicked someone, you could say you could bring in someone. She worked there. She wasn't brought in especially to do it. It's just she had a good way about her" (Michael, fc).

While Andrea, was particularly satisfied with how nice the formal carers were:

"You know, they're all very nice I have to say, everybody's been very nice in there and all her team, Doctor [name] is very nice and all the healthcare people on that team are really nice. I couldn't really fault them really, they're all very nice"
(Andrea, fc).

Formal carers did not place as strong an emphasis on competency. However, a minority of formal carers talk about being effective carers and ensuring that formal carers follow up on their work, as part of competent care.

There is significant consensus on the need for friendliness across all groups. The majority of all participants talk about how formal carers should be friendly and chatty in their interactions with care recipients. Friendliness is a catch all phrase for creating a sense of warmth, belonging and acceptance. Participants with dementia refer to friendliness and how it is important to get on well with the formal carer. Maura talks about a care setting she attends and sees friendliness as simple but important:

"They're quite nice yea yea am they're just ordinary really you know but they're just friendly with everyone kind of then you know and they're very friendly and we get on with each other so that's basically what it is really yea yea" (Maura, pwd).

All of the family carers concur conceptualising friendliness as talking with the person, being nice, pleasant and having compassion. James thinks that being pleasant but also competent is important:

“Say that would be kind of a pleasant personality we’ll call it would be one major thing I’d say in the job. But then how good or kind they’d be after that would be another next question” (James, fc).

Formal carers equally emphasise friendliness, again seeing it as being chatty, being open and having fun with the person with dementia. In particular, formal carers focus on the significance of engaging with and talking with the person; that they communicate well with the person with dementia in addition to providing care. Good communication is important for creating rapport which, in turn, leads to a better care relationship. Laura explains how developing a good formal care relationship is important:

“So I think the relationship and having a chat and a bit of fun and sometimes, you know, reminiscing like you know getting out photo albums. All that kind of thing I think is really important” (Laura, fcp).

For many formal carers the concept of friendliness extended to caring for and having genuine concern and love for the person with dementia. The majority of formal carers talk about how they are fond of the people they care for, that they are like family and they are concerned with their well-being. For some formal carers, getting close to the person with dementia enhances empathy, warmth, heart and compassion. Jackie, talks about the warm, loving relationship she has with the people she provides care to:

“I have all levels of dementia but I have I have a great rapport with them and they know, I know they say oh you should never get too involved but I love my clients. Ok yea they’re just like, like family to me” (Jackie, fcp).

6.5.2.2 Respect, honesty and trust

Half of the participants with dementia reference feeling respected in current care settings and how respect is important to them in formal care relationships. This

includes being treated with kindness, compassion, flexibility and not being patronised. Nuala emphasises how important being treated with respect is to her:

“I: What’s important to you in how the, the staff, the health care staff see you and interact with you how would you like them to think of you?”

P: I'd like them to have respect for me

I: Ok

P: Oh yea and eh respect my truthfulness and honesty

” (Nuala, pwd).

Family carers reference respect, conceptualising it as treating people with kindness, not being condescending, being patient, communicating one to one and respecting privacy. For formal carers respect came in many guises and was linked to the concept of dignity. It includes respecting peoples’ preferences, their privacy and space. For formal carers, showing respect is portrayed through how they interact with the person with dementia. Claire sees consulting with the person as a hallmark of respect:

“And generally I think, you know, seeking their views and what their preferences and likes and dislikes are I think is really, really important and what their I suppose what their wishes for themselves are. I think all of that shows a lot of respect and care for the person” (Claire, fcp).

Half of the participants with dementia refer to how important honesty is in the formal care relationship. Nuala is very clear that honesty and sincerity allow her to engage with and get on well with formal carers. For Nuala, this is all that is required for her to develop a good formal care relationship:

“I: If you were to describe them or I suppose what qualities they have that mean you get on well with them? How would you

P: They've sincerity

I: Ok

P: And honesty and that's good enough for me” (Nuala, pwd).

Interestingly, honesty was not emphasised as strongly by the other two groups with only one formal carer and no family carer referencing it. However they did refer to trust. The concepts of honesty and trust go hand in hand. Just under half of the

participants with dementia refer to trusting their formal carer, Robert, a participant with dementia living in a long-term care setting, shows how he trusts care staff:

“Ah well well I wouldn't be spoofed around here sure I wouldn't” (Robert, pwd).

Family carers place a similar amount of emphasis as participants with dementia on the importance of trust and its significance to the formal care relationship. However, the strongest emphasis on trust is from formal carers, who identify it as crucial in developing good caring relationships. As Karen explains, without trust the care relationship will not function:

“I: So between you and the clients that you care for, what would you say are the number, we'll say, the most important thing to develop?”

P: Am .. I suppose a trust, they have to trust you, don't they? People anybody, any relationship, you have to have trust, don't you” (Karen, fcp).

6.5.2.3 Knowing the person

People with dementia are clear about what qualities they want in formal carers. Over half of the participants cite familiarity with formal carers and other people in the care setting as important. For Christine, it is important for formal carers to get to know her, especially as she is uncertain of her future care needs:

“Think it is I think it's good for them to get to know me at this stage because I'm not things will change I'm sure am at least they kinda get to know me as I am now they'll be able to remember me as I will be” (Christine, pwd).

Under half of the family carers agree with participants with dementia about the need for formal carers to know the person with dementia, while, all of the formal carers emphasise the importance of knowing the person, with the majority emphasising that this process takes time. This is particularly so in relation to people with advanced dementia. Barbara explains the skills needed to interpret and understand non-verbal communication:

“So you build up and you'd say, you know what, ‘She hasn't drinkin', it's about being really aware and really observant and saying, ‘That lady actually she hasn't I've done two long days now and she hasn't taken a drop of any cup of tea that we've offered her', so hang on, offer her something else, you know” (Barbara, fcp).

Half of the formal carers reference knowing the person's routine and how that informs the care they provide. A minority of family carers also reference the importance of a routine and in particular how the person with dementia had 'settled' into a routine and that formal care should support this. A minority of formal carers identify the dangers of making assumptions about preferences, particularly if those preferences have been informed by formal carers or family carers rather than directly communicated by the person with dementia themselves. A third of the formal carers illustrate how the local community supported them in getting to know the person with dementia. Frequently, in local care settings care staff and other visitors are familiar with the person with dementia and have been over their life course. This finding links back closely to the person with dementia's discussion of place and environment in the first theme. Claire describes how local knowledge can be beneficial when getting to know a person with dementia:

"But what you'll find, what I find in [place name] is there's a lot of informality, not a lot but there's quite a bit in that I suppose rural nursing homes exist in a community, you know, and most of the people who work there are from that community, the owners are from that community. So I suppose when residents from that community come in, it's not like that's the start of the relationship, these are people who have known each other for decades" (Claire, fcp).

As part of knowing the person, a minority of all three groups refer to the need for formal carers to understand who the person is and really see the person for who they are. Engaging and connecting was emphasised by the participants as important in getting to know the person. Half of the participants with dementia highlight how it is important to feel drawn to and to get on well with the formal carer, that they were a source of comfort to the participant with dementia. This concept is reciprocated in the accounts of family carers where the majority refer to the need for formal carers to engage with the person with dementia. Noreen explains how one formal carer had engaged with her loved one:

"And and talk to him and ask him and just let him talk, draw him out what he likes, she knew in no time, he likes dogs, he likes farm animals, she was from the background, she let him talk and that made him like when they went out like to do the shower or anything like that. It wasn't like personal hygiene, it was a chat with

her and everything else was around it, she was there to listen to him” (Noreen, fc).

However, formal carers most strongly emphasise the need to engage with, connect with and be interested in the person with dementia. For formal carers this is an integral part of getting to know the person, being friendly and developing trust and being able to develop a good formal care relationship. Phil talks about engaging with the person with dementia:

“Because I think then I suppose it’s very difficult to care for someone with dementia you know what I mean. And kind of formally and informally, and I think if you have that kind of connection with them, it certainly helps to see the person behind the dementia, you know and you can then I suppose kind of pick and engage at some level” (Phil, fcp).

In order to get to know the person and to connect with the person with dementia, formal carers require support and tools to do so. All of the formal carers talk about using personalised tools to support the formal care relationship. They refer to the usefulness of care plans and the importance of the content of such plans, as well as using personalised tools such as life story books. Personalised care plans inform the formal carer about who the person is, which, for the formal carer is the essence on which to build a trusting care relationship. One formal carer conceptualises such tools as an effective method to ensure that all staff, including temporary staff get to know the person and develop a caring attitude towards that individual. Claire reflects on how providing a life story of the person with dementia to formal carers is a valuable tool:

“You’re just rostered to a ward for a day, you have no investment in that ward, getting to know the client, you know, you really don’t. However, if any of us were given a life story about a human being and told information about them, well straightaway you kind of care about that person, you know something about them” (Claire, fcp).

6.5.2.4 Empowerment

The majority of formal carers reference empowerment and supporting the person with dementia to live well. This includes supporting independence, enabling the person to participate in interests, not highlighting mistakes and assisting the person with dementia to find purpose and meaning in life. Ronan talks about supporting

the person with dementia to pursue their passions:

“Going back to what we were saying, working out what their passion is and making sure they can continue to do it and enable them to be able to do it, pursue it” (Ronan, fcp).

Geraldine explains how a resident in the nursing home she works in is teaching her Irish and what she thinks this means to the resident:

“But they now have a sense of duty and responsibility that if I’m stuck, I can come to them and we will she can teach me. I’m just thinking of one person in particular who she loves doing it. She’d she’d sit down, and she’d help you with your Irish and she’d get you to write out all these words and then the Irish beside them, so it just gives them that sense of importance as well and that they know that they’re needed, you know?” (Geraldine, fcp).

Empowerment was not referenced as much by the other two groups. A minority of participants with dementia refer to empowerment and conceptualise good care as supporting the person with dementia to live as independently as possible. One family carer refers to empowerment and in particular to a formal carer who was very good at supporting the person with dementia to do things for themselves.

6.5.2.5 Sense of security

Well over half of the formal carers conceptualise care as creating a sense of security for the person with dementia, encouraging feelings of safety and ensuring the person with dementia felt comfortable, relaxed and calm. Karen talks about the importance of creating a safe environment:

“To be treated and I suppose to create like ah to have to make the person feel that they’re in a safe environment. That they’re not in any way threatened like in any form. Do you know what I mean? Like I’m here they have to do things. Like, I’m there for them for whatever they want do you do you know what I mean?” (Karen, fcp).

This emphasis on sense of security is not as strongly reflected by participants with dementia, however, a minority did mention that they found it reassuring that services were there if they needed them. This falls outside of the discussion of the

formal care relationship but for some participants with dementia knowing that the care was available, that it was an option if they needed it, was reassuring. One family carer referred to how care is reassuring, talking of how the person with dementia felt safe in one setting they attended, allowing them to open up and interact more.

There were several additional concepts acknowledged by a minority of formal carers and family carers. These concepts were inclusion, comfort, quality of life, supporting a person to live in their own home and maintaining appearance. Pauline spoke about her role as a formal carer in supporting the person with dementia to be comfortable and enjoy a good quality of life:

“Yea. But that would be basically it isn’t it? Whatever they need, you’d have to put on. What is going to make life comfortable, enjoyable, for them. A good quality of life for them for this stage of life. Whatever it takes” (Pauline, fcp).

Along with formal carers, a minority of family carers also spoke about inclusion as important. When Cynthia was asked about what she thought her mother enjoyed about a day care setting she spoke about being included in activities:

“It was the activities, there was other people and I saw her in it and she was sitting down as quiet as anything, but she was part of a group and they’d be making something or, you know and she was really content and she’d be joining in on jokes more so very quietly but if there was a joke she’d laugh at it or if somebody did something funny, you know, or dropped something or something like that, you know, she’d help” (Cynthia, fc).

Overall, there is a significant amount of consensus in this subtheme but with stronger degrees of emphasis on different concepts by different groups. At its core supporting personhood is about developing good formal care relationships. This relationship is epitomised by traits such as competency and friendliness, respect, honesty and trust, knowing the person, empowerment and sense of security.

6.6 Discussion

The difficulty in interpreting changes to personhood reported by family carers and formal carers in this chapter, reflects the ambiguity around the conceptualisation

of personhood, already found in the policy analysis in Chapter 3. Ambiguity around personhood impacts on the type of care provided by formal carers (Hughes, 2001; Malloy & Hadjistavropoulos, 2004), and can have serious consequences for people with dementia (Hunter et al., 2013). If formal carers do not believe people with dementia have personhood, then the fundamental ethos of person-centred care is lost.

Policy should focus on reducing stigma and misunderstanding around dementia, particularly in relation to educating formal carers on: the existing evidence on personhood and the self, as well as the implications of not respecting personhood. In practice, this means providing specific training and education prior to, or in tandem with, person-centred care training to ensure that those providing care understand the concept of personhood and its implications for person-centred care. This must also include understanding the experiences of formal carers and their interpretation of change and equipping them with tools to deal with this change. This could include communication and observational tools, which allow formal carers to engage with and access the personhood of the person with dementia, in particular people with advanced dementia.

While there was difficulty interpreting changes to personhood, there was substantial agreement on its core elements such as: interests, traits and preferences, lifecourse experiences and important relationships. These findings reflect both theories and empirical evidence on the self (Sabat & Harré, 1992; Sabat & Collins, 1999; Batra et al., 2016) and relational personhood (Kitwood, 1997; Nowell et al., 2013; Borley & Hardy, 2017). This study provides clear guidance to policy and practice about what is important to the personhood of people with dementia and how this can be supported by formal care. It is evident that some of this knowledge is already known, with formal carers in this study, referring to the use of personalised tools and also many participants emphasising the importance of knowing the person to providing formal care. Of particular interest is that people with dementia and family carers also prioritised family as important, while family was not emphasised as strongly by formal carers. More consideration is required from formal care provision about providing care to the family unit, rather than solely the person with dementia. This reflects concepts put forward by Hellström et al. (2005) on couplehood and Nolan et al. (2004) on relationship-centred care. Further efforts are required, from policy and practice, to incorporate important relationships into formal care provision through normalising the experience of

dementia and ensuring that formal care is designed to empower the person with dementia and their family to continue to nurture important relationships and maintain the social self.

Relationship with place and environment was referenced by over half the participants with dementia as important, yet it was not emphasised as strongly by the other participants. The role of place has important implications in terms of how we think about personhood, and designing care structured around place, environment and community. The concept of place links in closely with social relationships. For example, one of the participants with dementia clearly expressed a preference for attending a day care service closer to her home as it was local and she knew everyone there. Although there has been some theoretical discussion on place and personhood (Chaudhury, 1999; Chaudhury, 2008), more in-depth research is required into the relationship between, personhood, identity and place for people with dementia. Dementia research can learn from existing studies within environmental gerontology in this regard (Rowles, 1983; Wiles et al., 2012). Interestingly, ageing in place is recognised at a national level in ageing policy (Department of Health, 2013), so there is engagement with the concept as a principle within policy circles. However, funding continues to be biased towards residential long-term care instead of care in the community (O'Shea et al., 2019). This is clearly detrimental to providing ageing in place. Policy and practice need to ensure that formal care is provided to the person with dementia in a place of their choosing and in a manner that supports them to engage with and remain part of their own community.

The study identified interpersonal and structural barriers to supporting personhood relating to conflict, a lack of understanding of dementia, issues around choice, flexibility, consistency, autonomy and other system barriers. Some of these barriers have the potential to be addressed quickly. For example, more training and education could help improve understanding of dementia. Making sure that formal carers have enough time with the person with dementia could be managed by assigning more time to each visit with a person with dementia, be it in the community or in a long-term care setting. However, this requires a recognition from policy of the importance of social interaction and care which moves beyond solely task-based and personal care. The issues around consistency were of interest as participants were often unclear whether they wanted consistency of personnel or not, depending on the nature of their relationship with the formal carer. For

example, sometimes participants in the study found other parties in the care triad to be a barrier to personhood. Research elsewhere has explored the complexity in trying to find balance in triadic care relationships (Quinn et al., 2012), while others have proposed relationship-centred communication strategies (Adams & Gardiner, 2005) to deal with this complexity.

In addition, formal carers need support from the system and the care setting, and in particular, do not need the care setting or system to be a further source of disempowerment to the person with dementia. The care setting should support the formal carer to maximise the autonomy of the person with dementia ensuring that they do not feel trapped or isolated in the care setting and the care relationship. This also needs to include how the personhood of the formal carer is supported in the care setting (Scales et al., 2017; Cooke, 2018; Kadri et al., 2018), and how they are given the tools, skills and support necessary to prioritise the personhood of the person with dementia.

Findings around choice and lack of choice is of particular interest. There were cases where people with dementia and family carers felt they had no choice in relation to care and so had to accept the care and supports offered to them. Social workers express similar beliefs about the experience of older people in relation to lack of choice in formal care provision in Ireland (Donnelly et al., 2016). Formal carers described choice as limited, depending on the care context. The issue of limited choice was perceived to be a particular problem in long-term care settings because of risks associated with other care recipients, but also as one participant put it because of the risk averse culture in some long-term care settings. Issues around choice impact at the core of personhood, denying the person with dementia autonomy and the right to have care and supports which suit their needs, preferences and personhood.

Finally, this study provides important information on key enhancers for personhood in formal care. These include: competency, familiarity and friendliness, respect, honesty and trust, knowing the person, empowerment and sense of security, many of which appear in different guises in person-centred care models (Kitwood, 1997; Brooker, 2007). As already referenced in the Chapter 1, the concept of respect is strongly linked to personhood (Kitwood & Bredin, 1992). Knowing the person including providing personalised care to the individual is central to person-centred care models (Brooker, 2007). One of the most important ways of enhancing personhood was communication; formal carers in particular, described a plethora

of different skills and methods for ensuring good communication. Additionally, there was a strong emphasis by formal carers on finding a balance in the care relationship. Formal carers spoke about many different strategies they used to persuade the person with dementia to engage with care, while avoiding upsetting the person with dementia. Finding the balance between too much risk and too little risk in the care relationship was also seen as important. However, these skills cannot exist in a vacuum and so how the care environment and the care system is set up is of vital importance, as McCormack and McCance (2006) emphasise in their model of person-centred care. Ultimately, the skills required of formal carers are complex, calling on the formal carer to be empathetic, flexible and practical.

6.7 Limitations

There are some limitations to this study. The absence of ethnographic methods in the study is a limit to fully exploring embodied definitions of selfhood. Unfortunately, engaging in such in-depth observational methods was beyond the scope of this work. There were some incidents of safeguarding or cherry picking of research participants by gatekeepers. This was a limitation in being able to access different types of participants for the study. Finally, while not a limitation, the entire process of conducting this study, including recruitment, interviews and analysis, proved to be time consuming.

6.8 Conclusion

Personhood is defined similarly across the three groups as involving the expression of self which includes the social self, preferences, family, lifecourse experiences and place. Family carers are the most likely to define personhood as lost or diluted due to dementia. Participants experienced a range of barriers to supporting personhood in the formal care relationship including limited choice, inconsistency, lack of understanding of dementia and time constraints. Traits of personhood supporting care include: knowing the person, friendliness, respect, honesty and trust, competency and sense of security. Skills required to create such traits and develop a good care relationship include: clear communication, humour and finding balance. This chapter has illustrated the complex and at times contradictory conceptualisations and understandings of personhood in dementia. Such conceptualisations have a significant influence on the formal care relationship and in particular the divergence in perceptions of personhood between people with

Chapter 6: Understanding personhood in formal care

dementia and formal carers which result in barriers, limits and conflicts to supporting personhood.

Chapter 7: Personhood, policy and practice

7.1 Introduction

This thesis has examined personhood within formal care provision in Ireland from a policy and practice perspective by carrying out a policy analysis, a qualitative evidence synthesis and an interpretative phenomenological study on the concept of personhood. This chapter outlines five key findings of the thesis as a whole, followed by implications for practice and policy arising from these findings. The chapter then examines the theoretical and methodological contributions of this thesis. Finally, the chapter explores areas of future research.

7.1 Key findings

In Chapter 1, the thesis laid out its central research question which was:

How is personhood in dementia conceptualised, expressed, facilitated and actualised in formal care provision in Ireland?

This was carried out in three phases, with three key research objectives.

Research objective one: To examine how personhood in dementia is currently conceptualised in dementia care policy in Ireland.

Research objective two: To explore, through qualitative evidence synthesis, how personhood is expressed, realised and practiced by people with dementia in formal care settings.

Research objective three: To identify the core elements, defining natures and fundamental meanings of personhood in dementia as experienced and practiced by people with dementia, their family carers and formal carers in Ireland in different settings.

The policy analysis in Chapter 3 addressed the first research objective, the evidence synthesis in Chapter 4 addressed the second and the empirical study in Chapters 5 and 6 addressed the third objective. In this chapter, the findings of all three studies have been amalgamated and consolidated, resulting in five key findings, as follows: ambiguity around personhood, core elements of the self, the importance of relationships, managing change and managing care arrangements.

7.1.1 *Ambiguity around personhood*

From the outset, this thesis acknowledged the existing ambiguity around personhood. Chapter 2 outlined how this ambiguity, a core characteristic of philosophical definitions of personhood, had filtered through to definitions of personhood in dementia. Chapter 3 evidenced the ambiguity around personhood in policy-making in Ireland, in both the Irish National Dementia Strategy (2014) and in submissions made in the development of the Strategy. This ambiguity was apparent in how the Strategy, while promoting personhood as a principle, did not provide practical and concrete steps to implementing it in practice. For example, none of the priority actions of the Strategy were personhood-related. Also, the stakeholder submissions had widely varied conceptualisations of personhood from a human rights based model to infantilising the person with dementia. For the submissions based in a biomedical model, there were very few references to personhood. Considering that 40% of the organisational submissions fit within a biomedical model, further training and education is required, within formal care in Ireland, on the importance of personhood and how to incorporate its core elements into practice.

In Chapter 4 and Chapter 6, the evidence synthesis and the empirical study, people with dementia were clear in their understanding and interpretation of personhood, especially when it came to identifying its absence within care experiences and relationships. However, ambiguity was present in the accounts of some of the family carers and the formal carers. Given the depth of theoretical and, to a lesser extent, empirical work on personhood in dementia, one would have expected the discussion on personhood in dementia to have extended beyond whether people with dementia have personhood or not. Certainly, the results of the evidence synthesis in Chapter 4 provide empirical evidence for the existence of all three selves (Sabat & Harré, 1992; Sabat & Collins, 1999), as well as relational aspects of personhood in dementia (Kitwood, 1997). However, it is important to acknowledge and address the ambiguity around personhood experienced by family carers and formal carers especially. It is clear that difficulty persists in relation to interpreting changes brought about by dementia and its meaning for personhood.

In formal care practice, uncertainty around personhood is detrimental to constructing the care relationship and denying personhood has considerable negative ramifications for the quality of care provided to the person with dementia (Hunter et al., 2013). If there is uncertainty around personhood then the whole

point of person-centred care is lost. Ultimately, understanding that every person with dementia is a person and respecting this very fact is critical. In order to support personhood, person-centred care needs to be rooted in the constituent elements of personhood, such as autonomy, respect, dignity and communication as well as supporting the self and social connections. However, this respect must be consistent and constant. It should not waver depending on the context or the stage of dementia the person is experiencing. Fundamentally, it boils down to understanding and respecting personhood as the basic starting point to providing any type of care and support. The empirical study provides clear guidance on how personhood can be supported in formal care relationships. This guidance includes being friendly, treating people with respect and honesty, and building trusting relationships in a manner that empowers the person with dementia and provides a sense of security. The role of policy now is ensuring that these skills can be embedded into practice.

7.1.2 Core elements of the self

The self and self-identity is unique to each person with dementia and consists of how they see themselves as a person. This thesis found a significant degree of consensus on the core elements of the self and what matters to people with dementia. This evidence was strongly present in the evidence synthesis and the empirical study. From this thesis, one can say that the self for people with dementia includes interests, preferences, traits, roles, lifecourse experiences, the social self and important relationships. Indeed, there was such significant support for important relationships and the social self that these concepts are discussed separately in the next subsection. These findings on the self reflect previous findings about the importance of relationships, role, hobbies and preferences to the self and personhood (Cohen-Mansfield et al., 2000; Cohen-Mansfield et al., 2006; Harris & Keady, 2009). The evidence synthesis found that people with dementia were actively involved in maintaining their sense of self through, for example, engaging in occupational and social roles.

Engaging in such roles was important to participants, with many referencing past and current roles when discussing self. Findings elsewhere reflect a similar understanding of the importance of meaningful roles in reaffirming sense of self (Genoe et al., 2010; Hellstrom et al., 2015; Lam & Keller, 2015). In the empirical study, nearly all of the participants emphasised how crucial it is to know the person with dementia, to know their interests and preferences in order to provide care and

connect with the person with dementia. Formal carers in particular, spoke about how they used personalised tools to assist them in getting to know the person with dementia. However, there was less clarity within the policy analysis around the self as there were mixed views across organisations on the importance of the self and equally ambiguity within the Strategy on how to support the self in practice. Overall, this evidence adds further weight to the importance of supporting the self when providing person-centred care (Fazio et al., 2018). The findings in this thesis contributes to existing research in the self in dementia, reinforcing the understanding that the self exists for people with dementia that it is an important aspect of personhood and that care should focus on knowing the person and designing care around this knowledge. The focus now is for policy to use this evidence to support the self in practice and regulation.

7.1.3 The importance of relationships

Important relationships and the social self are referenced as core elements of the self in the previous subsection, however, given their significance they are discussed separately here. The social and relational self is a key element of personhood (Kitwood, 1997). The policy analysis found some references to the social self and making sure that people with dementia remain involved with their own communities. These references were more likely to be contained within the organisational submissions which were based within a biopsychosocial or social model of dementia. In both the evidence synthesis and the empirical study participants identified relationships as vitally significant. Participants spoke about familial relationships and relationships with others, including formal carers and other care recipients. The importance of familial roles and social interactions to the self are supported by evidence from other studies (Harris & Keady, 2009; Frazer et al., 2012; Boyle, 2017). The relational nature of personhood and the self is recognised in the theoretical discussion on personhood, in Chapter 2, and is embedded in person-centred care models (Brooker, 2007). However, at times, the focus is on the relationship between the person with dementia and the formal carer. While, the formal care relationship is of importance, so too is recognising the importance of familial relationships to the self. In that regard, the evidence in this thesis provides some additional support for theories of couplehood and relationship-centred care (Nolan et al., 2004; Hellström et al., 2005), which extend models of care to include family carers. Designing care around important relationships means prioritising and nurturing opportunities for people with

dementia to have meaningful social interactions and connect with people who are important to their personhood. This may not always be family but a key goal of formal care design should be getting to know the person with dementia, who matters to them and constructing care to facilitate their most important relationships.

7.1.4 Managing change

The thesis finds that change plays a significant role in the experience of people with dementia, family carers and formal carers. In the evidence synthesis, participants with dementia experienced change brought about by dementia. In response to such changes, people with dementia use various self-maintaining and self-adjusting strategies, (Clare, 2003; Caddell & Clare, 2011a), at times, walking a fine line between acceptance and denial (Macquarrie, 2005). For people with dementia this change also has an impact on relationships (Eriksen et al., 2016). It is not surprising then, to see this change present in the accounts of family carers and formal carers in the empirical study, when interpreting changes to personhood. Family carers struggle between their need to protect the person they care for, their conceptualisation of the person and their respect for that person as who they are. When this image of the person with dementia changes it results in a shift in the dynamics of the relationship and increased complexity for the family carer in accepting, dealing with and adapting to that change. Equally, formal carers sometimes struggle to deal with the impact of change on the personhood of the person with dementia, at times seeing them as a person and other times thinking that personhood was lost. Supporting people with dementia and other parties in the care triad to deal with and adapt to change is important for creating acceptance and balance within the care relationship.

7.1.5 Managing care arrangements

All three studies made reference to place, community and care settings. In the policy analysis, some of the submissions referred to personhood as part of a model of community-based care. They sought to normalise the experience of people with dementia and ensure that they were supported to participate in their community, including the social life of that community. The Strategy equally reflects on the importance of supporting people with dementia to live in a place of their choosing. However, again detail on how this will be accomplished and implemented in practice is lacking. In the evidence synthesis, participants with dementia

experienced change brought about by the care setting or the care environment. The care environment, its structure, design and location can have a significant impact on the person with dementia and their family. The evidence synthesis found that people with dementia experienced a loss of autonomy and feelings of being trapped and imprisoned, particularly in residential care settings. In the empirical study, choice was highlighted as being very important for people with dementia. Evidence from formal carers showed how choice was limited within all care settings, particularly in residential care settings. Some formal carers referred to how regulation, resources and other system barriers prevented them from providing choice and supporting personhood. Limited choice and reduced autonomy have a negative impact on the person with dementia, creating feelings of disempowerment. Equally the physical care environment should support personhood and empower people with dementia to engage with others and the world around them (Bosco, Schneider, Coleston-Shields, & Orrell, 2019).

In the empirical study, the majority of participants with dementia, spoke about their relationship with place and environment. While there has been little empirical research into personhood and place in dementia (Baldwin et al., 2007), shared identity and community are found to be important in supporting and maintaining personhood across all care settings (Mullay et al., 2018). This finding gives further weight to evidence that older people, including people with dementia, prefer to remain living in their own home, in their own communities (Williams, Hughes, & Blackwell, 2005; O'Shea et al., 2017). It also emphasises the importance of place and the role of person-centred care in supporting ageing in place (McCormack, 2004). The location and integration of such settings into the community is also important.

7.2 Policy implications

This section discusses policy and practice implications for designing and delivering formal care services and supports which enhance personhood in dementia in Ireland. These include: a person-centred model of care provision, ageing in place, managing regulation and training and education. Implementing dementia policy in Ireland has a poor track record with the Irish National Dementia Strategy (2014) being the most recent effort in delivering dementia specific policy in Ireland. The Strategy's core principles of personhood and citizenship reflect a wider public appetite for supporting personhood through person-centred models in formal care provision (Department of Health, 2014; The Institute of Public Health in Ireland,

2018). This appetite is also present in regulation, where national standards for residential care settings are designed with person-centred care in mind (Health Information and Equality Authority, 2016). While there is clear support for personhood and person-centred care as a principle in Irish policy, the realisation of the concept in practice remains unproven. Provision of person-centred care in Irish nursing homes is questionable (Colomer & de Vries, 2016), as is the degree to which personhood or person-centred care outcomes are currently assessed for (Meagher & Conroy, 2015). The situation is hindered further by current resource allocation mechanisms. For example, policy supports the concept of ageing in place, yet funding continues to be biased towards long-term care. Policy emphasises the importance of psychosocial supports yet the funding for such supports is minimal (O'Shea et al., 2016; Keogh et al., *in press*). Currently, resource allocation for formal care for people with dementia is not prioritised to support core aspects of personhood, such as social interaction, relationships, family, sense of self and place.

To understand why this is the case, we need to consider the history of the formal social care system in Ireland, how it is designed and structured. The current system is built on a medical model, which focuses mainly on physical health problems and historically institutionalised those who did not fit within certain definitions of independence. The current system is top down, supply-side led and crucially lacks flexibility. For certain elements of formal care provision this is useful and appropriate. However, given the nature of dementia and the widely varied and different challenges people with dementia experience, it is not designed to support personhood within dementia. Participants, in the empirical study, experienced several structural barriers to personhood, including both a lack of any service and a lack of appropriate services. They found that choice was limited and they were compelled to accept any care that they received. For example, one participant wanted support to cook their own meals but was offered support with personal care and meals on wheels instead (support they didn't need). A more person-centred model would see choice given back to the person with dementia and their families. Recognising dementia as a disability (Shakespeare et al., 2019), is the first step in restructuring current conceptualisations of care away from paternalistic models to more rights based, empowered models. In practice this could mean providing people with dementia with personal assistants rather than home care assistants, thereby supporting the direct choices and preferences of the person with dementia. Personalised care has been shown to enhance the quality of care and quality of life of people with dementia in Ireland (Keogh et al., *in press*). Asking

people what they want and supporting them to achieve both individual and social goals works in Ireland. Part of this process may involve giving people with dementia control over their personal budgets. This is already happening in the United Kingdom (Alzheimer's Society, 2019), where people with dementia have been financially empowered to engage care services that match their preferences and needs.

This legacy of medicalisation also means that there is a much stronger emphasis on physical care relative to social and psychological supports which remain minimal and underdeveloped. Supporting people to be socially active and to maintain relationships and interests is very important to personhood. However, outside of pockets of good practice, an integrated model of biopsychosocial care does not currently exist within formal care provision in Ireland. Currently care in the community consists of home help and day care with minimal levels of psychosocial supports (O'Shea et al., 2016; Keogh et al., *in press*). There is little evidence of long-term care settings providing psychosocial supports either (O'Shea et al., 2019). Social support is particularly important for people with dementia because dementia itself undermines their ability to engage with their social network and community. While, the formal care system currently provides some opportunities for social interaction through day centres and other community activities, these tend to be generic rather than person-centred. For example, one participant in the empirical study was unhappy attending a day care setting as frequently as they did and would have preferred to be supported to go out for a walk and engage in their previous role as a farmer. Personalising the content of the care and support is critical to supporting personhood.

At the practice level, this presents several different possibilities. First, redefining the role of health care assistants providing them with the time and resources to support the person with dementia to engage in hobbies and attend events and social engagements. Second, a more integrated model which provides tailored information and on-going support to the person with dementia to adapt and manage change in the first year post diagnosis would be useful. Currently, the National Dementia Office is working on such an initiative through developing a Dementia Key Worker (Government of Ireland, 2018). Another possibility is using volunteer services such as befriending, drivers and other initiatives to provide a low cost method for people with dementia to remain connected with their community. Ensuring more and better psychosocial supports and social activities, is not

necessarily about providing new services but is also about examining existing opportunities within the community and then looking at practical ways to support people with dementia to engage with such activities. In an ideal world, the current system of formal care provision would be restructured, with the person with dementia and their families at the centre. However, all of the above solutions can work alongside the existing formal care model by developing a stronger focus on social and psychological supports that are tailored to the person with dementia, integrating existing care into a more holistic, biopsychosocial model of formal care.

Ageing in place is a key aim of the National Positive Ageing Strategy (Department of Health, 2013), with Ireland being the first country in the world to be acknowledged as age-friendly by the WHO (Age Friendly Ireland, 2019). However, resource allocation does not place the same emphasis on ageing in place as currently twice as much money is used to fund long-term care than community care (O'Shea et al., 2019). This is due to the fact that there is a statutory right to long-term care but not to home care, although the developments of rights for community-based care is currently been discussed, with new legislation pending (The Institute of Public Health in Ireland, 2018).

In Ireland, there are few alternatives to home care so if a person with dementia can no longer stay in their own home then most likely they will be moved to long-term care (O'Shea et al., 2019). Universal design, home adaptation and housing with care options for people with dementia in Ireland are weak. So too is the development of technological solutions that supports independent living at home. If a person with dementia does move to long-term care, they will find little integration between the community and the long-term care setting (O'Shea et al., 2019). Policy has already recognised the importance of place to older people in Ireland, it now needs to create independent, autonomous units within long-stay care settings for people with dementia which make integration with the local community easier. In practice, this means locating care settings in a place familiar to or close to the home of the person with dementia. It could also include providing community space for local organisations to run activities in day care settings or nursing homes. Another possibility is to run intergenerational activities supporting people with dementia to meet with local school children. Some small pockets of intergenerational work in nursing homes already exist in Ireland, but it is not commonplace. Additionally, providing transport and support to allow people with dementia living in nursing homes to get out into the community to engage in local events would be useful.

In reimagining care settings, policy and practice also need to examine the relationship between choice, autonomy and risk. While, regulating for formal care is of vital importance it should not be so restrictive as to be prohibitive to independent living. Further research and examination of regulation is required to understand how to manage and balance risk and autonomy. Sometimes, regulation designed to protect people with dementia in formal care settings may actually be disempowering. It is difficult to see how formal carers can be expected to provide person-centred care in a system, and under regulation, which denies personhood through an excessive emphasis on risk reduction. One formal carer, in the empirical study, reflected on how perception of risk changes from one care setting to the next. A wider conceptual discussion is required around the purpose of care settings, how much risk is acceptable and in whose interests. There is a critical balance to be achieved between ensuring choice and autonomy, and managing risk.

Policy must also seek to reduce ambiguity around personhood, and improve understanding and awareness of dementia. The implementation of the Understand Together public awareness campaign in Ireland has been successful in raising awareness amongst the general public (Hickey, 2019), as has additional GP awareness training. However, further training is required to ensure that formal carers understand and deal with the changes brought about by dementia and the meaning of this for personhood in particular. Supporting personhood requires a complex set of skills, which are about much more than providing personal or physical care. The evidence in this thesis, particularly, in the empirical study provides guidance on the skills and competencies which are required to support personhood in practice. For example, training and development must focus on equipping formal carers with advanced communication skills that allows them to treat people with dementia with respect, honesty and trust. Training must show formal carers the importance of getting to know the person and using personalised tools to do so.

Inevitably, a key issue facing policy and practice and a key determinant of service provision is cost. The statutory provision of long-term care means that it is prioritised over home care. However, providing more services and supports within the community has the potential to reduce the numbers of people with dementia going into long-term care (O'Shea & Monaghan, 2017). Additionally, the provision of personalised services based in a biopsychosocial model in the community have been found to be cost effective in Ireland (Cullen & Keogh, 2018; Carter et al., 2019).

If policy is serious about supporting personhood then it will need to provide more funding to increase the amount of time formal carers can spend with the person with dementia and to provide more supports beyond solely task-based care. A biopsychosocial model of formal care provision needs to be more varied and as such this in itself will cost more. However, in tandem with the voluntary sector, and other forms of social insurance or co-payment, there is the possibility for funding a more complete, holistic model of formal care provision. For example, there have been successful low cost pilot schemes in creating befriending services for people with dementia (Cullen & Keogh, 2018). If a biopsychosocial model of care is successfully implemented, an additional issue currently facing policy and regulation are the lack of concrete outcome measures for personhood. For example, the Irish National Dementia Strategy (2014) provided no guidance in how the realisation of its twin principles of personhood and citizenship should be measured. Research into the regulation of person-centred care in nursing homes in Ireland found existing assessment to be inadequate (Meagher & Conroy, 2015). Further research is required to develop a concrete set of measures that will provide quality assessment and assurance that care is supporting the personhood of people with dementia.

In conclusion, a lack of flexibility and the absence of choice in formal care provision makes it difficult to provide person-centred care for people with dementia in Ireland. The current one size fits all model is the antithesis to person-centred care and supporting personhood. The evidence in this thesis supports the idea that formal care provision that supports personhood cannot solely be about medical care and clinical provision. If personhood is the policy aim then formal care provision must react accordingly; so too should measurement and regulatory agencies. This includes thinking more creatively about care provision and design; moving towards a social model that emphasises visibility, inclusion and connectivity. While the personhood needs of people with dementia are multi-faceted, complex and in flux, the provision of formal care is often one dimensional, static and generic. Policy needs to examine how to better personalise and individualise current care provision so that the personhood of people with dementia is enhanced. If we are to provide person-centred care then the person has to be at the centre of the care model. Personhood should not be considered a goal which the system aspires to, rather it should be the foundation on which the formal care model is built.

7.3 Theoretical contributions

This thesis does not seek to make any theoretical contributions to the concept of personhood in dementia. However, it does find evidence to support existing theories. For example, the findings of the evidence synthesis and the empirical study support theoretical conceptualisations of personhood such as Kitwood's (1997) relational personhood and Sabat & Harré's (1992) proposition of the self. The evidence synthesis also merged findings from ethnographic studies of embodied selfhood (Kontos, 2004), with concepts of the self and relational personhood. It finds consensus on the core elements of the self and also the importance of, and strong need for, social relationships. Interestingly, the thesis also found evidence which support two of the critiques of current theories of personhood in dementia as outlined in Chapter 2; the concept of reciprocal personhood and relationship-centred care, and the discussion around place, environment and personhood. The thesis also contributes some additional thoughts in relation to the impact of change on personhood.

The thesis provides some support for theories of reciprocal personhood and wider discussions on relationship-centred care (Nolan et al., 2004; Adams & Gardiner, 2005; Hellström et al., 2005). In particular, formal care needs to fully acknowledge the importance of relationships, in particular familial relationships, to the personhood of the person with dementia. While there is significant evidence from formal carers in the empirical study supporting social interaction as important to personhood, there is less emphasis on the importance of familial relationships, something which was strongly emphasised by participants with dementia. Nolan et al. (2004) call for a strong focus on interdependence rather than independence in care models. Further theoretical contemplation is required about the importance and meaning of familial relationships to personhood and its constituent parts. The concept of relational personhood has already been explored to some extent in terms of embodied relational personhood, where the discussion focuses on moving away from a one-body one person logic of personhood (Jenkins, 2014; Zeiler, 2014). However, it needs to be developed further, through examining concepts of couplehood and how other cultures, outside of Western philosophy, think about group identity (De Craemer, 1983).

One of the critiques of Kitwood's work was that it did not deal with the idea of place and personhood sufficiently (Baldwin et al., 2007). The findings in this thesis show the importance of place and environment for some of the participants with

dementia. Further theoretical and empirical research is required to explore these findings. How does sense of place support personhood in dementia? Do local care settings hold stronger meaning to the person with dementia? Findings from environmental gerontology already support the link between place and identity (Rowles, 1983; Wiles et al., 2012), and such theory could be applied to research into personhood in dementia.

Finally, further conceptual understanding is required to make sense of the impact of change on personhood, along the dementia journey from diagnosis to end-of-life (Harris & Keady, 2009). Perhaps, one possible avenue for exploration is the conceptualisation of personhood as dynamic rather than static. One can argue that personhood changes for everyone over their life course and so attempting to define it by a set of fixed criteria discounts these transient elements of the self, an area which Harris and Keady (2009) argue needs further exploration. While there has been some empirical research into how people with dementia manage changes to personhood including the self-adjusting and self-maintaining strategies they use, there is less theoretical discussion on how to incorporate the concept of change into a conceptualisation of personhood. Perhaps, there is a reluctance to acknowledge personhood in dementia as changing because of the fear that this translates into an argument that personhood is lost following a diagnosis of dementia. However, there is evidence to show the existence of personhood at advanced stages of dementia, so theory needs to examine a model of personhood that is flexible and adaptable to change. Ultimately, this is not solely a critique of models of personhood in dementia, but more widely of static concepts of personhood in general. It is safe to theorise that people change and these changes impact on the self and personhood over the lifecourse and such change needs to be considered and incorporated into theoretical models.

7.4 Methodological contributions

The key aim of the thesis was to focus on personhood in formal care in dementia. The thesis did not seek to develop new methods in relation to dementia research. Many elements of the work incorporated well established methods, however, several newer methods were also used: namely GRADE CERQual analysis in the evidence synthesis and multiple perspective IPA in the empirical study.

The GRADE CERQual method for assessing confidence in the review findings is relatively new and was first published in 2018. Therefore, the evidence synthesis was one of the first to use it for synthesising qualitative research on the

perspectives of people with dementia. What it shows is that it is possible to examine the quality of the review findings using this method, providing confidence that the findings are a true reflection of the perspectives of the participants in the included studies. This is important given that the review synthesised data derived from both qualitative interviews and observational/ethnographic studies. It allows the reader to have particular confidence in the findings that were graded as high. Alternatively, findings that have a low level of confidence point to areas where further exploration or research is required.

Multiple perspective IPA is a relatively new and innovative study design. Traditionally, IPA studies tend to use homogenous groups with smaller sample sizes to maintain the idiographic nature of the method (Smith & Osborn, 2003). Several studies in dementia have used IPA to understand the lived experiences of people with dementia, using sample sizes from 6 to 20 (plus their spouses) (Pearce et al., 2002; Clare, 2003; Caddell & Clare, 2011a; Nowell et al., 2013; Johnson, 2016). This IPA study is based on a slightly larger sample size, due to the focus on multiple perspectives. The empirical study shows that this method is relevant and useful for examining the perspectives of the three groups in the care triad. Using a multiple perspective design provides a more in-depth and richer understanding of the phenomenon of interest, and in particular gathering the views of family carers and formal carers in addition to those of people with dementia has provided significant insight into why personhood is not always supported in formal care relationships. In particular, the analysis has identified differences in how each part of the triad view, support and promote personhood. This has important implications for service provision and practice for people with dementia.

Using IPA was challenging in several ways, one of which was analysing the linguistic element of the transcripts. Culturally specific language was contained in most interviews which at times made interpretation complex. For this reason, being familiar with the culture and the ambiguity of the language was useful: "Thus, we can say that IPA research is, in part, an inquiry into the cultural position of the person, and that to understand the experiential claims being made by a research participant, we also need a certain level of cultural competence" (Smith et al., 2009, p.195). Perhaps, understanding this cultural position is of even more importance when a participant has difficulty expressing themselves verbally. Listening to the recording during coding allowed me to better understand the tone and context in which the participant was speaking. This was of particular use in interviews with

participants with more advanced dementia who spoke less, the tone then gave me a better indicator of their meaning making process, what they had said and how they had said it.

7.5 Future research

There are several areas which require further exploration. The data from the qualitative interviews is extensive and while considerable exploration of it has been conducted in this thesis, there are further areas which have yet to be examined. For example, one finding from the empirical study was the lack of a strong consensus on the role and potential of communication in supporting personhood. This is an area that could be explored further within the data, examining how communication is conceptualised in an attempt to understand why there is a lack of consensus on what constitutes good communication. For example, one of the core elements of communication identified in the data was humour. Exploring the use of humour to improve communication in formal care relationships and settings is an area of further research.

There was no examination of the impact of gender or other broader socio-cultural influences on the experience of personhood in this thesis (O'Connor et al., 2007). Future research can examine the impact of gender on the results of the empirical study through sensitivity analysis in NVivo. This would examine how or if findings differ across genders for people with dementia, family carers and formal carers, and what the implications of this are in providing person-centred care and in training family carers and formal carers to support personhood.

Further research is also required in relation to understanding the meaning of place to personhood in dementia, and its implications for policy and practice. Secondary analysis of the discussions of participants with dementia in this study will further explore the meaning of place to those participants and the implications of this for their personhood and for formal care provision. It may also serve as a starting point for examining this concept on a larger scale with more people with dementia and their families. Plans are already in place to conduct a comparative analysis between the perspectives of formal carers on personhood in dementia in Ireland and in Canada. I conducted a small number of interviews with formal carers in Canada following a study visit to that country in 2017.

The overall findings of this thesis could serve as a framework for assessing how services and supports are designed and delivered to support personhood. An

example of such work would be to examine post-diagnostic services from a personhood perspective. Recent work on chronicling available services for people with dementia in Ireland would be helpful in this regard (Keogh et al., *in press*). In tandem with this an examination of the formal care system and structure would provide insight into institutional conceptualisations of personhood. How is the person with dementia treated and positioned by the formal care system? How is the system designed to support personhood or not? Essentially, this research would examine how the results of this thesis could be embedded into formal care provision in Ireland, providing concrete examples of how the system can be reshaped with the person with dementia and their families at its core.

7.6 Conclusion

Personhood in dementia is a complex concept. This thesis has found some consensus on the core elements of personhood that are important to people with dementia namely, sense of self and social relationships. It has pointed to how elements of the self are clearly defined by all parties in the care triad but that there is ambiguity around how the person with dementia is conceptualised. It finds that supporting social interaction and important relationships is vital to maintaining and sustaining personhood. It also found the need to support all parties in the care triad in order to manage the change that follows a diagnosis of dementia. The formal care system needs be recalibrated to put the personhood needs of the person with dementia at its core. This includes making sure that supports are not solely medical, but that psychological and social supports are in place. It also includes designing a model of formal care provision which provides choice and empowers the person with dementia and their families to engage care and supports which address their personal needs. Finally, keeping people with dementia connected to place and significant people in their lives remains central to a personhood model of care. The formal care system should, therefore, in the first instance, be focused on home care and when this is no longer possible care should continue to be focused on maintaining the basic elements of personhood for people with dementia.

Chapter 8: Conclusion

Personhood in dementia has long been identified as a key concept in designing care and services that support the quality of life and well-being of people with dementia. However, there is ambiguity, both theoretically and empirically, around personhood. Such ambiguity is also reflected in policy and in its lack of application in practice, including regulatory practice. This thesis set out to examine personhood in dementia and how it is conceptualised, expressed, facilitated and actualised in formal care in Ireland.

The thesis focused on establishing what the core tenants of personhood are and their implications for formal care provision, including policy, practice and regulation. The thesis engaged in a detailed and complex examination and analysis of personhood using three different methodological approaches; a policy analysis, a qualitative evidence synthesis and a multiple perspective IPA study. This approach allowed me to examine personhood from several different perspectives, thereby gaining a rich and in-depth insight into the phenomenon of interest.

The findings in this thesis contribute to existing scientific evidence of the continued existence of personhood for people with dementia. However, it also found ambiguity around the concept within the policy-making process, organisations working for people with dementia, family carers and formal carers. The belief that personhood is lost for people with dementia creates a desperate and nihilistic narrative around the experience of people with dementia. Policy and practice must focus on providing training and education to dispel such beliefs, using existing evidence, including this thesis, to ensure that those working with people with dementia recognise, respect and uphold their personhood.

This thesis provides further insights into the core elements of personhood and how these can be supported within formal care provision. These core elements include: sense of self, maintaining roles, keeping important relationships and facilitating the social self. Organising care around these core elements is important at the micro level, the level of individual relationships, as well as at the macro system level. Participants also reached consensus on the essence of personhood enhancing care. While, there is evidence to show that some of many personhood traits currently exist within formal care relationships in Ireland, the reality is that much more needs to be done to promote and support personhood within dementia care.

Chapter 8: Conclusion

There was also evidence on the impact of care settings and the importance of place to people with dementia. People with dementia have difficulty accepting and adapting to a diagnosis of dementia. At times this was hindered by having to deal with relocation to different care settings. Some of the discomfort around the care setting was related to feeling disempowered or excluded. There is a very clear impact on the autonomy of the person with dementia when they no longer have choice or control over their own life, particularly in relation to where they live. Formal carers pointed to how choice was limited within residential care, where people were often controlled in relation to all aspects of their lives.

Given the link between personhood and place, further research should examine how formal care can be provided in a setting and a place that supports the personhood of the person with dementia and does not impact negatively on autonomy and sense of self. This includes examining how services can be provided in a place of the person's choosing and how such services can empower the person with dementia to remain engaged with their own place and their local community. Facilitating connectivity is a key aspect of good quality, personhood-based care. This can be done through the use of a key link worker or some form of community connector charged with ensuring the visibility and inclusion of the person with dementia.

While dementia policy in Ireland supports personhood in principle, current resource allocation mechanisms do not. The current funding system is not person-centred and does not prioritise the personhood needs of people with dementia. Formal care provision needs to extend beyond its current biomedical model to include the social and psychological needs of the person with dementia. For this to happen, significant restructuring of the current system is required, where the system moves from being supply-side led, to one which is centred on the person with dementia and their family, allowing for control and choice to be given to the person with dementia, thereby empowering them to adapt to dementia and continue to enjoy a good quality of life.

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Appendices

Appendix A: CART analysis

	Completeness	Accuracy	Relevance	Timeliness	Reason for exclusion	Justification
Beard, R. L. and Fox, P. J. (2008). "Resisting social disenfranchisement: Negotiating collective identities and everyday life with memory loss." <u>Social Science & Medicine</u> 66 (7): 1509-1520.	Fully	Major	Partially	Fully	Relevance	Excluded as aim only partially focused on personhood and setting not a care setting
Beard, R. L., et al. (2009). "Managing disability and enjoying life: How we reframe dementia through personal narratives." <u>Journal of Aging Studies</u> 23 (4): 227-235.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
Borley, G., et al. (2016). "How does a woman with Alzheimer's disease make sense of becoming cared for?" <u>Dementia-International Journal of Social Research and Practice</u> 15 (6): 1405-1421.	Fully	Major	Partially	Fully	Relevance	Excluded as aim only partially focused on personhood and setting not a care setting
Boyle, G. (2017). "Revealing gendered identity and agency in dementia." <u>Health & social care in the community</u> . 25 (6), 1787-1793.	Fully	Major	Partially	Fully	Relevance	Excluded as aim only partially focused on personhood and setting not a care setting
Buse, C. and Twigg, J. (2016). "Materialising memories: exploring the stories of people with dementia through dress." <u>Ageing & Society</u> 36 (6): 1115-1135.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
Caddell, L. S. and Clare, L. (2011). "I'm still the same person: The impact of early-stage dementia on identity." <u>Dementia</u> 10 (3): 379-398.	Fully	Sole	Partially	Fully	Relevance	Exclude as not a care setting
Caradec, V. and Chamahian, A. (2017). "The epreuve of ageing with Alzheimer's disease." <u>Ageing & Society</u> 37 (5): 935-960.	Fully	Major	Partially	Fully	Relevance	Excluded as aim of study has a partial focus on personhood
Cedervall, Y., et al. (2015). "Maintaining well-being and selfhood through physical activity: experiences of people with mild Alzheimer's disease." <u>Aging & Mental Health</u> 19 (8): 679-688.	Fully	Major	Partially	Fully	Accuracy	Excluded as aim of study has a partial focus on personhood
Clare, L., et al. (2008). "Experience of living with dementia in residential care: an interpretative phenomenological analysis." <u>Gerontologist</u> 48 (6): 711-720.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood

Appendix A continued

	Completeness	Accuracy	Relevance	Timeliness	Reason for exclusion	Justification
Clemerson, G., et al. (2014). "Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed." <u>Dementia</u> 13 (4): 451-466.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
Frazer, S. M., et al. (2012). "How older women who live alone with dementia make sense of their experiences: An interpretative phenomenological analysis." <u>Dementia</u> 11 (5): 677-693.	Fully	Major	Partially	Fully	Relevance	Excluded as aim of study has a limited focus on personhood
Genoe, M. R. and Dupuis, S. L. (2011). "'I'm just like I always was': a phenomenological exploration of leisure, identity and dementia." <u>Leisure/Loisir</u> 35 (4): 423-452.	Fully	Sole/major	Partially	Fully	Relevance	Exclude as not a care setting
Genoe, R., et al. (2010). "Honouring identity through mealtimes in families living with dementia." <u>Journal of Aging Studies</u> 24 (3): 181-193.	Fully	Sole/major	Partially	Fully	Relevance	Exclude as not a care setting
Gillies, B. and Johnston, G. (2004). "Identity loss and maintenance: commonality of experience in cancer and dementia." <u>European Journal of Cancer Care</u> 13 (5): 436-442.	Fully	Sole	Partially	Fully	Relevance	Exclude as v little data
Griffin, J., et al. (2016). "Living with a diagnosis of behavioural-variant frontotemporal dementia: The person's experience." <u>Dementia</u> 15 (6): 1622-1642.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
Harman, G. and Clare, L. (2006). "Illness representations and lived experience in early-stage dementia." <u>Qualitative Health Research</u> 16 (4): 484-502.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
Harris, P. B. and Keady, J. (2004). "Living With Early Onset Dementia: Exploring the Experience and Developing Evidence-based Guidelines for Practice." <u>Alzheimer's Care Today</u> 5 (2): 111-122.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood

Appendix A continued

	Completeness	Accuracy	Relevance	Timeliness	Reason for exclusion	Justification
Harris, P. B. and Keady, J. (2009). "Selfhood in younger onset dementia: Transitions and testimonies." <u>Aging & Mental Health</u> 13 (3): 437-444.	Fully	Sole	Partially	Fully	Relevance	Exclude as not a care setting
Hedman, R., et al. (2013). "How people with Alzheimer's disease express their sense of self: Analysis using Rom Harré's theory of selfhood." <u>Dementia</u> 12 (6): 713-733.	Fully	Sole	Fully	Fully	Relevance	Exclude as not a care setting
Hedman, R., et al. (2016). "Expressed sense of self by people with Alzheimer's disease in a support group interpreted in terms of agency and communion." <u>Journal of Applied Gerontology</u> 35 (4): 421-443.	Fully	Sole	Fully	Fully	Relevance	Exclude as not a care setting
Hedman, R., et al. (2017). "Agency and communion in people with Alzheimer's disease, as described by themselves and their spousal carers." <u>Dementia</u> : 1471301217706268.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
Hellstrom, I., et al. (2015). "Chores and sense of self: gendered understandings of voices of older married women with dementia." <u>Int J Older People Nurs</u> 10 (2): 127-135.	Fully	Sole	Fully	Fully	Relevance	Exclude as not a care setting
Johnson, H. F. (2016). "Exploring the Lived Experience of People with Dementia Through Interpretative Phenomenological Analysis." <u>Qualitative Report</u> 21 (4): 695-711.	Fully	Major	Partially	Fully	Relevance	Excluded as aim only partially focused on personhood and setting not a care setting.
Kaufmann, E. G. and Engel, S. A. (2016). "Dementia and well-being: A conceptual framework based on Tom Kitwood's model of needs." <u>Dementia</u> 15 (4): 774-788.	Fully	Major	Partially	Fully	Accuracy	Excluded as aim of study has a partial focus on personhood
Lam, I. T. Y. and Keller, H. H. (2015). "Honoring Identity Through Mealtimes in Chinese Canadian Immigrants." <u>American Journal of Alzheimers Disease and Other Dementias</u> 30 (7): 662-671.	Fully	Major	Partially	Fully	Relevance	Excluded as aim only partially focused on personhood and setting not a care setting

Appendix A continued

	Completeness	Accuracy	Relevance	Timeliness	Reason for exclusion	Justification
MacRae, H. (2008). "Making the best you can of it': living with early-stage Alzheimer's disease." <u>Sociology of Health & Illness</u> 30 (3): 396-412.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
MacRae, H. (2010). "Managing identity while living with Alzheimer's disease." <u>Qualitative Health Research</u> 20 (3): 293-305.	Fully	Sole	Fully	Fully	Relevance	Exclude as not a care setting
Olsson, A., et al. (2013). "Persons with early-stage dementia reflect on being outdoors: a repeated interview study." <u>Aging & Mental Health</u> 17 (7): 793-800.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
Pearce, A., et al. (2002). "Managing sense of self: Coping in the early stages of Alzheimer's disease." <u>Dementia</u> 1 (2): 173-192.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
Phinney, A., et al. (2007). "Doing as much as I can do: the meaning of activity for people with dementia." <u>Aging & Mental Health</u> 11 (4): 384-393.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
Pipon-Young, F. E., et al. (2012). "I'm not all gone, I can still speak: The experiences of younger people with dementia. An action research study." <u>Dementia-International Journal of Social Research and Practice</u> 11 (5): 597-616.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
Robertson, J. M. (2014). "Finding meaning in everyday life with dementia: A case study." <u>Dementia-International Journal of Social Research and Practice</u> 13 (4): 525-543.	Fully	Major	Partially	Fully	Relevance	Excluded as aim only partially focused on personhood and setting not a care setting
Sabat, S. R. (2002). "Surviving Manifestations of Selfhood in Alzheimer's Disease: A case study." <u>Dementia</u> 1 (1): 25-36.	Fully	Sole	Partially	Fully	Relevance	Exclude as not a care setting

Appendix A continued

	Completeness	Accuracy	Relevance	Timeliness	Reason for exclusion	Justification
Sakamoto, M., et al. (2017). "'I'm Still Here': Personhood and the Early-Onset Dementia Experience." <u>Journal of Gerontological Nursing</u> 43 (5): 12-17.	Fully	Sole	Partially	Fully	Relevance	Exclude as not a care setting
Skaalvik, M. W., et al. (2016). "Expressions of Sense of Self Among Individuals With Alzheimer's Disease." <u>Research & Theory for Nursing Practice</u> 30 (2): 161-175.	Fully	Sole	Partially	Fully	Relevance	Exclude as not a care setting
Steeman, E., et al. (2007). "Living with dementia from the perspective of older people: Is it a positive story?" <u>Aging & Mental Health</u> 11 (2): 119-130.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood
Steeman, E., et al. (2013). "Managing identity in early-stage dementia: maintaining a sense of being valued." <u>Ageing & Society</u> 33 : 216-242.	Fully	Sole	Partially	Fully	Relevance	Exclude as not a care setting
Ward, R., et al. (2014). "'Once I had money in my pocket, I was every colour under the sun': Using 'appearance biographies' to explore the meanings of appearance for people with dementia." <u>Journal of Aging Studies</u> 30 : 64-72.	Fully	Limited	Partially	Fully	Accuracy	Excluded as aim of study has a limited focus on personhood

Appendix B: CASP qualitative checklist of included studies

CASP	Stated aims	Research methodology	Research design	Recruitment strategy	Data collection	Relationship between researcher and participants	Ethical issues	Data analysis	Clear statement of findings	Value of research
Anbäcken, Minemoto and Fujii 2015	✓	✓	✓	✓	✓	✓	✓	✓	X	✓
Batra <i>et al.</i> 2016	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Beard 2004	✓	✓	✓	✓	✓	X	X	✓	✓	✓
Borley and Hardy 2017	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Hung and Chaudhury 2011	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Kontos 2012	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Kontos 2004	✓	✓	✓	✓	✓	X	X	✓	✓	✓
Li and Orleans 2002	✓	✓	✓	✓	✓	✓	X	✓	✓	✓
Lloyd, Kalsy and Gatherer 2007	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Mills 1997	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Nowell, Thornton and Simpson 2013	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sabat and Harré 1992	✓	✓	✓	✓	✓	X	X	✓	✓	✓
Sabat and Collins 1999	✓	✓	X	X	✓	X	X	✓	✓	✓
Sabat <i>et al.</i> 1999	✓	✓	X	X	✓	X	X	✓	✓	✓

Appendices

CASP	Stated aims	Research methodology	Research design	Recruitment strategy	Data collection	Relationship between researcher and participants	Ethical issues	Data analysis	Clear statement of findings	Value of research
Saunders 1998	✓	✓	✓	X	✓	✓	X	✓	✓	✓
Shenk <i>et al.</i> 2002	✓	✓	✓	✓	✓	X	X	X	✓	✓
Shenk, Min-Xia and Zhi-Jun 2008	✓	✓	✓	X	✓	X	X	✓	✓	✓
Surr 2006	✓	✓	✓	✓	✓	✓	X	✓	✓	✓
Tolhurst and Weicht 2017	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Westius, Kallenberg and Norberg 2010	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Appendix C: GRADE CERQual evidence profile

1. Living with change	Two subthemes: Changing life Adapting to a changing life
2. Maintaining sense of self	Three subthemes: Important relationships Knowing who I am Continuity of self
3. Managing care arrangements	Three subthemes: Environmental changes Adapting to environmental changes Relationships in the care setting

1. Living with change

Changing Life

Key Summary Statement	Studies contributing to the review finding	CERQual Assessment	Explanation of CERQual assessment
People with dementia spoke about becoming aware of memory problems, through gradual progression of memory problems, feeling things weren't right, having the experience of forgetting things and defining moments.	Anbäcken et al. 2015, Beard 2004, Lloyd et al. 2007, Mills 1997, Sabat and Harré 1992, Saunders 1998	High confidence	Minor methodological concerns Very minor concerns re cohesion and adequacy Minor concerns re relevancy
Losing self: People experienced different types of loss. These included a loss of role in terms of no longer being able to do the things that they	Anbäcken et al. 2015, Batra et al. 2016, Borley and Hardy 2017, Li and Orleans 2002, Lloyd et	High confidence	Very minor methodological concerns Minor adequacy concerns

used to do, experiencing difficulty narrating self, an erosion of the self and physical decline.	al. 2007, Mills 1997, Nowell et al. 2013, Sabat and Harré 1992, Sabat et al. 1999, Shenk et al. 2008, Surr 2006, Westius et al. 2010		Minor concerns re relevancy No cohesion concerns
People had negative feeling around having dementia and the changes that this brought to their lives. Negative feelings included anger, devastation, confusion, being distressed and feeling frustrated.	Anbäcken et al. 2015, Beard 2004, Borley and Hardy 2017, Kontos 2012, Lloyd et al. 2007, Mills 1997, Nowell et al. 2013, Sabat and Harré 1992, Sabat and Collins 1999, Sabat et al. 1999, Saunders 1998	High confidence	Minor methodological concerns No concerns re adequacy and cohesion Very minor concerns re relevance
Some people spoke about positive feelings included feeling content, seeing a positive side of having dementia and taking it day by day.	Anbäcken et al. 2015, Batra et al. 2016, Beard 2004, Borley and Hardy 2017, Mills 1997, Tolhurst and Weicht 2017, Westius et al. 2010	High confidence	Very minor methodological concerns Very minor concerns re relevancy and cohesion Minor adequacy concerns

Adapting to a changing life

Key Summary Statement	Studies contributing to the review finding	CERQual Assessment	Explanation of CERQual assessment
Participants engaged in a continuum of strategies to adjust to the changes brought about by getting a diagnosis of dementia and experiencing memory problems. Participants spoke about accepting or partially accepting their diagnosis and/or symptoms of dementia.	Anbäcken et al. 2015, Beard 2004, Borley and Hardy 2017, Lloyd et al. 2007, Mills 1997, Nowell 2013, Sabat et al. 1999, Saunders 1998, Shenk et al. 2008, Tolhurst and Weicht 2017	Moderate confidence	Minor methodological concerns No concerns re cohesion Minor concerns re adequacy Minor concerns re relevance
Several studies showed how participants used denial as a way of managing dementia; this included strategies like not thinking about it, blaming it on getting older, or claiming not to have memory problems.	Anbäcken et al. 2015, Beard 2004, Borley and Hardy 2017, Lloyd 2007, Mills 1997, Nowell et al. 2013, Saunders 1998, Shenk et al. 2008, Tolhurst and Weicht 2017	High confidence	Minor methodological concerns No concerns re adequacy Very minor concerns re cohesion and relevance

Other participants used humour as a strategy to manage change.	Anbäcken et al. 2015, Beard 2004, Borley and Hardy 2017, Mills 1997, Sabat and Collins 1999, Saunders 1998, Shenk et al. 2008, Tolhurst and Weicht 2017, Westius et al. 2010	High confidence	Minor methodological concerns No concerns re adequacy or cohesion Very minor concerns re relevance
Many attempted to take back control over their circumstances by fighting back, focusing on what you can do, hiding, masking or minimising difficulties, lower expectations of oneself, staying active and tailoring techniques to manage.	Beard 2004, Borley and Hardy 2017, Li and Orleans 2002, Lloyd et al. 2007, Mills 1997, Nowell et al. 2013, Sabat and Harré 1992, Sabat and Collins 1999, Sabat 1999b, Saunders 1998, Shenk et al. 2008, Tolhurst and Weicht 2017, Westius et al. 2010	Moderate Confidence	Very minor methodological concerns Minor concerns re cohesion and relevancy No concerns re adequacy
Others spoke about the experience of telling others they had dementia including the benefits of being open about it, the support they received from others, but also adjusting to peoples' reactions when they told them.	Beard 2004, Lloyd et al. 2007, Nowell et al. 2013, Tolhurst and Weicht 2017, Westius et al. 2010	Low Confidence	No methodological concerns Moderate concerns about cohesion and relevancy Minor concerns about adequacy

2. Maintaining sense of self

Important relationships

Key Summary Statement	Studies contributing to the review finding	CERQual Assessment	Explanation of CERQual assessment
There were many references to family identity, and how family were important.	Anbäcken et al. 2015, Li and Orleans 2002, Lloyd et al. 2007, Mills 1997, Nowell et al. 2013, Shenk	High confidence	Minor methodological concerns Very minor concerns with cohesion and adequacy

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	et al. 2002, Shenk et al. 2008, Surr 2006, Westius et al. 2010		Minor concerns with relevance
Participants' talked about their changing role in the family because of dementia.	Anbäcken et al. 2015, Borley and Hardy 2017, Sabat and Harré 1992, Surr 2006	Moderate confidence	Minor methodological concerns Very minor concerns over cohesion and adequacy Minor concerns over relevance
They spoke about their childhoods, their parents and good and bad experiences and relationships in childhood and early life.	Anbäcken et al. 2015, Batra et al. 2016, Borley and Hardy 2017, Hung and Chaudhury 2011, Lloyd et al. 2007, Mills 1997, Nowell et al. 2013, Sabat and Collins 1999, Saunders 1998, Shenk et al. 2002, Shenk et al. 2008, Westius et al. 2010	High confidence	Minor methodological concerns No concerns re cohesion or adequacy Minor concerns re relevancy
Participants spoke about their spouses good qualities they had, their spouses' occupations and the effect of dementia on the spousal relationship.	Anbäcken et al. 2015, Batra et al. 2016, Borley and Hardy 2017, Hung and Chaudhury 2011, Mills 1997, Sabat and Harré 1992, Saunders 1998, Shenk et al. 2002, Shenk et al. 2008, Westius et al. 2010	Moderate confidence	Minor methodological concerns Very minor concerns re cohesion, adequacy and relevancy

Knowing who I am

Key Summary Statement	Studies contributing to the review finding	CERQual Assessment	Explanation of CERQual assessment
Participants referenced many different elements that formed their self-image such as appearance, beliefs, spirituality, values, cultural norms, education and gendered roles.	Anbäcken et al. 2015, Batra et al. 2016, Kontos 2004, Li and Orleans 2002, Mills 1997, Sabat and Harré 1992, Shenk et al. 2002, Shenk et al. 2008,	High confidence	Very minor methodological concerns Very minor concerns re cohesion and relevance No concerns re adequacy

	Surr 2006, Tolhurst and Weicht 2017, Westius et al. 2010		
Participants identified many different roles they played such as being a helpful daughter, fulfilling a domestic role, being a religious person etc.	Batra et al. 2016, Borley and Hardy 2017, Lloyd et al. 2007, Nowell et al. 2013, Sabat, 1999, Shenk et al. 2008, Surr 2006, Tolhurst and Weicht 2017	High confidence	No concerns re methodology No concerns re cohesion and adequacy Minor concerns re relevance
They also recognised their own strengths such as self-respect and, in general, were clear about who they were.	Anbäcken et al. 2015, Kontos 2004, Li and Orleans 2002, Mills 1997, Sabat and Harré 1992, Sabat and Collins 1999, Sabat et al. 1999, Saunders 1998, Shenk et al. 2008, Tolhurst and Weicht 2017, Westius et al. 2010	Moderate confidence	Minor methodological concerns Very minor concerns re cohesion and relevance Minor concerns re adequacy
Occupation was referenced frequently by participants and was strongly linked to and part of the self. People spoke about past jobs they were employed in and what they enjoyed about them.	Anbäcken et al. 2015, Batra et al. 2016, Borley and Hardy 2017, Hung and Chaudhury 2011, Li and Orleans 2002, Lloyd et al. 2007, Mills 1997, Nowell et al. 2013, Sabat and Harré 1992, Sabat et al. 1999, Saunders 1998, Shenk et al. 2002, Surr 2006, Tolhurst and Weicht 2017, Westius et al. 2010	High confidence	Very minor methodological concerns Very minor concerns re cohesion and adequacy No concerns re relevance

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Some spoke about the importance of having and keeping a sense of purpose.	Anbäcken et al. 2015, Li and Orleans 2002, Lloyd et al. 2007, Mills 1997, Sabat, 1999, Westius et al. 2010	Moderate confidence	Very minor methodological concerns Very minor concerns re cohesion and relevancy Minor concerns re adequacy
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Continuity of self

Key Summary Statement	Studies contributing to the review finding	CERQual Assessment	Explanation of CERQual assessment
Participants recognised changes in self because of dementia and spoke about the effect of changing roles on identity.	Anbäcken et al. 2015, Lloyd et al. 2007, Nowell et al. 2013	Low confidence	Minor methodological concerns Minor concerns re cohesion Moderate concerns re adequacy and relevance
These changes resulted in feelings of loss of self and an overall sense of loss with some finding meaning in life and others not.	Borley and Hardy 2017, Beard 2004, Lloyd et al. 2007, Mills 1997, Sabat and Harré 1992, Sabat et al. 1999, Surr 2006, Westius et al. 2010	High confidence	Very minor methodological concerns Very minor concerns re cohesion and adequacy Minor concerns re relevance
Participants responded to all of these erosions and encroachments on the self through different proactive strategies and attempts to maintain continuity of the self. These included managing their image and preserving their identity, communicating through metaphor being a member of a group and asserting self.	Beard 2004, Li and Orleans 2002, Lloyd et al. 2007, Mills 1997, Nowell et al. 2013, Sabat and Harré 1992, Sabat and Collins 1999, Sabat 1999b, Saunders 1998, Surr 2006, Tolhurst and Weicht 2017, Westius et al. 2010	High confidence	Very minor methodological concerns Very minor concerns re cohesion and adequacy Minor concerns re relevance
Participants also asserted and managed the self in how they choose to engage in activities, occupational and social roles. Many participants	Anbäcken et al. 2015, Kontos 2012, Kontos 2004, Li and Orleans 2002, Lloyd et al. 2007,	High confidence	Very minor methodological concerns Very minor concerns re cohesion, adequacy and relevance

engaged in caring roles within the care settings both at a social interactional level but also as a strategy to stay occupied and to find purpose.	Sabat and Harré 1992, Sabat et al. 1999, Surr 2006, Tolhurst and Weicht 2017, Westius et al. 2010		
Certain participants attempted to stay engaged but not necessarily active while others felt they did not have enough activity in their lives. Other participants choose not to do things while others were passive about getting involved. Some experienced a decline in activity and others mourned having to give up driving.	Batra et al. 2016, Borley and Hardy 2017, Hung and Chaudhury 2011, Kontos 2004, Li and Orleans 2002, Lloyd et al. 2007, Mills 1997, Nowell et al. 2013, Sabat and Harré 1992, Sabat et al. 1999, Tolhurst 2017, Westius et al. 2010	High Confidence	Very minor concerns re methodology Very minor concerns re cohesion and relevance Minor concerns re adequacy

3. Managing care arrangements

Environmental changes

Key Finding	Studies contributing to the review finding	CERQual Assessment	Explanation of CERQual assessment
Many participants experienced a loss of autonomy in long-term care settings and found that they were expected to adhere to the settings' rules and could not leave it which was also experienced by participants in day care settings and in their own homes.	Anbäcken et al. 2015, Batra et al. 2016, Beard 2004, Borley and Hardy 2017, Hung and Chaudhury 2011, Lloyd 2007, Mills 1997, Nowell et al. 2013, Sabat et al. 1999.	High confidence	Very minor methodological concerns No concerns re adequacy and cohesion Very minor concerns re relevancy
This denial of autonomy led to feelings of being trapped or imprisoned in long-term care settings.	Anbäcken et al. 2015, Borley and Hardy 2017, Hung and Chaudhury 2011, Kontos 2012, Lloyd 2007, Mills 1997, Nowell et al. 2013, Sabat et al. 1999, Surr 2006	High confidence	Very minor methodological concerns No concerns re adequacy and cohesion Very minor concerns re relevancy

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There were many references to negative feelings attached to the care settings including: anger, feeling abandoned, feeling like they were outsiders, feeling bored, confused, disrespected, frustrated and lonely.	Anbäcken et al. 2015, Hung and Chaudhury 2011, Li and Orleans 2002, Lloyd 2007, Mills 1997, Nowell et al. 2013, Sabat et al. 1999, Shenk et al. 2008, Surr 2006, Tolhurst and Weicht 2017	Moderate confidence	Very minor methodological concerns Very minor concerns re cohesion and adequacy Moderate concerns re relevance
There were also examples of people being content with the long-term care setting as well as day care and home settings this included feeling connected and important in the setting.	Anbäcken et al. 2015, Kontos 2004, Shenk et al. 2008 Nowell et al. 2013, Sabat and Harré 1992, Sabat et al. 1999, Tolhurst and Weicht 2017, Westius et al. 2010	High confidence	Minor methodological concerns No concerns re cohesion Very minor concerns re adequacy Minor concerns re relevance

Adapting to environmental changes

Key Finding	Studies contributing to the review finding	CERQual Assessment	Explanation of CERQual assessment
People highlighted the difficulties they had with adapting to long-term care settings such as making friends and feeling trapped.	Anbäcken et al. 2015, Nowell et al. 2013, Sabat and Harré 1992, Sabat et al. 1999, Shenk et al. 2008, Surr 2006	Moderate confidence	Minor methodological concerns Very minor concerns re cohesion, adequacy and relevance
Many attempted to maintain independence within the new settings, be it long-term care or community settings.	Anbäcken et al. 2015, Beard 2004, Borley and Hardy 2017, Li and Orleans 2002, Lloyd et al. 2007 Sabat et al. 1999	High confidence	Minor methodological concerns No concerns re cohesion, adequacy or relevance
Others spoke about getting to know the system and learning the 'rules' in the new care setting.	Lloyd et al. 2007, Nowell et al. 2013, Sabat et al. 1999	Moderate confidence	No methodological concerns Very minor concerns about cohesion and adequacy Minor concerns about relevance

Relationships in the care settings

Key Summary Statement	Studies contributing to the review finding	CERQual Assessment	Explanation of CERQual assessment
Relationships with other care recipients			
There were references to how participants sought to interact with other care recipients, through engaging in social etiquette, engaging in different social identities and roles, seeking company seeking approval from others connecting with other care recipients and developing a romantic relationship.	Anbäcken et al. 2015, Kontos 2012, Kontos 2004, Li and Orleans 2002, Lloyd et al. 2007, Mills 1997, Nowell et al. 2013, Sabat and Collins 1999, Sabat et al. 1999, Surr 2006, Tolhurst and Weicht 2017	High confidence	Very minor methodological concerns Very minor concerns re cohesion No concerns re adequacy Very minor concerns re relevancy
However, some participants did not succeed in efforts to interact with others and experienced social isolation.	Anbäcken et al. 2015, Hung and Chaudhury 2011, Li and Orleans 2002, Nowell et al. 2013, Sabat and Harré 1992, Sabat et al. 1999, Shenk et al. 2008, Surr 2006	Moderate confidence	Very minor methodological concerns Very minor concerns re cohesion and relevance Minor concerns re adequacy
Positive elements of these relationships included participants caring for other care recipients, having empathy with each other and enjoying friendships, fun and humour with other care recipients.	Anbäcken et al. 2015, Kontos 2012, Kontos 2004, Li and Orleans 2002, Lloyd et al. 2007, Mills 1997, Sabat and Harré 1992, Sabat and Collins 1999, Sabat et al. 1999, Shenk et al. 2008, Surr 2006, Tolhurst and Weicht 2017, Westius et al. 2010	High confidence	Very minor methodological concerns Very minor concerns re cohesion adequacy Minor concerns re and relevancy

<p>There were negative aspects to some relationships with participants being annoyed by other care recipients, having difficulty adjusting to living with others, feeling shame around other care recipients being frustrated by others and finding a lack of empathy from other care recipients.</p>	<p>Hung and Chaudhury 2011, Kontos 2012, Kontos 2004, Li and Orleans 2002, Lloyd et al. 2007, Nowell et al. 2013, Sabat and Collins 1999, Sabat et al. 1999, Shenk et al. 2008, Surr 2006</p>	<p>High confidence</p>	<p>Very minor methodological concerns No concerns re cohesion or adequacy Minor concerns re relevance</p>
<p>Relationships with formal carers</p>			
<p>There were many examples of positive experiences when interacting with formal carers such as carers becoming like family, seeing formal carers as peers, carers who were friendly and who used humour.</p>	<p>Hung and Chaudhury 2011, Kontos 2004, Lloyd et al. 2007, Sabat and Harré 1992, Sabat et al. 1999, Surr 2006 Tolhurst and Weicht 2017</p>	<p>High confidence</p>	<p>Very minor methodological concerns No concerns re cohesion Very minor concerns re adequacy and relevance</p>
<p>The importance of social interaction with carers was outlined by some authors and there were examples of participants connecting with carers, seeking their approval and having their preferences respected.</p>	<p>Hung and Chaudhury 2011, Li and Orleans 2002, Lloyd et al. 2007, Sabat 1999a, Sabat et al. 1999, Surr 2006</p>	<p>Moderate confidence</p>	<p>Very minor methodological concerns Very minor concerns re adequacy Minor concerns re cohesion and relevancy</p>
<p>Participants also experienced negative emotions from interacting with carers which included feeling confused, disrespected frustrated, ignored lonely, upset and worthless.</p>	<p>Anbäcken et al. 2015, Hung and Chaudhury 2011, Lloyd et al. 2007, Nowell et al. 2013, Sabat and Collins 1999 Saunders 1998, Shenk et al. 2008</p>	<p>High confidence</p>	<p>Minor methodological concerns No concerns re cohesion Very minor concerns re adequacy and relevance</p>

Appendices

Appendix D: Observation and reflection notes template

1. Date, time, and place of observation
 2. Specific facts, numbers, details of what happens at the site
 3. Sensory impressions: sights, sounds, textures, smells, taste
 - Describe the physical setting
 - Describe the social environment and the way in which participants interacted within the setting. This may include patterns of interactions, frequency of interactions, direction of communication patterns [including non-verbal communication], and patterns of specific behavioural events, such as, conflicts, decision-making, or collaboration.
 - Describe the participants and their roles in the setting.
 - Describe, as best you can, the meaning of what was observed from the perspectives of the participants
 - Record exact quotes or close approximations of comments that relate directly to the purpose of the study.
 - Describe any impact you might have had on the situation you observed [important!].
 4. Personal responses to the fact of recording field notes
 5. Specific words, phrases, summaries of conversations, and insider language
 6. Questions about people or behaviors at the site for future investigation
 7. Page numbers to help keep observations in order
-

Guidelines for the Reflective Content

- Note ideas, impressions, thoughts, and/or any criticisms you have about what you observed.
- Include any unanswered questions or concerns that have arisen from analysing the observation data.
- Clarify points and/or correct mistakes and misunderstandings in other parts of field notes.
- Include insights about what you have observed and speculate as to why you believe specific phenomenon occurred.
- Record any thoughts that you may have regarding any future observations.

Notes template designed from guidelines by (Chiseri-Strater & Sunstein, 1997).



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NUI Galway

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091 495461

Project Title: Personhood and Dementia

Dear _____,

(Gatekeeper for example nursing home manager)

My name is Niamh Hennelly. I am completing a PhD in the Centre for Economic and Social Research on Dementia in NUI Galway. As part of this work, I am carrying out interviews with people with dementia and their carers on their experience and perspectives on what it means to be a person. These interviews will be audio recorded and will last around 30 minutes for the person with dementia and one hour for their family carers. Participation is voluntary.

I am writing to you to request your help to recruit participants through your services/establishment/facility. I have enclosed a participant information sheet which describes in more detail what is involved in the study. I would be very grateful if you could examine it and consider whether you know of any people with dementia and/or their family carers under your care who might be willing to participate in this study.

If you have any questions please do not hesitate to contact me. I appreciate your time and consideration.

Yours sincerely,

Niamh Hennelly

Appendix F: Information sheet for person with dementia



NUI Galway
OÉ Gaillimh

Study title: Personhood and Memory Problems

Person with memory problems

You are invited to take part in a study about care for people with memory problems. This is information to help you decide if you would like to take part. Please take your time to decide.

What is the study about?

The study asks questions about what matters most to you about the care you receive from health and social care providers. The study asks about what is most important to you in relation to that care.

Why have I been asked to take part?

You have been asked to take part as a person with memory problems whose views matter. You may have been asked because you have been in contact with the likes of the Alzheimer Society of Ireland or the HSE or other care networks.

Do I have to take part?

No, it is completely up to you. If you decide to take part, you will be asked to sign a consent form. You can decide not to take part. You can change your mind at any time and you do not have to tell us why.

What does taking part involve?

Taking part involves an interview with the researcher, Niamh Hennelly. The interview will be relaxed. You can talk to Niamh on your own, or with your family carer. The interview will be audio recorded and will last around 30 minutes. Niamh will talk to you about your life now with memory problems and the relationships you have with the people who provide you with formal care. The interview may take place in your home, a day care centre or, if you live in long-stay care, the interview will take place there.

How long will my part in the study last?

If you agree to take part the study will last 18 months and we will only need your help, at the most, twice.

What are the benefits of taking part?

There are no direct benefits to you from taking part. But, your answers will help us understand care relationships for people with memory problems. This could lead to better outcomes and quality of life for people with memory problems and their carers in the future.

What are the possible risks of taking part?

There are no obvious risks to taking part. But, if any part of the interview makes you unhappy, please let Niamh know and she will stop straight away

Will my taking part in this study be kept confidential?

All information that is collected about you will be kept confidential. The information will not be shared with anyone else. It will not be possible to identify you in the study. Anonymous information will be stored and may be used for future research.

What will happen to the results of the study?

The results will form the basis of work aimed at improving the care of people with memory problems. Articles about the study will be published in academic journals one to two years after the study. Information about these will be up on our website at www.cesrd.ie.

Who can I contact if I have any concerns about the study?

If you have any concerns about how you were treated by the researchers or any other part of the study, please contact Prof. Eamon O'Shea on 091 495457 or eamon.oshea@nuigalway.ie.

Who has ethically approved the study?

The project has been approved by the Research Ethics Committee based in NUI Galway. If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact 'the Chairperson of the NUI Galway Research Ethics Committee c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie.

For more information about taking part please contact:

Niamh Hennelly: 087 3651397

Email: n.hennelly2@nuigalway.ie



Appendix G: Accessible information sheet for person with dementia

Information Sheet on Personhood and Memory Problems

<p>We want to improve the lives of people with memory problems and their family carers in Ireland.</p>	 
<p>We want to understand how people with memory problems are supported to be themselves by formal care.</p>	  
<p>You can help us by telling us your story and talking with us.</p>	

<p>We want to know about your relationship with any formal care you receive.</p>	 
<p>We want to know what parts of formal care support you to be yourself.</p>	 
<p>We want to know about you and what it means to be you.</p>	

What Will We Do With Your Information

<p>Examples of what worked well: We hope to provide formal care with information about how best to support the self-identity of people with memory problems in Ireland.</p>	
<p>Examples of what didn't work: We want to make sure that people with memory problems do not feel disrespected or ignored.</p>	

Appendix H: Information sheet for family carer



NUI Galway
OÉ Gaillimh



Centre for **Economic
and Social Research
on Dementia**

Participant Information Sheet: Family Carer

Study Title: Personhood and Memory Problems

Family Carer

You are invited to take part in a research study on care for people with memory problems in Ireland. Please read the following information carefully and take your time to decide whether or not you would like to take part.

What is the study about?

This study will examine how personhood is created and maintained for people with memory problems within formal care relationships in the health and social care system.

Why have I been asked to take part?

You have been asked to take part as a carer for a person with memory problems. You may have been asked to take part because you have been in contact with organisations like the Alzheimer Society of Ireland or the HSE or through other care networks. In order to take part in the study, you need to be 18 years of age or older and currently caring for a person with memory problems.

Do I have to take part?

Your participation is voluntary. If you do decide to participate, you will be asked to sign a consent form. You can decide not to take part, or you can change your mind at any time during the study and you do not have to give a reason.

What does taking part involve?

Taking part involves a face-to-face interview with the researcher, Niamh Hennelly. The interview will be audio recorded and will last around one hour. Niamh will ask you to talk about what you think are the most important elements of the identity and sense of self of the person you care for, what you see as the key elements of their personhood. Niamh will also talk about what this means for formal care and how you think formal care can best support personhood and treat people with memory problems as people first and foremost. You will be interviewed on your own, in a place of your choosing. The study will also interview the person that you care for. They can be interviewed alone or in your company.

How long will my part in the study last?

If you agree to take part the study will last 18 months and we will only need your help, at the most, twice.

How does this study benefit me?

There are no direct benefits to you from taking part. However, you will be adding to research to help us better understand the importance of personhood in formal care

relationships in memory problems This could lead to better outcomes and quality of life for people with memory problems and their carers in the future.

What are the possible risks of taking part?

There are no obvious risks to this study. However, if any part of the interview makes you unhappy, please let Niamh know and she will stop the interview immediately.

Will my taking part in this study be kept confidential?

All information that is collected about you will be kept strictly confidential and will not be shared with anyone else. It will not be possible to identify you as having taken part in the study. Anonymous information will be stored and may be used for future research.

What will happen to the results of the study?

The results will form the basis for improving the care of people with memory problems. Articles reporting and discussing the results will be published in academic journals one to two years after the study. Links to publications coming from this research will be available at www.cesrd.ie

Who can I contact if I have any concerns?

If you have any concerns about how you were treated by the researchers or any other part of the study, please contact Prof. Eamon O'Shea on 091 495457 or eamon.oshea@nuigalway.ie

Who has ethically approved the study?

The project has been approved by the Research Ethics Committee based in NUI Galway. If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact 'the Chairperson of the NUI Galway Research Ethics Committee', c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie

For more information please contact:

Niamh Hennelly: 087 3651397 n.hennelly2@nuigalway.ie

Appendix I: Information sheet for formal carer



NUI Galway
OÉ Gaillimh



Centre for **Economic
and Social Research
on Dementia**

Participant Information Sheet: Formal Care Provider

Study Title: Personhood and Dementia

Formal Care Provider

You are invited to take part in a research study on care for people with dementia in Ireland. Please read the following information carefully and take your time to decide whether or not you would like to take part.

What is the study about?

This study will examine how personhood is created and maintained for people with dementia within formal care relationships in the health and social care system.

Why have I been asked to take part?

You have been asked to take part as a formal carer for a person with dementia. You may have been asked to take part because you work with, or for, organisations like the HSE, the Alzheimer Society of Ireland or other care organisations. In order to participate in the study, you need to be 18 years of age or older and provide formal care to at least one person with dementia.

Do I have to take part?

Your participation is completely voluntary. If you do decide to participate, you will be asked to sign a consent form. You can decide not to take part, or you can change your mind at any time during the study and you do not have to give a reason.

What does taking part involve?

Taking part involves a face-to-face interview with the researcher, Niamh Hennessey. The interview will be audio recorded and will last around one hour. Niamh will ask you to talk about what you think are the most important elements of the identity and sense of self of the people with dementia you care for, what you see as the key elements of their personhood. Niamh will also talk about what this means for formal care and what you think is the best way to design and provide formal care to support personhood. You will be interviewed on your own, in a place of your choosing.

How long will my part in the study last? If you agree to take part the study will last 18 months and we will only need your help, at the most, twice.

What are the possible benefits of taking part?

There are no direct benefits to you from taking part. However, you will be adding to research to help us better understand the importance of personhood in formal care relationships in dementia. This could lead to better outcomes and quality of life for people with dementia and their carers in the future.

What are the possible risks of taking part?

There are no obvious risks to this study. However, if any part of the interview makes you unhappy, please let Niamh know and she will stop the interview immediately.

Will my taking part in this study be kept confidential?

All information that is collected about you will be kept strictly confidential and will not be shared with anyone else. It will not be possible to identify you as having taken part in the study. Anonymous information will be stored and may be used for future research.

What will happen to the results of the study?

The results will form the basis for improving the care of people with dementia. Articles reporting and discussing the results will be published in academic journals one to two years after the study. Links to publications coming from this research will be available at www.cesrd.ie.

Who can I contact if I have any concerns?

If you have any concerns about how you were treated by the researchers or any other part of the study, please contact Prof. Eamon O'Shea on 091 495457 or eamon.oshea@nuigalway.ie.

Who has ethically approved the study?

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For more information please contact:

Niamh Hennelly: 087 3651397 n.hennelly2@nuigalway.ie

Appendix J: Consent form



Consent Form: Personhood and Memory Problems

Participant Identification Number:

Please initial box.

1. I confirm that I have read the information sheet (dated / /) for the above study and have had the opportunity to ask questions.
2. I am satisfied that I understand the information provided and have had enough time to consider the information.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.
4. I understand that if I am unable to complete the study, or choose to withdraw, the information that I have provided so far will be included in the study unless I state otherwise.
5. I agree to take part in the above study.

Name of Participant	Date	Signature (If verbal, please indicate here)
Legally Authorized Representative	Date	Signature
Researcher	Date	Signature

If the participant is unable to give consent, the following should be recorded:

In my opinion, this participant cannot give consent


Reason(s):

Name of Researcher: _____ Date: _____ Time: _____















Seek proxy consent if the person assents to participating in the study

Accessible Consent Form

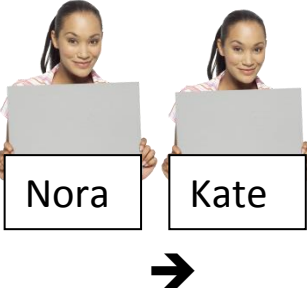











Personhood and Memory Problems

Consent form	
---------------------	--





My name is _____

	Please tick		
	I have enough information about the research.	 Yes	 No
	I was able to ask questions about the research.	 Yes	 No
	I understand that what I say will be recorded.	 Yes	 No
 	I am happy for the things I say to be used in the research. For writing a report and telling other people.	 Yes	 No

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	<p>I understand that my name will not be used.</p>	 <p>Yes</p>	 <p>No</p>
	<p>I understand that other people will not know what I said.</p>	 <p>Yes</p>	 <p>No</p>
	<p>I understand that Niamh will have to tell someone if I or someone else is at risk of being hurt.</p>	 <p>Yes</p>	 <p>No</p>
	<p>I understand that taking part means having a chat, answering a few questions and completing a form.</p>	 <p>Yes</p>	 <p>No</p>

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 	I agree to take part in the research.	 Yes	 No
--	--	---	---



Date _____



Sign _____

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Appendix L: Interview guide for person with dementia

<p><u>Introduction</u></p>	<p>Thank you for meeting with me. My name is Niamh Hennelly. I am a researcher from NUI Galway. I am interested in talking to you about yourself, about your life and especially about the supports that you receive from the HSE and other places. I have some questions I would like to ask you if you are happy to do so. There are no right or wrong answers to these questions. Please stop me if there is anything you don't understand. I will be recording this interview so that I don't have to write what you say down while you are talking. Everything you say will be kept confidentially within the research team and it will not be possible to identify you in the research. We will not share your responses with service providers. The interview will last around 30 minutes. I will check with you during that time that you're happy to continue. You can end the interview at any time and you don't need to tell me why. Also, you don't need to talk about anything that you are not comfortable talking about.</p>
<p><u>Consent</u></p>	<p>Have you any questions about what I explained? Are you willing to take part in the interview?</p>
<p><u>Opening questions</u></p>	<p>How are you? Tell me a little about your life now and in the past? How would you describe yourself as a person? What are the most important things about you? How, if at all, have you changed in recent years?</p>
	<p>General care</p> <ul style="list-style-type: none"> ➤ Tell me a little about the support/visits you receive from the HSE for example from the public health nurse, home help, day care centre ➤ What do you like about the care and support you receive? ➤ Is there anything you would like to change? <p>Are you happy to continue?</p> <p>Flexibility and choice</p> <ul style="list-style-type: none"> ➤ Do you have say/choice in the care and supports that you get? ➤ Are you asked for your views about what you would like to do when people call? ➤ Do the times and visits from HSE staff/day care suit you/your life? ➤ Do you have the same person visiting you all the time/caring for you at day care? ➤ Are you allowed/supported to do things for yourself? Even when there might be some risk involved? ➤ Are your likes and dislikes respected? <p>Are you happy to continue?</p> <p>Relationship/dignity/respect/supporting identity</p> <ul style="list-style-type: none"> ➤ Tell me a little about your relationship with the HSE staff who provide care and support? ➤ Do you know the home help/public health nurse/day care staff well?

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	<ul style="list-style-type: none"> ➤ Do you feel the care staff know you well as a person? ➤ Does the HSE visitor/staff know about your family and friends? ➤ Does the HSE visitor/staff know what's important to you as a person your likes/dislikes? ➤ Does the HSE visitor/staff know about what you do/used to do? ➤ Are you encouraged to do things you like, things that you are interested in/that have meaning for you? ➤ Are you encouraged to chat with other people at the? <p>Are you happy to continue?</p> <p>Communication</p> <ul style="list-style-type: none"> ➤ Are you able to communicate easily with the HSE visitor/staff? ➤ Does the HSE visitor/staff respond to your requests? ➤ Do you find it easy to understand them? ➤ Do you feel acknowledged and respected by the HSE visitor/staff? ➤ Do you feel the HSE visitor/staff communicates with you in an equal adult way? ➤ Does the HSE visitor/staff chat with you about things in general? <p>Are you happy to continue?</p> <p>Important things for you</p> <ol style="list-style-type: none"> 1. What is the most important things for you in regard to the care and support you receive from HSE visitors/staff? 2. What is most important to you in how HSE visitor/staff see you and interact with you? 3. Is there anything you would like to change in your relationship with the people who provide care and support to you?
<p><u>Possible prompts and probes</u></p>	<p>If so how/why?</p> <p>Would you like to tell me more about that?</p> <p>What happened next?</p> <p>What did you think?</p> <p>How did you feel?</p> <p>What did you do in response?</p>
<p><u>Closing</u></p>	<p>Is there anything more you would like to add?</p> <p>The information you have provided will be adding to research that will help to improve services and supports for all people with memory problems.</p> <p>Thank you very much for giving me your time and taking part in this interview. It is really appreciated.</p>

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Appendix M: Interview guide for family carer

<p><u>Introduction</u></p>	<p>Thank you for meeting with me. My name is Niamh Hennelly. I am a researcher from the Centre for Economic and Social Research on Dementia, NUI Galway.</p> <p>I am interested in talking to you about personhood in dementia. Personhood in dementia is about treating people with dementia with dignity and respect and in a way that supports their self-identity. It is about focusing on what matters most to the person with dementia and treating them as a person first and foremost.</p> <p>Specifically, I would like to hear about your experiences and thoughts about formal care provision for the person with dementia that you are looking after and how that care impacts on the personhood of the person with dementia.</p> <p>I am looking for your own personal experiences and opinions so there are no right or wrong answers. Please stop me if there is anything you don't understand. I will be recording this interview so that I don't have to write what you say down while you are talking. Everything you say will be kept confidentially within the research team and it will not be possible to identify you in the research. We will not share your responses with service providers. The interview will last around 1 hour. I will check with you during that time that you're happy to continue. You can end the interview at any time and you don't need to tell me why. Also, you don't need to talk about anything that you are not comfortable talking about.</p>
<p><u>Consent</u></p>	<p>Have you any questions about what I explained? Are you willing to take part in the interview?</p>
<p><u>Opening questions</u></p>	<p>How are you? Tell me a little about yourself and your life? How would you describe ...? What are the most important things to know about him? About you as a couple?</p>
	<p>Personhood in dementia is about focusing on what matters most to the person with dementia and treating them as a person first and foremost.</p> <p>General care</p> <ol style="list-style-type: none"> 1. Tell me a little about the support/visits receives from the HSE for example from public health nurse, home help, day care centre 2. How did she/he end up getting home help/day care? 3. Did she/he have a choice in what supports are currently provided? Is this what you wanted? 4. Is the care personalised? By that I mean it is designed to meet the specific needs of the person with dementia? If so how, if not why not? 5. What do you like about the care and support received by the person with dementia? 6. Is there anything you would like to change? 7. What do you think matters most to _____ in relation to the formal care they currently receive? 8. What matters most to you as their main carer? <p>Flexibility and Choice</p> <ol style="list-style-type: none"> 1. How important is flexibility and choice in relation to services and supports received by the person with dementia? 2. Does the person under your care have enough choice in regard to services and supports that you receive?

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	<ol style="list-style-type: none"> 3. Has the person with dementia been directly asked by the HSE about what services and supports they would like to have? 4. Have you been asked directly by the HSE about services and supports that are needed? <p>Relationships/dignity/respect/supporting identity</p> <ol style="list-style-type: none"> 1. What are the most important aspects of the care relationship between the person with dementia and formal care providers? 2. What does treating people with dementia with respect mean to you in relation to formal care provision? 3. What, in your view, does formal care that treats a person with dignity look like? 4. How can identity be enhanced for people with dementia through formal care provision? Can you think of an example? <p>Communication</p> <ol style="list-style-type: none"> 1. What is most important element in communicating with people with dementia? 2. What is good communication – have you got an example of good communication between formal care provider and person with dementia? 3. What might bad communication look/sound like – give example if you can? 4. What barriers to communication have you encountered/observed between formal care providers and the person with dementia under your care – give example if you can? <p>General questions</p> <ol style="list-style-type: none"> 1. If you had a blank sheet of paper and were asked to design care for ..., what would that look like taking into account the importance of personhood. By personhood I mean dignity, respect... (refer to definition at start). 2. How can care provision best focus on what matters to _____ and you as their family carer? 3. How do you think this could be measured? What would indicate to you that the care _____ receives focuses on what's important to them as a person? 4. How do you think it could be incorporated into regulation – how can the health service/government make sure that this is happening?
<p><u>Possible prompts and probes</u></p>	<p>If so how/why? Would you like to tell me more about that? What happened next? What did you think? How did you feel? What did you do in response?</p>
<p><u>Closing</u></p>	<p>Is there anything more you would like to add? The information you have provided will be adding to research that will help build measures for personhood, especially to do with formal care relationships Thank you very much for giving me your time and taking part in this interview. It is really appreciated</p>

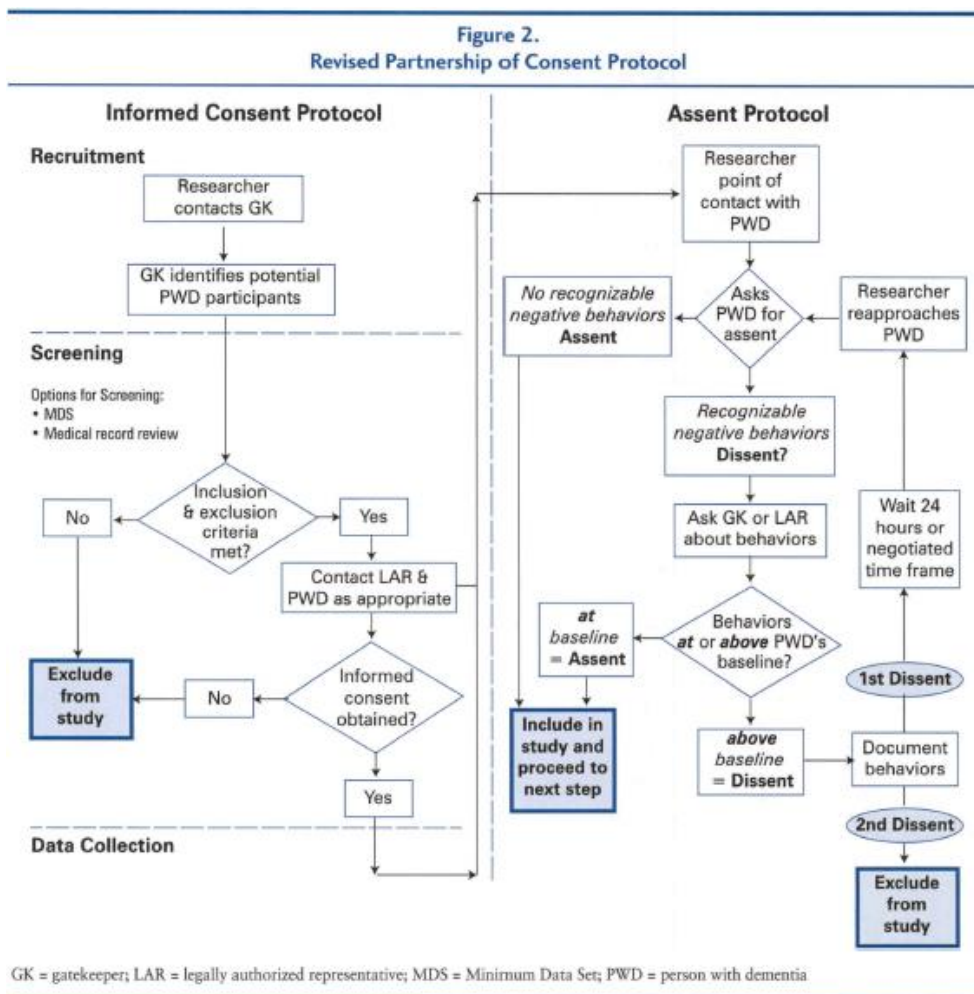
<p><u>Introduction</u></p>	<p>Thank you for meeting with me. My name is Niamh Hennelly. I am a researcher from the Centre for Economic and Social Research on Dementia, NUI Galway.</p> <p>I am interested in talking to you about personhood in dementia. Personhood in dementia is about treating people with dementia with dignity and respect and in a way that supports their self-identity. It is about focusing on what matters most to the person with dementia and treating them as a person first and foremost.</p> <p>Specifically, I would like to hear about your experiences and thoughts about formal care provision for people with dementia and how that care impacts on the personhood of the person with dementia.</p> <p>I am looking for your own personal experiences and opinions so there are no right or wrong answers. Please stop me if there is anything you don't understand. I will be recording this interview so that I don't have to write what you say down while you are talking. Everything you say will be kept confidentially within the research team and any information that identifies you will be removed. We will not share your responses with service providers.</p> <p>The interview will last around 1 hour. I will check with you during that time that you're happy to continue. You can end the interview at any time and you don't need to tell me why. Also, you don't need to talk about anything that you are not comfortable talking about.</p>
<p><u>Consent</u></p>	<p>Have you any questions about what I explained? Are you willing to take part in the interview?</p>
<p><u>Opening questions</u></p>	<p>How are you? Tell me a little about your professional role?</p>
	<p>Personhood in dementia is about focusing on what matters most to the person with dementia and treating them as a person first and foremost.</p> <p>General care</p> <ol style="list-style-type: none"> 1. Tell me a little about the contact you have with people with dementia 2. What do you think matters most to people with dementia in relation to formal care? <p>For example</p> <ol style="list-style-type: none"> 3. Is the care people with dementia get personalised? By that I mean it is designed to meet the individual's expressed needs? If so how, if not why not. – tease out expressed needs. 4. Are a person's preferences normally included in their care plan? <p>Next, I'd like to ask your opinion on things like</p> <p>Flexibility and Choice</p> <ol style="list-style-type: none"> 1. How important is flexibility and choice in relation to services and supports received by people with dementia? 2. Do people with dementia normally get choice in the services and supports they receive? Within your service and in general? If not why not

	<ol style="list-style-type: none"> 3. Are people with dementia asked by health/social care services about what services/supports they would like? 4. Are there services and supports that you think people with dementia should receive but don't? Give me some examples. 5. Do current care patterns and structures allow the person with dementia to do things for themselves as much as possible? If not why not <p>Relationships/dignity/respect/supporting identity</p> <ol style="list-style-type: none"> 1. What are the most important aspects of the care relationship between formal providers like yourself and people with dementia? 2. How important is it that you know things about the likes and dislikes of the person with dementia? 3. How important is consistency in relation to care provision- that the same person normally looks after the person with dementia? 4. How can identity be enhanced for people with dementia through formal care provision? Can you think of an example? 5. What does treating people with dementia with respect mean to you in relation to formal care provision? Can you think of an example? 6. What, in your view, does formal care that treats a person with dignity look like? Can you think of an example? <p>Communication</p> <ol style="list-style-type: none"> 5. What is good communication between formal carers and people with dementia? Can you give an example 6. What might bad communication look/sound like? Can you give an example 7. What are key facilitators and barriers to communication that you have encountered/observed between people with dementia and formal care providers? Can you give an example? <p>System Barriers</p> <ol style="list-style-type: none"> 1. What elements of your work environment support personhood and person-centred care for people with dementia? 2. What do you see as barriers to supporting personhood relationships in your work place? 3. Is your work environment supportive of person-centred care for example are the building well-designed and suitable for people with dementia 4. Have you had training in personhood and what it means for person-centred care? <p>General questions</p> <ol style="list-style-type: none"> 1. If you had a blank sheet of paper and were asked to design care for ..., what would that look like? Specifically focusing on the personhood of the person with dementia. By personhood I mean dignity, respect, communication... 2. How can care provision best focus on what matters to the person with dementia and their families?
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	<ol style="list-style-type: none"> 3. How do you think personhood could be measured within formal care? What would indicate to you that the care a person with dementia receives focuses on what's important to them as a person? 4. What is the key outcome you look for in relation to the care of people with dementia 5. How do you think personhood could be incorporated into regulation, for example in HIQA guidelines and requirements?
<p><u>Possible prompts and probes</u></p>	<p>If so how/why? Would you like to tell me more about that? What happened next? What did you think? How did you feel? What did you do in response?</p>
<p><u>Closing</u></p>	<p>Is there anything more you would like to add? The information you have provided will be used to will be adding to research that will help build measures for personhood, especially to do with formal care relationships. Thank you very much for giving me your time and taking part in this interview. It is really appreciated</p>

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 Appendix O: Consent and assent protocol



(Batchelor-Aselage et al., 2014, p. 16)

Appendix P: Distressed person protocol

Ethics Protocol

The following is a procedural protocol for assisting participants who may become distressed while being interviewed for the Centre for Economic and Social Research on Dementia research projects.

If a participant becomes distressed or upset during the interview;

1. Ask the person if they would like to take a break and if they would like you to switch off the recorder.
 - If the person continues to be upset, ask the person if they would like to end the interview and if they would like you to call someone to spend time with them, such as a son or daughter or someone from the local community (e.g. priest, community worker, public health nurse).
 2. Before leaving, ask the person if it would be ok to call them (or their caregiver) later in the day or the next day to make sure they are ok. Alternatively, ask them if they would like to have someone from the local community (e.g. priest, community worker, public health nurse etc.) call them to make sure they are ok.
 3. Before leaving, and if appropriate, ask the person if they would like the names and numbers of national and local contacts that might be helpful to talk to. If they say yes, hand the person the sheet of national and local contact names and details of people and organisations that may be of some help to them.
 4. If the distress arises as a result of disclosure of abuse or there are reasonable grounds for concern, e.g. where there are indicators that a person with dementia is in a situation of abuse (such as neglect, emotional abuse, physical abuse, or financial abuse) the person who made the disclosure will be informed that this information cannot be kept completely confidential as it will have to be passed on to the appropriate authorities. A referral will be made immediately to the relevant authorities.
-

National Organisations and Numbers

- **Senior Help Line** (older people support line)
1850 44 0444
- **HSE Information Line** (information on service and elder abuse support)
1850 24 1850
- **Samaritans** (provides emotional support)
1850 60 9090
- **Aware** (mental health support)
1850 30 3302
- **Alzheimer National Helpline** (Provides advice for accessing services and supports)
1800 34 1341
- **Sage** (Independent Support and Advocacy Services)
1850 71 9400
- **Citizens Information**
0761 07 4000

Appendix Q: Researcher safety protocol

Researcher Safety

Ethics Protocol

The following is a procedural protocol for helping ensure the safety of researchers while conducting fieldwork as a part of the research being undertaken by the Centre for Economic and Social Research on Dementia (CESRD).

Field Researcher Experience and Training

The researchers conducting the fieldwork will be experienced qualitative researchers who have either worked with or completed research with older people, people with dementia, or other vulnerable groups in a community setting. In addition, all researchers conducting fieldwork will undergo a day-long training session on the research protocols. This will involve going through interview and group discussion guides, but also instruction on researcher and participant safety and communication procedures.

Safety Procedures for Field Researchers

Each field researcher will be asked to follow the procedures below for their own safety while conducting fieldwork. In all cases, participants will be accessed through professional gatekeepers working with the person with dementia and/or their family carer. Additionally, local Garda will be contacted to let them know that the interviewer is in the neighbourhood.

Travel to and from field sites

Where public transport is not available;

- Researchers will be asked to ensure that their vehicle is of road-worthy condition.
- Researchers will be asked to ensure that their vehicle has adequate fuel for each journey.

Accommodation

When conducting fieldwork in community settings, if an overnight stay should be required, the researcher will be booked into accommodation in reputable hotels and guest houses within the cities and communities.

Communication

- Researchers will be asked to ensure that their mobile phone is fully charged each day.
 - Researchers will be asked to keep their mobile phone on them at all times and switch it to silent during fieldwork.
 - Researchers will be asked to call Prof. Eamon O'Shea research leader of the CESRD team each day to confirm their whereabouts and their work activities for that day. They will contact Prof. O'Shea before and after carrying out each interview.
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Appendix R: Coding nodes for the empirical study

Theme 1: The conceptualisation of personhood

Name	Files	References
Interpreting changes to personhood		30 472
Personhood as unchanged		23 121
Personhood as changing		19 175
Person with dementia's view of personhood		8 176
Expressions of personhood		30 747
Interests, preferences and traits		30 309
Lifecourse experience		25 91
Social self		25 136
Family		15 169
Relationship with place and environment		9 42

Theme 2: Barriers to supporting personhood

Name	Files	References
Interpersonal barriers		26 223
Conflict		20 121
Lack of understanding of dementia		20 102
Structural barriers		29 488
Autonomy		13 52
Choice		28 145
Consistency		25 72
Flexibility		17 43
Other system barriers		25 176

Theme 3: Personhood in the formal care process

Name	Files	References
Traits of personhood-enhancing care		30 922
Competency and friendliness		30 243
Respect, honesty and trust		28 169
Knowing the person		27 311
Empowerment		17 85
Sense of security		13 28
Inclusion		9 24
Comfort, relaxed, calm		8 22
Quality of life		7 13
Supporting person to live at home		6 14
Maintaining appearance		6 13
Communication skills for personhood-enhancing care		27 343
Simple communication		26 139
Finding balance		15 179
Humour		12 25