

**HOLDING ONTO ME IN THE CONTEXT OF DEMENTIA: A CLASSIC
GROUNDED THEORY STUDY**

Thesis Presented for the Award of Doctor of Philosophy

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Declaration

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Abbreviations

ADMCA	Assisted Decision Making Capacity Act
ASI	The Alzheimer Society of Ireland
CGT	Classic Grounded Theory
CW	Care Worker
DCAH	Day Care at Home
DCC	Day Care Centre
DOH	Department of Health
DRAT	Dementia Research Advisory Team
FC	Family Carer
GP	General Practitioner
GT	Grounded Theory
HSCPs	Health and Social Care Professionals
HSE	Health Service Executive
MASS	Memory Assessment and Support Clinic
MSP	Malignant Social Psychology
NMBI	Nursing and Midwifery Board of Ireland
NDS	National Dementia Strategy
NDO	National Dementia Office
PHN	Public Health Nurse
PPI	Public and Patient Involvement
YOD	Young Onset Dementia

Abstract

Holding on to Me in the Context of Dementia: A Classic Grounded Theory

Within the literature, there is much debate regarding the loss or persistence of self in the context of dementia, particularly advanced dementia. Yet there is a lack of consensus as to what constitutes self. Sense of self for people with dementia can be vulnerable to the attitudes of others, impacting how others see them and how they see themselves. This has implications for person-centred care and support, wellbeing and autonomy.

The aim of this study was to generate a theory, explaining how people with dementia process or resolve issues relating to sense of self, understood primarily in terms of their main concern of *losing me*.

Classic Grounded Theory methodology was used to achieve the study aim. Concurrent data collection and analysis consisted of 26 semi-structured interviews and six published autobiographies written by people living with dementia. Person and Public Involvement (PPI) was used to enhance relevancy, robustness and meaningful engagement with people with dementia.

The theory of *Holding on to Me* was generated and consists of three main properties: *Holding Tighter*, where individuals hold tighter to the core elements of themselves, who and what has meaning for them. *Letting Go*, where individuals let go of certain aspects of their lives they can no longer manage or control in order to hold on to their overall sense of self. Finally, individuals engage in *Relational Grappling*, sustaining and forging connections that assist in achieving their goals, whilst balancing these relationships with maintaining sense of self and independence.

This research provides a dynamic multivariate theory of how people living with dementia hold on to their sense of self. It offers valuable insights for families, caregivers, healthcare providers, and policymakers, in terms how the self can be recognised and supported in dementia, impacting wellbeing, promotes independence and autonomy and reduces excess disability.

Chapter 1

Introduction to the Main Concern and Overview of the Thesis.

1.1 Introduction

This thesis presents the classic grounded theory (CGT) *Holding on to Me* that explains how people living with dementia hold on to their sense of self in the context of the dementia. In this introductory chapter the main concern of participants within the substantive area of this study is identified as *losing me* . To enhance the readers understanding of *losing me* some theoretical accounts of self are examined, with particular reference to self and dementia. Finally, the theory *Holding on to Me* is briefly introduced and a sequential outline of the thesis chapters given. Some aspects of terminology relating to perspectives of self relevant to this study are also clarified. Firstly, to offer a background and context to the study, this chapter provides an overview of dementia and ways it can be understood.

1.2 Dementia

The global population is ageing, with the number of over 60-year-olds set to almost double to twenty-two percent of the total population by 2050 (World Health Organisation, 2024). In Ireland the number of people aged over 65 years has risen from 569,000 to 806,000 between 2013 and 2023, with this number expected to rise to 1.6 million by 2051 (Central Statistics Office, 2024). Longer life is to be welcomed and brings opportunities for people and society. However, it also increases the prevalence of age related conditions such as dementia (World Health Organisation, 2024). Alzheimer’s Disease International (2019), estimate that over 50 million people are living with dementia worldwide with this number set to treble in the coming decades, with impact and cost not only to the person living with dementia, their supporters and society but also to health and social care services (Alzheimer Disease International, 2019). This picture is reflected in Ireland with approximately 65,000 people living with dementia and this number expected to rise threefold in the coming decades (Health Service Executive, 2020). In Ireland the majority of people with dementia (63%) live at home, with an estimated 19,000 living in long term care settings (Pierse, O’Shea and Carney, 2019). Furthermore, one in ten people diagnosed with dementia have younger onset dementia (under 65 years) (O’Shea, Keogh and Cooney, 2019).

Dementia is a collective term used to describe several neurodegenerative disorders including Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia and Frontotemporal Dementia. There are many different types of dementia, the most common type being Alzheimer's Disease (Dementia UK, 2025). Although the presentation of the various dementia subtypes can differ, all dementias are associated with varying degrees of progressive cognitive and functional decline. Furthermore, the condition impacts memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement (Andrews, 2015). Dementia may also be associated with non-cognitive symptoms including depression, agitation, anxiety and psychosis (James, 2011). Physical health is also impacted, not only in terms of the added complexity of managing comorbidities but also deteriorating motor skills and mobility, increasing the risk of falls, and further health complications (Andrews, 2015). Additionally, there is added complexity associated with a diagnosis of young onset dementia.

There is increasing awareness that dementia is not only experienced by older people. Young onset dementia (YOD) refers to dementia where the symptoms start prior to the age of 65 years. Hendriks *et al.* (2021) in their systematic review and meta-analysis studying the prevalence of young onset dementia, identified the global prevalence rate at 1.1 per 100,000 of the population between the ages of 30-64, with the rate rising to 77.4 per 100,000 of the population for 60-64-year-olds. The number of people living with young onset dementia in Ireland is estimated at between 2,906 and 4,311 (Pierse, O'Shea and Carney, 2019). Yet there are many challenges in terms of accurate and timely diagnosis and support provision for this population (Kilty *et al.*, 2023). Their needs are often very different than people living with older onset dementia, particularly from an economic and psychological point of view, with these needs going largely unmet in the current Irish healthcare system (Fox *et al.*, 2020). Moreover people with younger onset dementia are more prone to the negative attitudes of others. Werner, Raviv-Turgeman and Corrigan (2020), noted that college students surveyed had more stigmatising attitudes towards people with younger onset dementia than they had towards older people with dementia. There are many factors for healthcare workers to consider in supporting people with YOD to meet their needs, not least that they should be actively involved in co-designing supports. This adds to the complexity in terms of offering an all-encompassing definition of dementia.

When reviewing the literature there are several definitions of dementia proposed.

The World Health Organisation (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” (World Health Organization, 2017, p. 2)

Within the clinical setting, the definition of dementia is often based on disease classification models such as International Classification of Diseases (ICD) 10 and Diagnostic and Statistical Manual of Mental Disorders (DSM) 5. ICD-10 Classification of Mental and Behavioural Disorders classify dementia as:

“a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.”(ICD-10 Version:2019).

Further, in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in 2013 the term dementia was replaced with neurocognitive disorders. *“A diagnosis of major neurocognitive disorder (dementia) requires evidence of significant decline in one or more of the following cognitive domains: complex attention, executive function, learning and memory, language, perceptual-motor function, and social cognition, and that the cognitive deficits interfere with independence in activities of daily living”* (American Psychiatric Association, 2013). Yet, despite the move to a newer term, D’cruz (2021) argues that the definitions continue to emphasise issues of cognitive decline, with little emphasis on the emotional and behavioural impact of dementia. Moreover, within these definitions there is little or no reference or understanding of the concept of personhood, autonomy or identity of the person living with dementia (D’cruz, 2021). Yet, loss of personhood, autonomy and identity is often something that people living with dementia and their caregivers fear most (D’cruz, 2021).

In recognition of this and in a move away from a primarily biomedical model of dementia (Kitwood, 1997) offered an understanding of dementia that focussed on maintaining

personhood for the individual with dementia. Essentially, the essence of Kitwood's work is in seeing the person rather than concentrating on the diagnosis and underpins the notion of person-centred care. Additionally maintaining and supporting personhood is central to key policy documents in Ireland, including The National Dementia Strategy (Department of Health, 2014) and the Model of Care for Dementia in Ireland (Begley *et al.*, 2023). Despite this personhood and indeed person-centred care is a concept that is often struggled with in busy clinical practice settings (Kitwood 1997; Brooker, 2007; Dewing, 2008; Fazio *et al.*, 2018). This may not be surprising since as seen above the dementia definitions primarily used in clinical practice often focus on a biomedical model of dementia.

1.3 Ways of Understanding Dementia

The literature offers numerous models of understanding dementia, offering different perspectives, including biomedical/neuropsychiatric approach, person-centred approach, relationship centred approach and citizenship approach (Downs, Clare and MacKenzie, 2006; Baldwin, 2008; Brannelly, 2011). These perspectives are often used interchangeably, and no single understanding is seen as the definitive truth (Downs, Clare and MacKenzie, 2006). Instead, individuals and society typically adopt a variety of understandings to comprehend dementia (Downs, Clare and MacKenzie, 2006). In fact, excellence in dementia care can only be achieved by utilising and acknowledging these multiple perspectives (Cahill, O'Shea and Pierce, 2012).

1.3.1 Biomedical Model

Within the literature, the medical model is often referred to by various terms such as the neuropsychiatric model, cognitive paradigm and the biomedical model. Despite these different terms it is widely acknowledged that the biomedical model, historically, is the most dominant and influential framework for understanding dementia care (Kitwood, 1997; Gilmour and Brannelly, 2010; Cahill, O'Shea and Pierce, 2012). The biomedical model primarily focuses on the signs and symptoms of dementia, often viewing cognitive decline as the central factor in understanding the lived experience of the condition (Downs, Clare and MacKenzie, 2006; Baldwin, 2008). In this approach, individuals living with dementia are perceived as ill, victims of their condition, with a poor prognosis and diminishing sense of self (Sabat, 2019). Given that dementia is progressive and incurable, people living with dementia can be seen as having little hope (Pritchard and Bartlett, 2024). This can result in

the person becoming largely invisible, with much of the emphasis being on helping the caregiver manage the disease progression and associated challenges.

This can position people living with dementia as passive recipients of care, leading to a perceived loss of self. This perspective can result in people living with dementia being seen as “*socially dead*” (Brannelly, 2011, p. 664). Brannelly (2011) suggests that perceptions of social death or social life can significantly influence others’ attitude towards the person, contributing, at best, to paternalism and at worst to stigma and discrimination. The models inherent focus on illness may also foster fear, leading to ineffective care practices and restricting independence and social inclusion (Sabat, 2018). This perspective is not reflective of the people living with dementia participating in this study, who actively struggle to promote and maintain their wellbeing.

Nevertheless, it cannot be denied that the biomedical model of understanding dementia has led to positive advances in medical science. This has led to exciting developments that have enhanced our understanding of brain health and prevention of dementia (Livingston *et al.*, 2024) as well as increasing our understanding of the different dementias. It has also led to the possibility of game changing disease modifying treatments that have the potential to slow down the progression of the condition (Leroi *et al.*, 2024). Additionally, it was important for participants to understand, from a biological point of view, what was happening or could happen to them and what they could do to slow down progression and enhance their brain health.

So, whereas it is crucial to understand the biological aspects of dementia, it is equally important to recognise the impact of other factors on the experience of living with dementia such as environment, learning, activity, isolation, relationships, and the views of others and wider society.

1.3.2 Person-Centred Care Model

In contrast to the biomedical model, Tom Kitwood, introduced the concept of person-centred dementia care (Kitwood, 1997). This model emphasises the interaction between neurological impairment, psychological factors, and the environment (particularly the social context) (Downs, Clare and MacKenzie, 2006; Brooker, 2007). Unlike the biomedical model, with its focus on cognitive decline, Kitwood’s approach suggests that wellbeing and illbeing as

well as deterioration, is not solely due to cognitive decline, but should be understood in terms of the maintenance of personhood.

Kitwood (1997, p. 8) defines personhood as: *“a standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust.”* A key outcome of person-centred care is the preservation of personhood despite cognitive decline (Brooker, 2007). Kitwood (1997) identifies three main discourses related to the concept of personhood. Firstly transcendence, where life itself is sacred, and the inherent dignity of being is respected. Secondly, ethical discourses, which affirm that individuals have inherent value, making respect for the person essential. Thirdly, social psychology, when promotion of personhood is linked to self-esteem, the roles people occupy in social groups and the integrity and continuance of sense of self.

So, with promotion and maintenance of personhood at its foundation, person-centred dementia care encompasses the interplay between the individual and social and environmental factors. In shifting the perception of people living with dementia, person-centred care places them at the centre of care as active participants rather than passive recipients. Brooker (2007, p. 13) has expanded on the work of Kitwood (1997) in outlining four key elements of person-centred care:

V: Value base that asserts the intrinsic worth of all human beings, regardless of age or cognitive ability.

I: Individualised approach that recognises the uniqueness of the person.

P: Understanding the world from the **P**erspective of the person.

S: Creating a **S**ocial environment that supports the psychological needs of the person.

However, person-centred models of understanding dementia have been criticised by others who feel that there is a need to move on from a person-centred approach to a more relationship focused model.

1.3.4 Relationship Model

In a move to a more relationship centred model of dementia, Adams (2008), whilst acknowledging the work of Kitwood, argues there is a need for a move from person-centred care to relationship centred care. He suggests that there should be a focus on equality and communication within the triad of the person living with dementia, their family and healthcare workers. Nolan *et al.* (2006) concur, reiterating the importance of relationships in dementia care. To improve the care of older people, through relationship centred care, in residential care, Nolan *et al.* (2006) developed the Senses Framework. The premise of the framework is that within the care environment people should have a sense of security, belonging, continuity, purpose, achievement and significance (Nolan *et al.*, 2006; Watson, 2019). Furthermore, the Senses Framework, the authors argue, provides a guide for staff education and learning. The focus is on all people within the care environment as equally important. Whilst recognising the central role of relationships for the person living with dementia Adams and Gardiner (2005), caution that power imbalances can exist, particularly if there is collusion between two parties in the triad, whose wishes might differ from the other. Moreover, the perspectives and wishes of people living with dementia can differ significantly from those of their families (Wolfe *et al.*, 2021). Additionally, it must be noted that advocates of person-centred care, argue that relationship centred care does not signify a move on from person-centred care as relationships are an integral element of person-centred care (Brooker, 2007; Kitwood (eds. Brooker), 2019). Indeed, Kitwood and Bredin (1992, p. 269) stress that to support personhood for the person living with dementia, personhood should be seen in “*social terms rather than individual terms*”.

1.3.5 Citizenship model

The citizenship model of dementia emphasises that people living with dementia are entitled to the rights and responsibilities of full citizenship. Bartlett and O’Connor (2007) argue that unlike adopting approaches that focus on individual experiences, the citizenship model addresses broader issues such as discrimination, disability, and the socio-political environment. In 2016, The Alzheimer Society of Ireland, developed a charter of rights for people living with dementia (Alzheimer Society of Ireland, 2016). It set out to ensure that people living with dementia have the same civil and legal rights as other citizens, free from discrimination in an inclusive society. Adams and Gardiner (2005), in their scoping review of the literature relating to citizenship in dementia, identified four key themes that

underpinned citizenship discourses. Firstly, the relationality of citizenship, secondly, facilitated agency and autonomy. Thirdly, attention to stigma, discrimination and exclusion and fourthly, recognition of the possibilities for identity and growth. In addition to the impact dementia and related symptoms, have for older populations, they and their supporters also experience significant issues which can add to the disability associated with a diagnosis of dementia. These include stigma regarding dementia, accessing diagnostic and support services and denial of rights, impacting autonomy (Kitwood, 1997; Sabat, 2001; World Health Organization, 2017). These themes have implications for the impact of others and society on how people living with dementia exercise their rights, maintain their wellbeing and hold on to their sense of self. As such they are referred to and discussed throughout this thesis.

1.4 Impact of Dementia

The impact of dementia extends beyond the individual diagnosed, impacting families, caregivers, health and social care services and society as a whole (World Health Organization, 2017). Globally, the economic cost of dementia is over 1 trillion US Dollars (Alzheimer's Disease International, 2018). From an Irish perspective, in terms of economic costs, it is estimated that the cost of dementia care in Ireland is 1.69 billion per annum, with 48% attributed to family care, 43% to residential care and formal health and social care services contributing 9% to the total costs (Connolly *et al.*, 2014). Furthermore, it is estimated that 180,000 people in Ireland are currently or have been caring for a family member or partner living with dementia (Alzheimer Society of Ireland, 2025b). It is evident that dementia is a complex and nuanced condition that cannot be positioned in a one size fits all approach. It is therefore important to understand dementia in a variety of contexts, from a variety of perspectives and in terms of impact on the individual, families, caregivers, organisations and society (Cahill *et al.*, 2012). It is within this context that the main concern of participants in this study is now introduced.

1.5 Introducing the Main Concern of Participants

Glazer (1998) identifies two key organisational features in grounded theory. Firstly, identifying the main concern of participants and secondly identifying the core category, or how they resolve or process their main concern. While engaging in this process Glaser (1998, p. 125) warns about the importance of remaining open to the emergence of the main concern and to ensure "*that the "what's going on" problem NOT be known before the research*

starts”. This limits the potential to study what Glaser (1998 p.125) refers to as the “*wrong problem*”. This study initially set out to explore the perspectives of people living with dementia relating to the concept of autonomy. I felt this topic was important and timely given how the legislative landscape in Ireland regarding decision making had recently changed. I was, therefore, interested in the perspectives of people living with dementia in terms of, what autonomy meant to them and how it could be promoted and maintained. As a nurse supporting people living with dementia, I felt there was a need to highlight and champion a human rights-based approach to dementia that promotes wellbeing, autonomy, self-determination and inclusion. Furthermore, I was aware that the concept of autonomy, and what that actually means for the person in everyday life, is ill defined, particularly in advanced dementia (Wolfe *et al.*, 2021; Serbser-Koal *et al.*, 2024). However, despite this being of particular interest to me and relevant to my area of clinical practice, autonomy, at least, as referred to in the literature and professional discourses, did not emerge as the main concern of participants in this study.

Glaser (1998) argues that researchers must remain open to “discovery” when embarking on a grounded theory study and that it should be the participants who decide what the study is about, that is the identification and resolution/processing of their main concern. He states “*The grounded theory problem and its continual resolution is always there, as participants always have a main concern they are dealing with. In contrast, the professional, preconceived problem, while of interest to the profession or some professional, is often not there, and if there, not of great concern to the participants in the substantive area*” (Glaser, 1998, p. 115).

For participants in this study *losing me* emerged as their main concern. So, *losing me* and how people living with dementia in this study process or resolve this concern is then the focus of this thesis. However, it is important to distinguish *losing me* from other losses experienced by people living with dementia.

1.5.1 Loss

From the very beginning of data collection, loss featured in some shape or form for all participants. Participants experienced loss in a variety of ways, for example, due to illness, growing older or changes in life circumstances. Yet, the loss associated with a diagnosis of dementia seemed to have a greater impact as it had implications that lead to loss of who they

are, how they see themselves, how others see them and their sense of themselves. There were several different properties associated with loss, loss of trust in one's own ability, loss of future dreams, loss of memory, fear of getting lost, loss of roles, loss of identity. Yet within the myriads of losses, how each individual addresses the loss/potential loss is linked to what has meaning and matters to them in terms of their sense of self.

1.5.2 Losing Me

Identifying the main concern of participants involved carefully analysing the data to uncover what participants saw as their central issue in their experiences. I began by open coding of interview transcripts, field notes and memos. I frequently wrote memos to identify patterns for recurring concerns repeatedly addressed by participants as they emerged. Although all participants talked about loss in some form, physical, emotions, cognitive, linguistic and functioning, loss as the main concern was conceptualised as *losing me*. Within this study, *losing me* refers to participants expressing their perception of a fear of losing sense of self, who and what is important to participants, holds meaning for them, and their sense of who they are. The study data suggest that *losing me* has two main influencing factors that distinguish loss from the perception of *losing me*, namely, meaning and social context.

1.5.2.1 Impact of Meaning to Losing Me

Within the context of dementia some participants wondered who they are now. In Kevin Quaid's autobiography, "*I am KEVIN. Not Lewy!*" (Quaid, 2021, Chapter 21) he has a poem written by an American gentleman, William Cramer entitled "Who Am I". William lives with Dementia with Lewy Bodies. His question is reflected by many participants in this study, in that they all speak at length about who they were and are, house builder, cyclist, dancer, dentist, the driver of the family, the helper, the musician. Whilst in the natural course of a life, roles change, it seems to be more difficult to accept when the person's identity and what matters to them, who they see themselves as being, is threatened by dementia. The participants generally accept that life changes and several participants state that the changes they are experiencing are part of growing older. The changes that were more difficult to accept were threats to who they are and characteristics about themselves that hold meaning for them. This could reflect itself in retaining their humour, recognising their children, continuing to drive, remaining at home, maintaining independence, continuing to read. Essentially any myriad of things that are important to the person in terms of holding on to their sense of self. This was illustrated by one lady who was seen by others and indeed

viewed herself as the matriarch of the family: “*I was always the boss...my independence is very important; I want to be able to keep active as long as possible*”. When this was proving more difficult for her, she lamented “*...and then you feel “oh God is this the stage I’m at?” and you just sit down you have a good cry...*”. Rather than simply the loss of independence, it was the meaning associated with the loss of independence in terms of sense of self that was of concern to the participant.

Telling their stories was a way for participants to introduce who they are outside of their diagnosis of dementia. They took delight in this and became animated in helping me to ‘see’ who they are. So, whereas the person experiences a loss of a role, this may not have meaning and importance in terms of the person’s sense of self. Assigned meaning, for participants, was often the distinguishing factor in terms of impact of potential loss on sense of self. Such loss, of what matters to the person, is referred to, within the study by one participant, as the “*ultimate disaster*” and by another as something they “*would rather die*” than have happen.

1.5.2.2 Impact of Social Context to *Losing Me*

In terms of the impact of social context on *losing me*, dementia awareness and stigma played key roles. The role of dementia awareness was evident when participants talked about their experience of people they knew with dementia and how they did not appear to be themselves anymore and behaved in ways that were contrary to their former selves. Even if they did not know someone living with dementia, there was a fear of telling others of a diagnosis and of what the future might hold in terms of the potential of losing what has meaning for their sense of self. Several participants worried about what would become of them and how the changes associated with dementia would impact on how they saw themselves and their loved ones saw them. One participant illustrated this when she said, “*I said to [Daughter], there’s only one thing I want to hold onto if I can, my sense of humour.*”

Again, this was often influenced by their view of dementia, what they had heard and if they had experience of dementia with regard to a relative or friend. Bryden’s 2018 book: “*Will I still be me: finding a continuing sense of self in the lived experience of dementia*” challenges this notion, stating that despite her cognitive and linguistic ability faltering as her dementia progresses, she still possesses a sense of self (Bryden, 2018). Yet for participants, the fear remained that they would *lose me*, their sense of self and who they are in the context of their

diagnosis and particularly as dementia progresses. For one gentleman this related to his ability to connect with his family, something that was very important to him and his sense of self. When referring to his ability to continue to do this in advanced dementia he asked “...*can they talk... can they talk... not gobildy gook.... Can they be clear?* [referring to people with advanced dementia] ...*so you can still survive?*”.

His view was influenced by his experience of others living with dementia but also by dementia awareness and the stigma associated with dementia.

This fear is reflected in the literature, with loss of self being broadly associated with progressive dementia (Millett, 2011). Dementia is often viewed from a nihilistic perspective, regarded by many as a form of living death and something that is feared and dreaded (Schweda and Jongsma, 2022). This view is often underpinned by an assumption of a progressive loss of self, and subsequently, personhood, identity and agency (Mentzou *et al.*, 2023). Yet there must also be caution as stigma and stereotypes associated with dementia also play a role in the fear of losing self, labels such as the “living dead” portray people with dementia as being not themselves, as having lost themselves (Low and Purwaningrum, 2020). This can impact not only how society sees the person but how they see themselves (Bhatt *et al.*, 2021). Moreover, a clear comprehension of the concept of self can be elusive and used interchangeably with concepts of personhood and selfhood adding to the complexity of defining the concept (Millett, 2011; Mentzou *et al.*, 2023).

The concept of loss or persistence of self, in the context of dementia is explored in detail in Chapter Five, whilst introducing the theory. However, for the purposes of clarity and context for the rest of the thesis it is worth briefly examining the concept of self in this chapter.

1.5.3 The concept of Self

“Being yourself”, “minding yourself”, “being true to yourself” are all phrases that are regularly used in everyday parlance, often without much thought. Self is portrayed as being an integral part of being human and as such a prerequisite of being a member of the human race (Bryden, 2018). Yet there is little consensus as to what constitutes self (Norberg, 2019). Furthermore, within the context of a diagnosis of dementia there is a fear of alterations in sense of self that could impact how others see the person and how they see themselves (van Wijngaarden, Alma and The, 2019; Mentzou *et al.*, 2023). Additionally, memory has long

been considered as being intertwined with self, resulting in fear that loss of memory could lead to loss of self (Strikwerda-Brown *et al.*, 2019). This fear is driven, in part, by perceptions of dementia, societal stigma and how it is “seen” both by the person and by others (Cahill, 2021). Phrases such as “the long goodbye”, “living death” and “empty shells” used in society and in the media help to consolidate this view (Rosin *et al.*, 2020; Schweda and Jongsma, 2022).

Understanding the concept of self can be elusive (Millett, 2011) and has been the subject of much debate over centuries (Woźniak, 2018). Taylor (1989, p. 34) Taylor, in offering a modern perspective, argues that the self is determined by what matters to itself:

“We are selves only in that certain issues matter for us. What I am as a self, my identity, is essentially defined by the ways things have significance for me...To ask what a person is, in abstraction from his or her self-interpretations, is to ask a fundamentally misguided question, one to which there couldn’t be an answer”. This statement underscores the importance of meaning in the formation and maintenance of self. The importance of meaning is a fundamental pillar of symbolic interactionism (Blumer, 1969).

For Blumer (1969), the father of Symbolic Interactionism, the concept of self was central to his thinking. Blumer was greatly influenced by the work of earlier writers, associated with the symbolic interactionist tradition such as Mead (1934) who referred to self in terms of a subject-object distinction (Blumer, 1969). Mead (1934), referred to self as subject as *I* and self as object as *Me*. Blumer (1969) argues that persons can only respond to others by the virtue of their possessing a “self”. Drawing on the work of Mead, he defines self as follows:

“It means merely that a human being can be an object of his own action. Thus, he can recognise himself, for instance, as being a man, young in age, a student, in debt, trying to become a doctor, coming from an undistinguished family and so forth. In all such instances he is an object to himself, and he acts towards himself and guides himself in his actions towards others on the basis of the kind of object he is to himself.” (Blumer, 1969, p. 12).

So, in reading this passage, *I* (as subject) can distinguish several *Me*’s (as object), student, young man, family member and so forth. In doing so, it can be surmised that ‘self’ from the perspective of symbolic interaction is not a single entity but rather refers to multiple selves. Additionally, Blumer (1969) posits that human beings have a self and this allows them to interact with themselves. Blumer (1969, p.13) suggests that “ *self-interaction exists*

fundamentally as a process of making indications to oneself....indications that he uses to direct his action". This resonates with participants in this study as self-interaction was central to the relationships people living with dementia have with themselves. It seemed to signify not only an expression of self, but also influence of what Blumer calls "self-indications" on the direction of action in terms of holding on to their sense of self. So, if people living with dementia are vulnerable to self-stigma, this could impact on their "self-indications" and so their direction of action in terms of how they resolve or process their main concern.

Also recognising the multidimensional nature of self, and from a social constructionist perspective, Sabat (2018) suggests that there are three different aspects of self. Self 1 refers to *"the experience of oneself as an individual who is one and the same person from moment to moment"* (Sabat, 2018, p. 137). Self 2 refers to *"mental and physical attributes past and present"* and includes beliefs, intellectual achievements, height and eye colour. Self 2 is not erased due to a diagnosis of dementia (Sabat, 2018 p. 139). Self 3 refers to the *"socially presented aspect of us"*. This aspect of self is vulnerable in dementia, largely due to its construction being primarily based on how others see the person and therefore is more prone to stigma and discrimination (Sabat, 2018 p. 141). However, stigma and the negative attitudes of others, impacts not only on how others see the person living with dementia but also in how they see themselves, possibly leading to self-stigma (Nguyen and Li, 2020).

Kitwood (1997) as discussed earlier moved away from a medicalised view of dementia, proposing that the focus should be in nurturing and maintaining the personhood of the person living with dementia. In doing so, Kitwood (1997, p. 8) defined personhood as *"a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust"*. However, some individuals can experience significant cognitive and linguistic difficulties, particularly in advanced dementia, that can limit their ability to outwardly express their sense of self. As a result, they may be perceived by others as lacking inner personhood, essentially an "empty shell". This poses a significant risk to the recognition and affirmation of their inherent personhood (Kitwood, 1997; Kontos, 2005). Additionally, Kontos (2005) offers a further consideration in the debate on self. She posits that Kitwood (1997), while moving away from a biological view of dementia has largely ignored the corporeal, embodied self, which persists even beyond relationships and in spite of

diminished cognitive abilities, residing in the pre-reflective body (Kontos, 2004; Kontos and Martin, 2013). These perspectives of self in dementia are discussed in detail in Chapter Five.

So, it appears that the concept of self is more complex than the ability to remember facts or the changes in neuronal pathways in the brain (Post, 2000). Christine Bryden (2018) concurs, arguing that loss of self due to dementia is a misconception and one that is usually perpetuated by people not living with dementia. She refers to this as the outsider view and that from her insider view, of the lived experience of dementia, there is no loss of self. Yet, *losing me* is a very real and present concern for participants. This thesis examines the perspectives of people living with dementia in terms of their holding on to their sense of self in the context of dementia and offers a theory to explain the actions that people living with dementia take to resolve and process their main concern, *losing me*, and hold on to their sense of self, *Holding on to Me*.

Note: In this study, there are several terms used that can be open to various interpretations and indeed are often used interchangeably. For the purposes of clarity in referring to ‘Me’ and ‘Self’ in this thesis, the reference is to a multidimensional sense of self that incorporates what matters to the person. In turn, *losing me* refers to losing a sense of self. Additionally, in exploring self, selfhood and personhood the term self is used unless a specific term is used by an Author (for example in Kitwood’s work, or work referring to Kitwood’s person-centred care in dementia the term personhood is used).

1.6 Overview of the Thesis

1.6.1 A Theory of *Holding on to Me* in the Context of Dementia.

Once the main concern was identified it then became the focus for building categories and eventually a core category (Gibson and Hartman 2014). *Holding on to Me* refers to ways in which participants process or resolve their main concern, *losing me*. *Holding on to Me* emerged as the core category. In this thesis, the theory of *Holding on to Me* is explained comprehensively. The methodological approach, including methods used are explored in detail and judged in accordance with recognised criteria.

1.6.2 Sequence of Chapters

In Chapter Two, the methodology of grounded theory is critically examined. This study is aligned with classic grounded theory, developed in 1967 by Glaser and Strauss (Glaser and

Strauss, 1967) and evolved by Glaser (Glaser, 1978, 1998, 2002). A rationale for this alignment is explored.

In Chapter Three, the aspects of doing grounded theory such as data collection and analysis are explored in detail. Data sources in this study are identified as twenty-six semi-structured interviews, associated field notes and memos and six published autobiographies. Additionally, ethical considerations are discussed, including issues of consent.

In Chapter Four, the processes and practicalities relating to Person and Public Involvement (PPI) are examined in terms of people living with dementia and their supporters contributing to research to enhance the meaningful engagement of people living with dementia throughout the study. The practicalities and challenges of using PPI within the study are discussed. Points of compatibility and possible tension between PPI and Classic Grounded Theory (CGT) are also explored.

In Chapter Five, the core category of *Holding on to Me* is introduced. The extant literature and theory relating to the persistence or loss of self in dementia are explored. Finally, an overview of the classic grounded theory, *Holding on to Me* is presented.

In Chapter Six, the first sub core category, *holding tighter* is introduced and explained. This refers to patterns of action in which people living with dementia participating in the study *Hold on to Me* by resisting the loss or taking of things that are integral to their sense of self, what and who has importance for them.

In Chapter Seven, the second sub core category, *letting go* , is examined. *Letting go* refers to patterns of action, in which participants *Hold on to Me* by *letting go* of things they cannot control or that pose a threat to their ability to hold on to their sense of self.

In Chapter Eight, the third sub core category, *relational grappling* and its properties are explored. *Relational grappling* is concerned with how people living with dementia in the study hold on to their sense of self through getting along with others and themselves. Fundamentally, it refers to how the person is seen by others, how they see themselves and how these perspectives influence actions that either support or hinder *Holding on to Me* .

Chapter Nine contains an in-depth discussion relating to the implications of the theory. This is explored in terms of its impact on how self is understood, from the viewpoint of the person themselves, but also others and society, in the context of a dementia diagnosis. Implications and recommendations for care practice, education and future research are also critically examined.

Finally, in Chapter Ten, there is a focus on judging the quality of the theory using Glaser's criteria of fit, relevance, work and modifiability (Glaser, 1998). Theoretical and methodological contributions of the study are presented. Study limitations are discussed and concluding comments made.

1.7 Summary

Within this chapter *losing me* is introduced as a main concern for people living with a diagnosis of dementia, participating in this study. *Losing me*, refers to the fear of losing sense of self and it is this inference that is used throughout this thesis. Additionally, ways of understanding dementia are explored. The dominant understanding of dementia underpinning this thesis is that of person-centredness and the promotion and maintenance of personhood, and so in explaining the main concern of participants, the concept of self must also be reflective of this ideology. Therefore, an understanding of the concept of self that recognises its multidimensional nature, influenced by the thinking of Kitwood (Kitwood, 1997), Blumer (Blumer, 1969), Mead (Mead, 1934) and Sabat (Sabat and Harré, 1992; Sabat, 2002, 2018) is proposed. This is discussed in greater detail in Chapter Five. Finally, an overview of the remaining chapters of the thesis is given.

This chapter provides a context and signpost for the rest of the thesis. The next chapter explores grounded theory methodology, before moving on to an in-depth examination of the methods of doing grounded theory in this study in Chapter Three.

Chapter 2

Grounded Theory Methodology

2.1 Introduction

The previous chapter outlined the main concern of participants in this study, *losing me*, and this thesis endeavours to explain how they resolve or process it. Classic Grounded Theory (CGT) has been chosen as the methodology best suited to fulfil this goal. Within this chapter to present a cogent argument for the use of grounded theory and particularly classic grounded theory in this study, a methodological overview of grounded theory (GT) is explored.

2.2 Grounded Theory Research: A Methodological Overview

GT research was developed in the 1960's by two American sociologists, Barney Glaser and Anselm Strauss. GT as a research methodology emerged from their own empirical inquiry into the topic of dying called "Awareness of Dying" in 1965 (Glaser and Strauss, 1965, 1967). The aim of grounded theory is to generate an explanatory, multidimensional theory that uncovers processes inherent to the phenomenon. Their reasoning for the development of grounded theory was that, in their view, the majority of sociological research had focussed on how existing theory could be tested or verified. In a divergence of what had gone before, Glaser and Strauss (1965, 1967) wanted to generate new theory from empirical data, rather than testing existing theories. Theory, therefore is not the starting point as there may be no existing theory to explain the phenomenon. They distinguish theory generated from the data (inductive) with theory generated by logical deduction from a priori assumptions. In doing so, they argued that theory derived from data originating in the social world is more relevant and robust.

2.2.1 Processes Involved in Grounded Theory

Glaser and Strauss (1967) required grounded theorists to use a combination of openness and systematic processes, with the aim of generating theory from data rather than testing extant theory (Glaser and Strauss, 1967). To this end there is an emphasis on discovery rather than preconceived ideas and assumptions (Glaser, 1998). For Glaser and Strauss (1967) theory that is grounded in the data or discovered is more relevant within the substantive area. Discovery of a grounded theory is a systematic process. Research starts with a broad question about a general topic or subject. Data is collected within the substantive area relevant to the general topic. This can include any type of data and method of collection once they are in

keeping with the research topic area (Glaser and Strauss, 1967; Glaser, 1998). Incidents are identified and the data are coded and compared with other incidents to start to identify emerging categories through a cyclical, interactive, iterative process of data collection and analysis (constant comparative method) (Glaser and Strauss, 1967). The analytic procedures start with comparing incident to incident, moving to incident to category property, then category to category. As analytic comparisons progress, codes and categories become increasingly more conceptual, providing the basis for theory generation (Glaser 1998). Subsequent data collection is informed by emerging categories in a process called theoretical sampling (Glaser, 1998). Theoretical sampling requires that the researcher decide where to go to collect more data to develop and ultimately saturate each category (Glaser and Strauss, 1967; Gibson and Hartman, 2014). Throughout the process of conducting grounded theory Glaser and Strauss (1967) directed the researcher to engage in detailed memo writing. Memos according to Glaser (1998, p.177) are the “...*theorising write-up of ideas about substantive codes and their theoretically coded relationships as they emerge during coding, collecting and analysing data and during memoing*”. It is a central tool for the grounded theorist and informs other grounded theory processes such as data collection, coding (substantive and theoretical) and theoretical sampling (Glaser, 1978).

Grounded theory is distinct from other qualitative methodologies as it has a specific aim, that is, developing theory to provide a greater understanding of studied phenomena (Glaser and Strauss, 1967). Theory generation is through a systematic process, namely constant comparative analysis, in which data are collected and analysed concurrently. The term constant comparative analysis is used widely in sociology and anthropology and so it is important to clarify the term constant comparative analysis in grounded theory (Glaser and Strauss, 1967). Glaser and Strauss (1967) argue that the general use of constant comparative analysis is often limited (to use on larger social units such as organisations), not so much by the method itself but by the researchers using it. They state that their use of constant comparative analysis as a “*strategic method for generating theory assigns the method the fullest generality for use on social units of any size, large or small...*”. As such it can be particularly useful in examining small social entities such as hospital wards, or even individuals (Glaser and Strauss, 1967 p. 21).

Another key element of theory generation in grounded theory is conceptualisation. Holton (2008, p.10) states “*Classic grounded theory is not about accurate, descriptive reporting of*

findings in a study, nor is it an act of interpreting meaning as the participants in a study ascribe it; rather, it is an act of conceptual abstraction". Glaser (2002a) argues that this affords the researcher the conceptual licence, autonomy and freedom to generate theory to understand complex phenomena based on the empirical data selected rather than "*forcing*" data to verify existing theory. In later work Glaser (1978, 1998, 2005) more fully clarified grounded theory concepts and processes such as conceptualisation, memo writing, coding, theoretical sensitivity and theoretical coding. These processes are discussed in detail with relevance to this study in chapter Three, "Doing Grounded Theory".

2.2.2 Epistemological and Ontological Considerations

Glaser (2005, p. 145) states that "*The quest for an ontology and epistemology for justifying GT is not necessary. It will take these on from the type of data it uses for particular research FOR THAT RESEARCH ONLY.... Whether GT takes on the mantle for the moment of prepositivist, postpositivist, postmodernism, naturalism, realism etc, will be dependent on its application to the type of data in a particular research*". Gibson and Hartman (2014) argue that one reason for considering philosophical perspectives is in identifying which type of grounded theory is most suitable to fulfil the aims of the study. For example, they suggest that the difference between classic grounded theory and constructivist grounded theory is essentially a philosophical one regarding the nature of knowledge (epistemology) and the nature of reality and truth (ontology) (Gibson and Hartman, 2014). Therefore, to ascertain the most appropriate grounded theory methodology for this study it is important to consider epistemological and ontological perspectives and how they relate to this study.

Crotty (1998, p.8) states that epistemology is "*a way of understanding and explaining how we know what we know*". It addresses how knowledge is generated and communicated (Scotland 2012). Ontology, according to Crotty (1998, p. 10) is defined as "*the study of being*". López-Alvarado (2017) further argues that ontology relates to perspectives of reality and what we believe to be the truth. In considering epistemological and ontological perspectives, two contrasting epistemological outlooks, objectivism and subjectivism align with two contrasting ontological standpoints realism and relativism, respectively. Objectivism assumes knowledge exists independently of human subjectivity and meaning derives from the real world (Crotty, 1998; Levers, 2013) aligning with ontological realism. By contrast, subjectivism believes that social phenomena arise from human perception and

interaction (Denzin and Lincoln, 2005; Levers, 2013; López-Alvarado, 2017) thus aligning with ontological relativism.

2.2.2.1 Realism

Realism asserts that reality exists independently of human awareness (Levers, 2013) and is discoverable using objective measures (López-Alvarado, 2017). Positivism and post-positivism are situated within realist ontology (Weaver and Olsen, 2006). Positivism is epistemologically objectivist, assuming that reality exists independent of human perception and can only be discovered through objective enquiry (Scotland, 2012; Pretorius, 2024). It seeks to explain relationships and causality (Creswell, 2009; Scotland, 2012) using controlled quantitative methods (Nicolls, 2009). However, claims of absolute truth and true objectivity have been challenged (Weaver and Olsen, 2006). Additionally, practical challenges such as uncontrollable or unknown variables add to the limitations of positivism (Scotland, 2012).

Post-positivism arose in recognition of the limitations of positivism, particularly the notion of absolute truths (Weaver and Olsen, 2006; Panhwar, Ansari and Shah, 2017; Pretorius, 2024). Post-positivists accept the fallibility of knowledge in terms of absolute truth and complete objectivity (Scotland, 2012; Levers, 2013). It emphasises mixed methods research design whilst continuing to focus on objective, scientific investigation of phenomena (Panhwar, Ansari and Shah, 2017). Post-positivism, like positivism seeks to understand causal relationships through experimentation and correlation studies but differs in that participant's perspectives are often sought (Scotland, 2012). Whilst post-positivists acknowledge their role in the research process, they try to limit bias through reflexivity (Pretorius, 2024).

In essence, the emphasis of realism is on objectivity (Levers, 2013) and generalisability (Scotland, 2012). Additionally, realist methodologies often overlook participants lived experience and agency (Nicholls, 2009; Scotland, 2012). As such this approach is deemed unsuitable for this study, the aim of which is to explore the perspectives of people living with dementia.

2.2.2.2 Relativism

In contrast to realism, relativism rejects a single objective reality, recommending multiple realities that are shaped by human experience (López-Alvarado, 2017). From the relativist perspective reality emerges through human interaction with the world (Crotty, 1998). Constructionism and interpretivism are both underpinned by relativist ontology (Levers, 2013). Constructionism aligns with subjectivist epistemologies. At first glance this would seem to align with the aims of this study. However, constructionist perspectives in research involve the researcher and participants co-creating knowledge (Guba and Lincoln, 1994; Pretorius, 2024). This gives rise to a concern regarding constructionism including misinterpretation of appearances for reality, given the possibility of multiple constructions of reality (Lee, 2012). Given that people living with dementia are often vulnerable to stigma and the preconceived ideas of others, particularly as their ability to communicate verbally diminishes (Kitwood 1997; Alzheimer Europe 2016; Sabat, 2018; Alzheimer's Disease International, 2024) this raises concerns for application of this perspective to this study.

Interpretivism assumes multiple realities that are socially constructed (Saunders, 2009). It prioritises understanding meaning in context (Fossey *et al.*, 2002; Weaver and Olsen, 2006) recognising that knowledge is value-mediated (Levers, 2013). Denzin and Lincoln (2005 p.22) suggest that in interpretivism research is “*guided by the researcher's set of beliefs and feelings about the world and how it should be understood and studied*”. In a similar vein to constructionism researcher reflexivity is crucial in acknowledging their role in co-creating understanding (Houghton *et al.*, 2012; Pretorius, 2024). Harvey and Land (2017) suggest that interpretivism's subjective focus makes it popular in nursing research. Despite this, the focus on interpretation and co-creation could again, as seen with constructionism make people living with dementia vulnerable to researcher unconscious stigma and preconceived ideas. Additionally, Hammersley (1992) casts doubt on the usefulness of findings of studies using a relativist approach given that legitimacy can be claimed by a multiplicity of perspectives. So, in terms of this study, both realism and relativism can be seen to be problematic, given the reasons stated above. This is not to say that there are not merits to these perspectives, but only that for the purposes of exploring the perspectives of people living with dementia within this study alternative perspectives need to be explored.

2.2.2.3 Subtle Realism

In considering a different perspective, Hammersley (1992) offers a possible middle ground between realism and relativism in subtle realism. Subtle realism acknowledges the existence of an external reality while recognising that access to it is mediated through subjective perception (Hammersley, 1992; Andrews, 2012). The goal is to portray reality through multiple perspectives, each regarded as equally valid, rather than to replicate reality itself (Hammersley, 1992). This allows for the stance of “*reasonable confidence*” (Murphy *et al.*, 1998, p. 69) in findings without claiming absolute certainty, aligning well with classic grounded theory’s emphasis on systemic emergence of theory from data. To this end this perspective was deemed to be the most appropriate to fulfilling the aims of the study and therefore informs the choice of grounded theory methodology.

2.3 Grounded Theory Methodologies

Since its inception in the 1960’s grounded theory has diverged into three main streams. Firstly, classic grounded theory, as originally developed by Glaser and Strauss and subsequently further developed by Glaser (Glaser, 1978, 1998; Glaser 2005). Secondly, Straussian (Strauss and Corbin, 1990). Thirdly, Constructivist Grounded Theory by Charmaz (Charmaz, 2014). Certain essential characteristics of grounded theory remain in all three methods, such as constant comparative analysis, theoretical sampling, memoing and differentiating between substantive and formal theory (Kenny and Fourie, 2015). However, Kenny and Fourie (2015) further argue that there are areas of contention between the Classic, Straussian and Constructivist grounded theory, namely philosophical positions, methods for coding and use of literature. These divergences are discussed with relevance to the rationale for using classic grounded theory in this study.

2.3.1 Classic Grounded Theory

Glaser and Strauss (1967) had another objective in developing Grounded Theory methodology, that of addressing the criticisms of qualitative research, in terms of rigour and relevance to science. This has resulted in arguments that classic grounded theory is rooted in objectivist philosophies, advocating the ideals of positivism (Charmaz 2000, Mills *et al.* 2006). However this has been disputed by Glaser (Glaser, 2002; Glaser and Holton, 2004; Kenny and Fourie, 2015). Glaser argues that grounded theory is a general inductive method (Glaser 1998). For Glaser “all is data” rather than focusing on what is qualitative or

quantitative. In saying this he places the emphasis on the relevance of the data to the study, rather than epistemological standpoints. Glaser (1998, p. 3) states that grounded theory is neither quantitative nor qualitative but simply “*the systematic generation of theory from data acquired by a rigorous research method*”. This point is further clarified by Glaser and Holton (2004, p 10) who state that grounded theory “*stands alone as a theory generating methodology. It is a general methodology. It can use any data...*”. Simmons (2011) argues that classic grounded theory can therefore be described as occupying a middle ground in that it generates a theory that is subjectively person focussed, whilst also following a rigorous, systematic method for data collection and analysis. In a similar vein, Smith-MacDonald *et al.*(2020) suggests that classic grounded theory offers researchers a robust, rigorous research method, that is person-centred in its focus on generating theory that is grounded in the substantive area. This would therefore also ensure that the aims of the study are successfully attained.

2.3.2 Straussian Grounded Theory

In a divergence from classic grounded theory, Strauss (1987) and Strauss and Corbin (1990) whilst also promoting an inductive approach, particularly in the early stages of coding, also advocated elements of deduction as necessary and even suggested that elements of interpretation are inevitable in the analysis process. In what is termed Straussian or Evolved grounded theory, Strauss (1987) and later Strauss and Corbin (1990) place a strong emphasis on the interpretation of the gathered data by both the participants and the researcher. As such, Straussian grounded theory is placed within an interpretivist perspective (Levers, 2013). New ideas about data analysis such as axial coding were also introduced in their book (Strauss and Corbin, 1990) to systematically deduct or ‘force’ codes and categories from the data. This is in a sharp contrast to the inductive processes in which codes and categories ‘emerge’ advocated originally by Glaser and Strauss (1967) and then in Glaser’s own work (Glaser, 1978, 1998; Glaser and Holton, 2004).

Additionally, in contrast to classic grounded theory Strauss and Corbin argued for the use of literature before and throughout the study to inform and guide the researcher (Strauss and Corbin, 1990). Yet Glaser (1998) argues against conducting a review of the literature in the substantive area for several reasons including, to prevent preconceived ideas and extant theory impacting on the emergent theory. Moreover, and more practically, in grounded theory the researcher does not know which literature to review that will fit the substantive

area, until it has been ‘discovered’. Indeed Glaser argues that through spending time and energy on a literature review prior to discovering the main concern in the substantive area, the researcher could be tempted to “*force a commitment to a non-problem*”(Glaser, 1998, p. 69). However, he did acknowledge that there are times when, particularly in doctoral research, a literature review prior to the study is required (by the researcher, not the classic grounded theory method). Additionally, he believes that the researcher should indeed read to enhance their theoretical sensitivity, just not literature directly related to the substantive area (Glaser, 1978). It is only when the theory emerges that the researcher can know which literature is relevant, and it is then that the theory should be nested in the literature (Glaser, 1998).

2.3.3 Constructivist Grounded Theory

In agreement with Strauss, Charmaz (2014) also promoted the use of literature reviews before and throughout the grounded theory process to enhance theoretical sensitivity and guide the researcher. Charmaz, a student of Glaser and Strauss, in a departure from both Classic and Straussian grounded theory, adopted a constructivist philosophy (Kenny and Fourie, 2015). In developing constructivist grounded theory Charmaz believed that the researcher plays a key role in “constructing” the theory and that their influence and interpretation of the data must be acknowledged (Charmaz, 2014; Gibson and Hartman, 2014). Within constructivist grounded theory, openness to discovery and emergence of theory are no longer the main focus (Gibson and Hartman, 2014). Rather, Charmaz advocated an “*imaginative engagement with the data*” (Charmaz, 2014, p. 168). In recognising the role of the researcher in constructivist grounded theory, Charmaz (2014) places emphasis on the reflexivity of the researcher in understanding how researchers and participants interpret meanings and actions.

Moreover, in a move away from an inductive focus, which she saw as being limited, Charmaz’s constructivist grounded theory, introduced an additional principle of reasoning, abduction as an important element of theoretical sampling (Charmaz, 2014). Charmaz (2014, p. 200) states that abduction is “...*a mode of imaginative reasoning researchers invoke when they cannot account for a surprising or puzzling finding*”. Charmaz (2014, p. 201) clarifies that abductive reasoning is not merely “*mental leaps*” but requires a re-examining or gathering of data to “*subject your new theoretical interpretations to rigorous empirical*

scrutiny". Constructivist grounded theory is associated with a relativist ontology (Kenny and Fourie, 2015).

2.3.4 Choice of Classic Grounded Theory in this Study

As recommended by Dunne (2011) the decision as to which grounded theory approach to adopt was decided early in the research process as it was essential to all elements of the study design process, including the decision as to when to review the literature relating to the topic. Moreover, the differences between Classic, Straussian and Constructivist grounded theory mean that they should not be used interchangeably (Glaser and Holton, 2004; Kenny and Fourie, 2015). Classic grounded theory was chosen as most appropriate for this study as it provided the flexibility and rigour needed to understand the often unexplored perspectives of people living with dementia. Additionally, as there was little known about the perspectives of people living with dementia relating to autonomy my position in subscribing to discovery, emergence, openness and theory generation grounded in the data was a valid one. It enabled the generation of a theory that was empirically grounded, person-centred and sensitive to context in the substantive area, whilst avoiding the interpretive risks of alternative grounded theory methodologies. Further elaboration of the rationale for choosing a classic grounded theory approach is discussed in terms of maintaining an openness to discovery.

2.4 From Beginning to End: Staying Open to Discovery

A central tenet of classic grounded theory is staying open to emergent and earned relevance of codes and categories throughout the process of theory generation. Glaser believes that all codes and categories should be derived from the data, essentially emerging and earning their place in the theory generated (Glaser, 1998). To this end, the researcher must start with an "openness to discovery" and the use of systematic procedures. Furthermore, the researcher begins with a general topic of inquiry, and using a process of constant comparative analysis of the data identifies codes, categories and the evolution of theoretical properties within the categories. To further develop the emergent categories "theoretical sampling" is used to identify comparisons and variations. This procedure is repeated until no additional data can be found to develop the category, termed as "theoretical saturation". Through progression of these procedures, higher level concepts can be identified, resulting in the development of theory that is grounded in the data (Glaser and Strauss, 1967).

The openness to discovery, described above and the inductive approach, championed in classic grounded theory is important in this study for several reasons. Firstly, dementia research often excludes the perspectives of people living with dementia (Gove *et al.*, 2018) and this is a central aim of this study. Therefore an inductive approach, as advocated by Glaser (1978, 1998, 2002), rather than deductive or interpretative approach is essential. Glaser (1998, p. 116) states:

“It is about time that researchers study the problem that exists for the participants in the area, not what is supposed to exist or what a professional says is important. “Whose relevance” drives the focus of a research project....and it will emerge if it is not derailed by what the researcher thinks is relevant beforehand and forces it on the study...”

This brings me on to my second point. Although the initial project was to explore the perspectives of people living with dementia relating to autonomy, this would have been a disservice to the participants, as although their main concern was indirectly related to autonomy (see Chapter Nine), autonomy was not their main concern. As Glaser posits, the researcher’s original idea might not be what participants feel the study should be (Glaser, 1998) and I wanted to ensure the project was addressing their concerns. Extensive and consistent memo writing, particularly reflective memo writing and Person and Public Involvement (PPI) (see Chapter Four) helped to identify possible biases and ensure that the relevance (as referenced by Glaser above), belonged firmly with the participants. Additionally, people living with dementia are particularly vulnerable to stigma and discrimination (Kontos *et al.*, 2020; Nguyen and Li, 2020). Moreover, stigma and discrimination in healthcare continues to be a significant challenge for people living with dementia (Alzheimer Disease International, 2019). Staying open and an inductive approach including memo writing means preconceived ideas and assumptions do not impact on the analysis process. How this relates to this study is discussed in greater detail in Chapter Four in relation to the use of Person and Public Involvement (PPI) in this study.

In classic grounded theory, remaining open continues throughout the research process. Glaser (2005) argues that staying open is particularly relevant during the memo sorting and writing up stages, where the research must remain open to theoretical codes (TC). Theoretical coding does not happen as easily as substantive coding, especially for novice researchers. This often results in this stage being excluded from the research process. Glaser (2005, p.3) argues the researcher should “*master sensitivity to as many TCs as possible*”.

The researcher must begin with familiarising themselves with the theoretical codes and theoretical coding families. Hernandez (2009) advocates this as a good place to start as it can help the researcher become theoretically sensitive to the emergence of theoretical codes, during and even before the memo sorting process. This again, can be a confusing process for as Glaser (1978, p. 72) states, theoretical codes are “*amazingly flexible, several may fit the same data*”. The challenge then, is not to force a preferred or “pet” theoretical code onto the data, but to remain open to its emergence (Glaser 2005).

Glaser’s premise that grounded theory should be for the most part inductive has been criticised as “naive” by other grounded theorists (Bryant, 2002; Charmaz, 2014). They argue that it is not reasonable to assume that researchers do not have a certain level of prior knowledge and that this would inevitably influence their inquiry (Charmaz, 2014). Glaser (1978) countered this criticism by stating that it is not so much what is known (about the specific field of inquiry) but the level of transparency on the part of the researcher as to what is already known and what is derived from the data. In fact, Glaser (1978) believed that it was essential that researchers have prior theoretical learning (not specifically related to the area of inquiry, particularly in the initial phases) in order to fully evolve codes and categories that best “fit” the field of inquiry. This he refers to as theoretical sensitivity (Glaser, 1978).

2.4.1 Theoretical Sensitivity

Theoretical sensitivity is essential to all elements of grounded theory. It requires that the researcher is sufficiently “theoretically sensitive” so as to be able to conceptualise and formulate emerging theory. Theoretical sensitivity is developed over time and is based on both previous experiences and knowledge as well as developing from the emerging theory (Glaser and Strauss, 1967). Again, this comes with a caution as theoretical sensitivity can be lost if there is a focus or over emphasis on preconceived ideas, extant theory or past experiences. So therefore, according to Glaser (1978, p. 3), the first step in achieving theoretical sensitivity is to enter the field with as few preconceived ideas as possible. This was a particular concern for me as I have worked with people living with dementia and their families and indeed worked in healthcare settings for many years. As such I had a knowledge of extant theory and also a wealth of experiential learning. Memo writing, person and public involvement and supervision assisted me in challenging preconceived ideas and assumptions. This is discussed in further detail in Chapters Three and Four.

2.5 Summary

The purpose of the study was to ascertain the experiences and perspectives of people living with dementia and their families/supporters. Therefore a qualitative methodology was most likely to garner the required data. Furthermore, as there was currently little known about the topic and the purpose was to elicit perspectives and discover new theory, grounded theory methodology was appropriate to this study. Moreover, classic grounded theory offers an inductive, rigorous, systematic approach that focuses on the emergence of theory that is grounded in the perspectives and experiences of participants. As such Classic Grounded Theory (CGT) was deemed to be the best fit for this study. Chapter Three explores in detail the methods of doing grounded theory.

Chapter 3

Doing Grounded Theory

3.1 Introduction

Having provided a rationale for the use of classic grounded theory for this study, this chapter explores the methodological approach underlying data collection and analysis. Furthermore, to meet the aims of the study, the research strategies and methods used are explored, with particular reference to engaging people living with dementia in research.

3.2 Aim of the Study

This study began with an interest in how from their own perspective, people living with dementia experienced issues relating to autonomy. The initial aim of the study and therefore the focus for data collection at the beginning of the study was:

- To gain greater understanding of autonomy from the perspectives and experiences of people living with dementia and their families/carers.

Consistent with the inductive focus of classic grounded theory, the initial data collection consisted of a broad, general question. Subsequent iterations of data analysis and data collection identified the main concern of participants and subsequently the focal point of the study. As discussed in Chapter One, in the context of dementia, the participants main concern was conceptualised as *losing me*. Subsequently, this became the focus of data collection and analysis. Glaser (1998, p.115) states:

“Grounded theory accounts for the action in a substantive area. In order to accomplish this goal grounded theory tries to understand the action in a substantive area from the viewpoint of the actors involved. This understanding revolves around the main concern of the participants whose behaviour continually resolves their concern. Their continual resolving is a core variable. It is the prime mover of most of the behaviour seen and talked about in the substantive area. It is what is going on! It emerges as the overriding pattern”.

Therefore, the subsequent aim of this study was:

- To generate a multivariate grounded theory of how people living with dementia, resolve or process *losing me*. In essence, the aim was to explain how people resolve or process threats to their sense of self in the context of dementia.

3.3 Population

People with a diagnosis of dementia. I was cognisant that the criteria for inclusion might change as the study progressed, particularly as theoretical sampling occurred (Birks and Mills, 2015). This was not the case in this study and is discussed in greater detail later in this chapter.

3.3.1 Inclusion Criteria

Potential participants were included if they had a diagnosis of dementia and if they had sufficient verbal ability to take part in the interview, even if communication aids were needed to support conversation. Additionally, the person with dementia needed to be able to give informed and explicit consent, either written or verbal (recorded).

3.3.2 Sampling

Initially purposive sampling was used as only those living with dementia and their families/carers would be able to generate the rich data required. However, as concepts revealed themselves from the data, theoretical sampling was used to develop the theory. Theoretical sampling is defined as:

“...the process of data collection for generating theory whereby analyst jointly collects, codes, analyses his (sic) data and decides what data to collect next and where to find them, in order to develop his (sic) theory as it emerges” (Glaser and Strauss 1967, p 45).

This is discussed in greater depth later in this chapter as it is an essential element of the constant comparative method.

3.4 Recruitment

The initial step was to recruit people living with a diagnosis of dementia. This was done through the Memory Assessment and Support Service Clinic¹, using purposive sampling. Within the literature it is acknowledged that recruiting people with dementia and their families to research projects is challenging, often impacting on the quality of research involving people with dementia. Bartlett, Milne and Croucher (2019) suggest there are

¹ In line with the Model of Care for Dementia in Ireland (Begley et al 2023), Memory Assessment and Support Clinics offer people experiencing memory difficulties and their families, multi-disciplinary diagnostic, treatment and post diagnostic services. the clinics have an emphasis on integration within the community.

several reasons why people with dementia take part in research, including altruistic motives or access to health and social care practitioners, and that these may change over time. Alzheimer's Research UK (2020) argue that although a survey of the general public in the UK showed that 89% of those surveyed said they would like to take part in clinical research, there are particular challenges relating to the participation of people living with dementia in research. Firstly, the cognitive and functional impairments associated with a diagnosis of dementia. Secondly, a lack of awareness in both the general public/families and clinicians. The Alzheimer Society of Ireland "*Team Up for Dementia Research*" aims to provide people with dementia opportunities for engaging in research by connecting them with researchers conducting studies relating to dementia (Alzheimer Society of Ireland, 2025a).

In relation to my own study, recruitment was quite challenging in terms of accessing people with dementia. Staff and family members acted as gatekeepers, often meaning that the person with dementia did not even get the chance to say if they would like to participate. Whereas gatekeepers are important this warranted further reflection. In a study that set out to explore the perspectives of people living with dementia relating to autonomy, I wondered about paternalism and if potential participants had been given the opportunity to participate. Bartlett, Milne and Croucher (2019) identify the importance of knowing the gatekeepers, who aid the recruitment process and their barriers and motivations for assisting with the recruitment process. In relation to people with dementia this can be because they often need someone to support them to take part in the study and this can be seen as time consuming for the family member or friend, who often have other obligations. Additionally, some people with a diagnosis of dementia do not want to acknowledge it or be reminded of it, therefore it was decided not to post out a blanket invitation to all individuals known to the clinic (Bartlett, Milne and Croucher, 2019). For clinicians and gatekeepers, there can be uncertainty as to what they are being asked to do, the research may not be a priority for them, they may not be sure as to the benefits of the study and they may find recruitment difficult in the busy clinical environment. Therefore, with cognisance of the study environment, careful planning and detailing of the recruitment process was necessary to maximise success.

The successful recruitment of participants to research involving people with dementia involves flexibility, adaptation and the use of innovative approaches (Tam *et al.*, 2021). Bartlett, Milne and Croucher (2019) argue that recruitment processes need to be personalised and tailored to the individual with dementia, and that nurse researchers need to be flexible

in their approach to maximise opportunities for people living with dementia to participate in studies. This flexibility needed to extend to the study setting to balance the needs of the study, with the needs of potential participants and gatekeepers. The initial plan had been to advertise the study using posters and leaflets. In the clinical area there were generic expressions of interest forms and participation information leaflets. The clinician could inform the potential participant that a study was underway and if interested they could give the participation leaflet. The expression of interest form would be completed (by attaching the patient sticker) and I would then contact the participants with further information. This did not yield many recruits, mainly due to the issues detailed above. After a period of time, I went back to the gatekeepers and discussed what potential issues could be interfering with successful recruitment. They identified, firstly, not being sure what to say and the challenges of discussing the study during the consultation, which is often subject to time pressures. Secondly, the staff within the clinical setting had many challenges including high staff turnover, redeployment and COVID 19. Yet despite this they were still eager to help with the study recruitment.

To address the first issue, I engaged with the gatekeepers to try to understand the difficulty. A key challenge for me had been explaining to gatekeepers in a succinct way, how they can explain the study to potential participants. There seemed to be a general lack of awareness relating to what autonomy is and how it could be explained to people with dementia and their families. This was an important learning point for me as if autonomy was such a difficult concept to articulate and explain, how then can it be promoted and maintained in clinical practice? There is much discussion within the literature, from advocacy groups and within best practice documents about the importance of promoting and maintaining autonomy after a diagnosis of dementia (Government of Ireland, 2014; Alzheimer Society of Ireland, 2016). Yet there seems to be a lack of general consensus as to what it means and subsequently a disconnect with what autonomy means in practical terms in everyday life (Smebye, Kirkevold and Engedal, 2015; Wolfe *et al.*, 2021). To try to address the difficulties gatekeepers had in understanding the study, I devised expression of interest sheets for staff with scripted wording to help them give information to people living with dementia and their families relating to the study and their possible participation. This was kept as high level as possible, and I could then contact interested parties and give more details on the study. Again, success was very limited, but the issue had changed from difficulty explaining the study to time limitations in the busy clinical setting.

Lech *et al.* (2021) in their paper discussing recruitment strategies, barriers and facilitators for recruiting general practitioners and people with dementia for their study, suggest several strategies, used flexibly can be the key to success. They indicate that involving gatekeepers in the research early in the process, good communication and adapting to the study environment are essential. Given that it was difficult to give details about the study within the busy clinical environment it was decided with the team that, in the first instance they would identify any potential participants. Secondly, a named gatekeeper would contact potential participants later by phone and ask if they would be interested in the project. This could be done at less busy clinic times and was more doable for the gatekeepers. Thirdly, with the potential participant's permission, I would then call them with further information. This process was successful in recruiting the 26 participants for the study.

Communication skills and expertise in communicating with people with dementia are essential to the success of recruitment (Lech *et al.*, 2021). Within the study, there was a need to build rapport and ensure that I was giving potential participants enough information, in a way they could understand and in their preferred communication method. If the participant showed interest in taking part in the study, an information pack, including easy read participant information leaflet, consent form and "Knowing Me Document" (Appendices 8,4,3) was sent to them to allow them time to peruse the documents, seek assistance or ask questions if needed. There was also time at the beginning of each interview, where the person with dementia was given the opportunity to seek clarification and ask questions if needed. Every effort was made to ensure that the person with dementia was given every opportunity to give informed consent to participation and this included providing accessible information, in a timely manner and providing opportunities for clarification and questions (Health Service Executive, 2024b). The participant documents were co-developed and reviewed by the Dementia Research Advisory Team, Person and Public Involvement (DRAT PPI) group to promote accessibility and relevance. This was an extremely important process and the insights of the DRAT PPI group in terms of use of language and ensuring inclusivity were invaluable. The issue of consent is examined in greater detail in the following paragraphs.

3.4.1 Participant Profile

Twenty-Six people living with dementia were recruited for this study consisting of thirteen women and thirteen men. The date since dementia diagnosis ranged from six months to four

years. The age range of participants was from sixty-two years to eighty-one. Seven participants lived alone (with good family supports). The remaining participants lived with either their spouse (eighteen, with support from adult children) or an adult child (one with support from other adult children) (Appendix 9).

3.5 Ethical Considerations

Ethics approval for this study was granted by the local Hospital Research Ethics Committee and approved by Dublin City University Research Ethics Committee (Appendix 1).

The Dementia Enquirers Gold Standards for Ethical Research DEEP/Dementia Enquirers/Innovations in Dementia (2023, p. 6) set out six standards along with a useful checklist to ensure thoughtful consideration of the ethical issues related to involving people with dementia in research.

Table 1: *Dementia Enquirers Gold Standards for Ethical Research*

Standard	Action
Working in real partnership (co-production)	This research study was informed by a Dementia Research Advisory Team (DRAT, PPI), who were involved in the design of the participant leaflets, interview schedule and techniques and as “critical friends” throughout the data collection and analysis process (see Chapter Four)
Respect and acknowledgement	The DRAT PPI team ensured that all language used was person-centred, personal bias and assumptions were challenged, and a flexible approach was used to ensure meaningful involvement for both participants and the DRAT PPI team.
Safety and wellbeing	Safety and ensuring wellbeing is discussed later in this chapter and also the section on interview techniques. Although measures were devised to avoid participant distress it

	was important to balance the potential risk of upset with the wish of the participant to take part in the research study.
Informed consent and capacity	Please see in the section below regarding the consent process
Confidentiality and anonymity	Confidentiality was assured and all data was anonymised. All legislative and best practice guidelines were adhered to in relation to data processing.
Information that is simple, accessible and open	All participant documents were co-designed and reviewed by the DRAT PPI team, to ensure clarity, accessibility and use of person-centred language. Additionally, information was presented in a variety of formats including words, pictures and verbally.

3.5.1 Addressing Issues of Capacity and Consent

In accordance with the *HSE Consent Policy* relating to healthcare research (Health Service Executive, 2024a), *HSE National Policy for Consent in Healthcare and Social Care Research* (Health Service Executive, 2024b) and the *Assisted Decision Making (Capacity) Act* (Government of Ireland, 2015), capacity to consent is presumed unless proven otherwise and should be ascertained using a functional approach. This involved assessing that:

- The participant understands in broad terms and believes the reasons for and nature of the decision to be made.
- The participant has sufficient understanding of the principal benefits and risks of an intervention and relevant alternative options after these have been explained to them in a manner and in a language appropriate to their individual level of cognitive functioning.
- The participant understands the relevance of the decision, appreciates the advantages and disadvantages in relation to the choices open to them and is able to retain this knowledge long enough to make a voluntary choice.

- The participant communicates their decision in their preferred form of communication, whether verbal, writing, signs, pictures or assistive technologies.

In terms of proxy consent, the consent in health and social care research document clearly states that no other person can give consent or refusal to participate in research. However, it is also stated that it is essential for the researcher to identify the previous will and preference of the person with dementia and that they should not be excluded from participation, purely on their capacity to consent (Health Service Executive, 2024b). To ascertain the person's willingness or refusal to participate, on an ongoing basis throughout the encounter it was essential that I understand how the individual person with dementia communicates and continually monitor the person for signs that they may wish to discontinue participation. Additionally, it was important that the person's opportunity to participate was based on their ability to understand the aims of the study and what was being asked of them, rather than a cognitive score which can be an inaccurate predictor of ability to consent or assent to participate in research (Dewing, 2007; Alzheimer Europe, 2020; Health Service Executive, 2024b). Therefore, a Process Consent Model, devised by (Dewing, 2007, 2008b) was used. This model is often used in research involving people living with dementia and consists of several steps (Haraldsdottir, Lloyd and Dewing, 2019; Samsi and Manthorpe, 2020; Diaz-Gil *et al.*, 2023; Pyer and Ward, 2024). In this study I used a modified version adapted by Samsi and Manthorpe (2020). This involved a four-step process:

1. Preparation and Background: To assist the participant in making their decision to consent/or not consent, information about the study was provided in an easy read format two weeks prior to the interview to allow them to peruse the documents, with the assistance of family or friends if they wished. Additionally, a short questionnaire asking about the person's biography, indicators of wellbeing and illbeing and establishing usual ways of expressing assent and signs of wellbeing and illbeing ("Knowing me") was sent to assist me in interpreting non-verbal cues. This also helped to highlight any sensory issues the person might have. Permission was sought from the person living with dementia prior to the completion of the knowing me document.
2. Initial Consent: This involved using a variety of verbal, written and visual information to enhance understanding of what the person was being asked to do. Information was provided in the preferred format of the participant (written/pictorial/verbal), and the participant was asked to relay back their own

understanding of the aim of the study and what they were being asked to do (Samsi and Manthorpe, 2013). The principles of assent and dissent do not demand the same levels of understanding as informed consent but maintain respect for the person living with dementia's autonomy, voluntariness and enables them to be involved in line with their values, wishes and preferences (Black *et al.*, 2010; Gove *et al.*, 2018; Samsi and Manthorpe, 2020). The principles of assent and dissent require that the researcher pay close attention to the behavioural and non-verbal cues that might signify assent (wish to continue) or dissent (wish to stop) throughout the research process. I have extensive experience in communicating (including recognising non-verbal cues) with people living with dementia and their families in clinical, domiciliary and research settings. Additionally, extensive field notes were maintained, detailing methods used for gaining consent and decisions made.

3. Ongoing Consent: This involved monitoring for well-being and ill-being and revisiting consent as required throughout the interview.
4. Feedback and Support: This involved providing feedback to the participants/family/carers (with permission of and respecting the confidentiality of the participant). I also indicated that should any safeguarding issues arise, these would be reported to the relevant authorities.

3.5.2 In Relation to Informed Explicit Consent

Under Irish and European Union legislation, all researchers must be cognisant of giving consideration to explicit consent and the possible need for a consent declaration where participants are unable to consent to the use of their data (Government of Ireland, 2021; Health Research Data Protection Network, 2022; Health Service Executive, 2024b). After consultation with the Health Research Consent Declaration Committee (Health Research Consent Declaration Committee, 2025), they directed me to the Data Protection Officer in the University who would help me decide if a consent declaration was required. The Data Protection Officer advised that there was no need for a consent declaration, as all participants would be able to give informed explicit consent. I also linked with other researchers in similar fields of research to discuss issues of informed and explicit consent to ensure I was adhering to best practice and legislative requirements. However, the responsibility for ensuring explicit consent for data processing was with the researcher. As such, I addressed the issue of explicit consent in several ways after consultation with the Health Research Consent Declaration Committee and the University Data Protection Officer.

Firstly, to ensure that prospective participants could give informed explicit consent for data processing, I presented the information in a variety of ways including verbal, written and pictures, giving enough time to peruse the documents and ask questions if needed. Secondly, with the guidance of the Data Protection Officer in the University I ensured that both the participant information leaflet and the consent form detailed how the participant's information was to be processed and stored. I then went over this information again with the participant prior to the interview and asked them to summarise what they understood in their own way. Consent was documented and where the participant had difficulty with writing, there was also a verbal record of consent prior to the interview.

3.5.3 Safeguarding Participants Living with Dementia in Research

To ensure the wellbeing of the participant, including that a trusted friend or family member could stay with them during the interview or in an adjacent room, according to their wishes. In accordance with national policy and procedures relating to *Safeguarding Vulnerable Persons at Risk of Abuse Policy and Procedures* (Health Service Executive, 2014), I was aware that if I had any concerns regarding the safeguarding of participants, I had responsibilities under HSE procedures and policies, that included:

- Ensuring the immediate safety of the participant and informing the relevant authorities and Safeguarding and Protection team.
- Contacting An Garda Siochana as appropriate.
- Ensuring referral to Tusla where a child is identified as being at risk of harm.
- Outlining in writing all relevant information.

Additionally, I provided contact details of support organisations should the person living with dementia or their caregivers require them (Appendix 12).

3.5.4 Safeguarding in the Aftermath of COVID 19

Interviewing commenced in April 2022 as such provision needed to be made to ensure that a protocol for COVID 19 safeguards for participants was developed. With this in mind, all standard precautions, including hand hygiene and mask wearing were adopted where applicable. I also conducted a wellbeing call prior to the interview to inquire if participants

or other people living in the house had any COVID 19 symptoms. Additionally minimal equipment was brought into the house and cleaned afterwards.

3.6 Data Collection

Glaser (1998) argues that any type of data can be used in grounded theory and that the emphasis should be not on what data is collected but rather its relevance for the study. In this study, data consisted of twenty-six face to face interviews, field notes, memos and six autobiographies. Interview data were obtained through semi structured interviews with people living with dementia. Each interview lasted between 40-85 minutes, which would be in line with length of interview identified in the literature regarding grounded theory studies (Foley and Timonen, 2015).

3.6.1 Interviews

Considering the chosen study methodology and aims of the study, the most appropriate method for data collection was deemed to be semi-structured, face-to-face interviews. Face-to-face interviews allowed me to not only hear what participants had to say but also note non-verbal behaviours which can provide valuable data (Dunwoodie, Macaulay and Newman, 2023). This is especially important when conversing with people living with dementia. Each of the interviews was audio-taped and transcribed (fully initially, then as detailed notes) to ensure accuracy of data collection. This is discussed in greater detail later in this chapter. Permission was sought from participants to audiotape the interviews.

McGrath, Palmgren and Liljedahl (2019) suggest that there are a number of elements in the interview process, including developing the interview schedule, conducting the interview and developing rapport, data analysis and ethical considerations. Development of the interview guide (Appendix 5) is an essential element of the interview process and should reflect the aims and objectives of the proposed study (Alamri, 2019). In consultation with the DRAT PPI team, cognisance was given to wording, sequencing and types of questions and use of “probes”. Although there are disadvantages to interviewing, such as being labour intensive (Alamri, 2019), they were deemed to me the most appropriate data collection method in fulfilling the aim of this study. Field notes and memos also formed an element of data collection (Glaser, 1998) and were used for analysis.

3.6.2 A Flexible Approach to Interviewing

To promote meaningful engagement of people living with dementia in the interview process, planning is essential (Samsi and Manthorpe, 2020). The development of easy read participant information, consent processes and safeguarding have already been addressed in the previous section of this chapter. I arranged the interviews at a time that most suited the person to ensure they were able to participate fully. Additionally, I tried to reduce disruptions during the interview by choosing a quiet spot where the person was comfortable, ensuring I had all equipment with me and that the person had everything they needed. Time was given at the beginning of each interview for some general chit chat and also to peruse the consent form and participant leaflet, answer any questions and ensure the person understood what was being asked of them.

A vital element of CGT is an openness to discovery and for me this extends to engaging with the people who will be contributors to and participating in the research study. Remaining open affords the opportunity to enter into the person's world and meet them where they are at, with no preconceived ideas about what will come from the encounter. This was particularly important to me as I was aware that people living with dementia are often vulnerable to the preconceived ideas and biases of others. To this end I sought the help of the DRAT PPI team, who from the perspective of their lived experience advised how to best approach the interviews.

Person-centred, conversational style interview techniques adapted to individual participants, helped me build rapport and trust with the people living with dementia and their supporters. This allowed them to relate their perspectives and experiences in their own way and in their own time. There was no set structure and flexibility was key to connecting with the person where they were at that moment. For example, when participants found it difficult to tell me about their experiences, to help them feel more comfortable we would engage in an activity or topic that they enjoyed, such as knitting, singing, looking at books or looking at photos. It was when we were engaged in these activities that participants became animated, telling me about their past, their future and their concerns. They became more confident and assertive in the conversation and were able to be themselves, rather than a person who is often "unseen" due to a focus on their diagnosis of dementia. This resulted in an empowering experience for both the person and myself. Additionally, I summarised points participants made during the interview to ensure I had interpreted what they said correctly.

Taking part in conversation was more challenging where participants had difficulty communicating verbally. I used communication aids, when necessary, such as pictures to allow participants to communicate when they needed a bit more time, needed help to find a word, or wanted to stop. Additionally, a “knowing me” document was sent out to participants prior to meeting them and included questions, regarding preferred name, family, friends, pets and communication preferences. This, when completed, aided awareness of non-verbal cues of assent and dissent as well as helping me understand topics that could aid building a rapport with the person. However, it was rarely used as participants were able to verbalise their wishes to me. When this document was not completed, we would have a brief conversation at the beginning to ensure I was aware of any sensory or communication difficulties. I also made sure to carry a hearing amplifier with me in case it was needed and ensure the environment was free from distracting noises.

As stated, words are just one way in which people communicate and it was important for me to create an environment in which we could both feel relaxed and simply enjoy being together. Being present in the conversation and not rushing or transferring anxiety was very important to me. It is also essential in conversations with people living with dementia, who can be very responsive to the anxiety of others (Sabat 2018). As a novice researcher, I was anxious to do justice to the participants and in essence do a good job. I was aware of this anxiety and also that I was often rushing from a busy clinical environment to conduct the interview. Therefore, to counter this I would perform a centring, breathing exercise prior to going into the participant’s residence and this allowed me to be present and relaxed in the conversation. This helped me to “*take an intentional stance*” (Sabat, 2018, p. 94) during the interview. An intentional stance recognises that the person living with dementia has something to communicate, verbally or nonverbally, even if that something is unclear at first. From this stance, I used “*indirect repair*” (Sabat 2018, p. 96) to clarify or summarise points to ensure I had not mistaken what the person was trying to communicate to me.

Samsi and Manthorpe (2020) argue that the researcher’s duty to the participant does not only exist during the interview. They posit that consideration needs to be given to remaining vigilant for non-verbal cues that could signify that the person is distressed. Given my extensive experience over many years supporting people living with dementia and the intentional stance discussed above, I was watchful for signs of distress. Additionally, the

person was offered assistance if required and farewells were managed sensitively. Moreover, reassurances of confidentiality were kept and transcripts anonymised as soon as possible in accordance with ethical and best practice guidelines (Samsi and Manthorpe, 2020). Throughout the process there was cognisance of ethical and legislative requirements.

3.6.3 Inclusion of Loved Ones in the Conversations

On occasions, the participant would request or allow their loved one to remain with them throughout the encounter. At times this posed a challenge in ensuring that the person with dementia was the main participant and not overshadowed by the person accompanying them. However, on occasions their insights would add depth to the encounters with the person living with dementia. Their involvement in the conversation was negotiated with the person with dementia and their loved one prior to the interview. If loved ones were present they signed the written consent form after receiving information about the study and being given time to ask any questions. This was accounted for in the ethical application and inclusion criteria of the study and where they made comments this was included in the data analysis.

3.6.4 Developing an Interview Schedule

In grounded theory, the initial question was a broad, open ended one relating to the substantive area (Charmaz, 2014) (Appendix 5). In developing the broad question, I did so in collaboration with the DRAT PPI team. Additionally, the DRAT PPI team aided me in developing a conversational style approach in interview technique. This process was invaluable as they were able to identify some assumptions that could be drawn from some of the questions, and therefore the language needed to be changed.

In addition to the broad question, I also used probing questions to explore further a topic brought up by the participant (Foley and Timonen, 2015). I used summary questions, when I needed clarification and summarised the conversation briefly at the end of the interview. Even when the process of theoretical sampling had commenced and I was refining categories, I continued to use an initial broad question and then followed up with more focused questions, careful not to be leading but with a clear focus in refining and elaborating my categories.

3.6.5 Audio Taping and Transcribing

Each encounter was recorded verbatim. Although this method is often seen as inherent in good quality qualitative research, adding to the robustness and validity to the study, this

would not have been the opinion of the founders of grounded theory (Covan, 2007; Rutakumwa *et al.*, 2020). I had recorded the encounters verbatim as I was worried, as a novice researcher, about missing some key piece of information. Rutakumwa *et al.* (2020) in their comparative review of conducting in-depth interviews with and without audio-recording found that the level of detail in recording and detailed interview scripts was comparable. Glaser (1998) suggests that researchers should not “*waste the time and money taping interviews...*”. He indicates that it delays theoretical sampling and shows a lack of confidence in the researcher. Instead, he advocates developing the skill of keeping detailed field notes for analysis and immediate memo writing.

In contrast, Charmaz (2014) argues that coding depends on having solid data and that this cannot be assumed when interviews are not audio taped and transcribed verbatim. She also states that the process of transcribing data verbatim is beneficial to coding, giving the researcher a deeper level of understanding and affording the opportunity to recode old data (Charmaz, 2014). Although I kept detailed field notes after each interview, I also recorded my interviews, perhaps due to the lack of confidence that Glaser (1998) mentions. Full verbatim transcription took place in the initial twelve interviews, then detailed recording notes related to new or emerging codes, concepts and categories were kept. The process of constant comparative analysis and theoretical sampling delimited the data as the study progressed, and the core category was identified. Therefore, although continuing to remain open I felt it was unnecessary to transcribe verbatim the later interviews, as the purpose was to identify variations and saturate the codes and categories.

3.6.6 Field Notes

As stated, Glaser (1998) advocated keeping detailed field notes of each encounter with participants. Covan (2007) describes three types of field notes. Firstly, descriptive (general observations), secondly methodological (relating to methods/future methods) and finally theoretical (relating to emerging theoretical ideas). Field notes were extremely important in this study as it allowed me to record my observations, non-verbal language of participants and interactions in the participant/caregiver dyad. They also provided a forum for recording emerging ideas and identify where I felt I needed to explore in further interviews. The field notes also offered me a learning opportunity to reflect on my interview technique and hone my note taking skills.

3.6.7 Use of Autobiographies

Participant interviews were not the only data source in this study. I also read and analysed six published autobiographies written by people living with dementia. These autobiographies were particularly helpful in terms of theoretical sampling (see theoretical sampling, p. 52) for variation and refinement of emergent categories. The published autobiographies were chosen during theoretical sampling with reference to their relevance in adding variation and depth to the development and saturation of the core category and sub-core categories. They provided longitudinal, first-person accounts of young onset dementia and various sub types of dementia. Additionally, the telling of their perspectives was not in any way constrained by my questioning. Furthermore, given that the autobiographies were written over a period of time it allowed me to identify patterns of action over time as dementia progresses. This longitudinal exploration across many years of living with dementia, was especially possible in reading Christine Bryden's autobiographies, spanning from 2005-2018 (Bryden 2005, 2012, 2018). This would not have been possible within the scope of the semi-structured interviews.

I had initially been hesitant to use autobiographies as I wanted to ensure I was staying true to the methodology. Additionally, there was limited guidance on the method of using autobiographies in grounded theory (Ravenek, 2017). Glaser and Strauss (1967, p. 253) argue that there is no reason why autobiographies cannot be used to generate theory, stating, in relation to gaining insights from interviewees, that "*If we can do this with an interviewee or an informant, why not with the author of an autobiography...*". The autobiographies were analysed using the same process as the interviews. Essentially, I analysed them as if they were a large transcript.

3.6.8 Autobiographies Analysed

Bryden, C (2005) *Dancing with Dementia: My story of living positively with dementia* (Bryden, 2005).

Bryden, C (2012) *Who will I be when I die?* (Bryden, 2012).

Bryden, C. (2018) *Will I still be me? Finding a continued sense of self in the lived experience of dementia* (Bryden, 2018).

Michell, W. (2019) *Somebody I used to know* (Mitchell, 2019).

Quaid, K. (2021) *I am KEVIN! Not LEWY* (Quaid, 2021).

Smith, R. (2021) *If memory serves me wrong: A memoir of theatre, love and loss to early onset Alzheimer's* (Smith, 2021).

3.7 Data Analysis

3.7.1 Constant Comparative Analysis

Glaser and Strauss (1967, p. 103) state that as the analysis processes in grounded theory are still reliant on the “*skills and sensitivities*” of the researcher. The aim of constant comparative analysis is not to guarantee that other independent researchers would reach the same conclusions if analysing the same data but to allow some flexibility in theory generation (Glaser and Strauss, 1967). Grounded theory is based on the systematic generation of theory from data, through a process of constant comparative analysis. Glaser and Strauss (1967, p. 105) describe four stages of the constant comparative method. Firstly, comparing incidents applicable to each category. Secondly, integrating properties and their categories. Thirdly, delimiting the theory. Fourthly, writing the theory. This is not a linear process and whilst moving to the next stage the previous stage/s can still be operational and relevant to subsequent stages until the analysis is complete.

3.7.2 Comparing Incidents Applicable to Each Category

Glaser and Strauss (1967, page 106) state that the defining rule for the constant comparative method is “*while coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category.*” During constant comparative analysis I kept an evolving set of mind maps that I recorded on notebooks but also on a large whiteboard. I also used the Outline function in Microsoft Word to help me organise emerging codes and categories. Having a visual representation of incidents, codes and categories helped me to not only organise data but also see patterns, variations, and identify possible avenues for further exploration through theoretical sampling.

Glaser and Strauss (1967, p. 107) state that as categories and properties of categories emerge, these will form two groups, those constructed by the researcher and those “*abstracted from the language of the research situation*”. They suggest that the first relates to an explanation by the researcher of the second abstracted from the data which relates to a behaviour or action. Having completed a number of iterations of this process of comparison it is then time to stop coding and write emerging ideas (Glaser and Strauss, 1967).

3.7.3 Memo Writing

Another pivotal element of the constant comparative method is memo writing. There are no specific definitions as to what memos involve (Gibson and Hartman, 2014). However Glaser (1978, p. 83) offers this useful statement: *“The core stage in the process of generating theory, the bedrock of theory generation, its true product is the writing of theoretical memos. If the analyst skips this stage by going directly to sorting or to writing- he is not doing grounded theory. Memos are the theorising write-up of ideas about codes and their relationships as they strike the analyst while coding. Memos lead, naturally to abstraction or ideation. Memoing is a constant process that begins when first coding data, and continues through reading memos or literature, sorting and writing papers or monographs to the very end. Memo-writing continually captures the ‘frontier of the analysts thinking’ as he goes through either his data, codes, sorts or writes”*. This process proved invaluable in assessing the relevance of incidents, codes and categories. As theoretical notions regarding things such as incidents, codes, patterns and categories emerge it is then time to *“stop coding and record a memo on your ideas”* (Glaser and Strauss 1967, p. 107). According to Glaser and Strauss (1967, p. 107), this rule regarding memo writing is designed to *“tap into the initial freshness of the analyst’s theoretical notions and to relieve the conflict in his thoughts. In doing so, the analyst should take as much time as necessary to reflect and carry his thinking to its most logical (grounded in the data, not speculative) conclusion”*. This guidance against speculation helped me to keep memo writing within the realms of the data (see logical versus conceptual deduction discussed in theoretical sampling).

Glaser and Strauss (1967) also describe discussions amongst teams associated with the research as being useful in clarifying ideas. This is relevant in this study as “theoretical notions” were discussed in supervision sessions allowing greater clarity as well as generating further theoretical ideas. Theoretical ideas were also discussed with the DRAT PPI team in their role as “critical friends” and again this helped to clarify as well as generate further ideas. However, in these instances, I was careful to ensure that any theoretical ideas generated were memoed and grounded in the data, thus ensuring that as Glaser and Strauss (1967) had warned, any “*theoretical notions*” that had the potential to inform theory development were grounded in the data and not speculative.

Many hundreds of memos were written throughout this study and were split into methodological memos (about the method), theoretical memos (about the emerging codes,

concepts and theory) and reflective memos (reflections on completing the study). The memos varied in length and theoretical memos became more conceptual over time, aiding theoretical sampling and theoretical coding (Bryant and Charmaz, 2007). A central tenet of memo writing is that it is immediate (Glaser, 1998). As I was analysing data from the study, or even engaged in another activity altogether, I would immediately stop as an idea, possible code or category presented itself and memo. Some memos would cease to be important as the study progressed, and others would be elaborated upon and become more focused. See Appendix 11 for examples of memos.

3.7.4 Codes as the “Building Blocks of Theory”

Coding, according to Glaser (1978, page 55) *“gets the analyst off the empirical level by fracturing the data, then conceptually grouping it into codes that then become the theory that explains what is happening in the data”*. In essence the conceptual code is the relationship between the data and the theory (Glaser, 1978). Following on, by *“developing the hypothetical relationships between conceptual codes (categories and their properties) which have been generated from the data as indicators, we “discover” a grounded theory”* (Glaser, 1978 p. 55). However, again it was important to memo ideas, codes and possible relationships to see if they ultimately “earn” a place in the theory. Memo writing within the limits of the data also helped me stay within the realms of the data and not become vulnerable to the lure of preconceived ideas or extant theory (Glaser, 1978). It also helps the analyst to *“transcend the empirical nature of the data”*, thus not becoming too descriptive and failing to conceptualise (Glaser, 1978 p. 55). Glaser (1978) states that there are essentially two types of codes, substantive and theoretical. Substantive codes conceptualise the empirical data in the substantive area of research and theoretical codes conceptualise possible relationships between the substantive codes and how they are then integrated as hypotheses into the theory (Glaser, 1978).

3.7.5 Open Coding

Open coding involves the line-by-line coding of the data gathered. The main aim of this phase is to find the core category. Using the transcribed interviews, field notes and memos line by line coding identifies what is happening in each meaningful unit of data and summarises it in one or two words. If the incident occurred again, I would then stop and revert back and then compare the two incidents and stop and write a memo. There may also

be broader codes that might relate to larger pieces of text, again Glaser (1978) advises to note and memo how the line-by-line codes relate to this.

Glaser (1998, p. 140) suggests three main coding questions:

1. What category does this incident indicate?
2. What property of a category does this incident indicate?
3. What is the main concern of the participants?

Initially much of the analysis was descriptive, in that I was merely identifying and labelling units of data (line by line coding), identifying patterns of behaviour from the data (See Fig.1, page 52). Although the aim of CGT is to be conceptual rather than descriptive, this can take many iterations of the process and remaining close to the data, often means that the initial analysis was quite descriptive, remaining true to the participants' own words. Time must be given to this process to try to avoid falling into the trap of what Glaser (1998) would refer to as "forcing the data" and in effect forcing the data to fit the preconceived ideas of the researcher or extant theory.

Indeed, one of the key challenges I faced at this stage was not to "force" preconceived ideas on the data. Also, as I completed more interviews, I had to guard against simply reverting to the labels or codes that I identified in previous interviews. Furthermore, in an effort to conceptualise it was easy to fall into the trap of assigning labels and codes to units of data without truly reflecting what the participant was saying. This was discussed during supervision and upon reflection what the participant actually said and how they phrased it, was so much more powerful and relevant in terms of remaining grounded in the data. The use of in vivo coding helped with this process. For example, several participants used the phrase "*getting on with it*". I had thought about resilience or coping as possible codes to reflect this but upon consideration "*getting on with it*" was much more powerful in explaining what people actually did. It therefore became the code.

Another issue I found was that I needed to keep reminding myself to not move away from what the participants were saying as I tended to overthink initially and then latch onto something, again "forcing" the data, rather than being patient as Glaser has advised (Glaser, 1998). Simmons and Gynnild (2024) suggest that many novices to classic grounded theory struggle with trusting the grounded theory method but counsels that with losing the fear, patience and strictly abiding by the method the process will bear fruit in the emergence of a

grounded theory. This phase ends when the process of coding results in the discovery of the core problem and capturing it in a core category. The core category must be central and related to as many different categories as possible.

3.7.6 Developing the Core Category

The main objective of open coding is to identify a core category (Gibson and Hartman 2014). The core category signifies how participants resolve or process their main concern in the substantive area. A key challenge was to identify when to stop open coding. I was aware that to prematurely decide upon a core category could result in a weak theory that does not adequately fit or is workable within the substantive area. There were several occasions when I felt I had identified the core category. However, when I further analysed the data, wrote memos and discussed in supervision, it was apparent that although the categories identified were important to the participants it was not their main concern (although related to it). Throughout this process, I tried out several potential core categories that although went some way to explaining the main concern of the participants, did not fully account for or relate to other categories, in essence they did not pattern out. For example, “being me”, although seeming to have earned the place as core category, upon further analysis did not adequately account for what was truly important and meaningful for participants. Finally, *Holding on to Me* was identified as a core category.

3.7.7 Selective Coding

Glaser (1978, p. 61) states that to “*selectively code for a core variable, then, means that the analyst delimits his coding to only those variables that relate to the core variable in sufficiently significant ways to be used in a parsimonious theory. Further analysis is “guided by the core variable”* (Glaser 1978, p. 61). Therefore, the researcher is significantly delimiting coding of additional data (through theoretical sampling) to the core category and those related to the core category (Holton, 2007, 2010). To achieve this my memo writing became more focused to identify areas for further theoretical sampling.

Grounded theory, according to Glaser (1978, p. 62) is based on a concept-indicator model, by which a link is formed between empirical data and the concepts.

“From the comparison of indicator to indicator the analyst is forced into confronting similarities, differences and degrees of consistency of meaning between the indicators which generates an underlying uniformity which in turn results in a coded category and the

beginning of properties of it. From the comparisons of further indicators to the conceptual codes, the code is sharpened to achieve its best fit, while further properties are generated until the code is verified and saturated.” (Glaser 1978, p. 62).

This ensures that concepts have ‘earned’ their way into the data and the subsequent theory and that in turn this is grounded within the empirical data (Glaser 1978). Glaser (1978) cautions analysts, particularly novice ones to be patient with the processes of grounded theory. It was too easy for me, in my haste, to assign indicators to potential concepts, or developing potential concepts without adequate verification or saturation. This resulted in my having to go back to the data again and either ensuring the concepts had ‘earned’ their place or in some cases discarding them as they did not pattern out and were more based on what I thought was happening rather than grounded in empirical data.

So, concepts in grounded theory are derived from the comparison of multiple incidents. For example, one concept that emerged in this study was “truth telling”. Several incidents described by participants contributed to this concept, which was then assigned a code. From there I selectively coded and theoretically sampled additional data, either from new or previously collected sources, to determine whether “truth telling” would continue to emerge as a recurring concept.

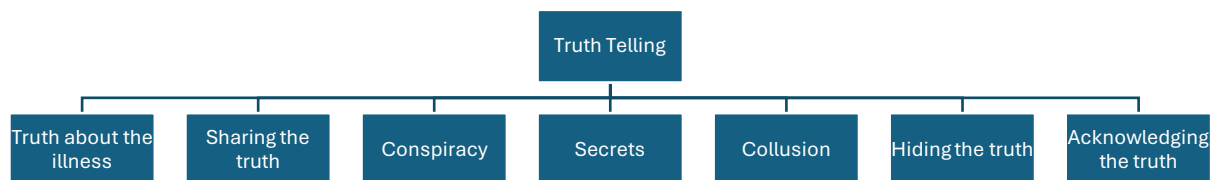


Figure 1: Truth Telling Concept

So as can be seen, the concept of truth telling had many different incidents assigned to it, and, as stated above, through a process of selective coding and theoretical sampling could then be decided whether or not the concept had earned relevance in terms of the emerging theory.

3.7.8 Theoretical Sampling

As already stated, initial sampling in this study uses purposive sampling. As the codes and categories began to emerge, theoretical sampling was used to detail as many variations, look for patterns and add richness to the data.

According to Glaser (1978, p. 36) *“Theoretical Sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges. The process of data collection is controlled by the emerging data, whether substantive or formal.”* It is a pivotal process in grounded theory and allows the researcher to delimit and focus the collection and analysis of data, thus reducing the risk of becoming overwhelmed by the data or collecting the same data over and over again. It is essential to the moving forward of the research process and not only is directed by the emerging theory but also directs where to look next for the development and elaboration of categories, connections with other codes, variations and properties. To saturate codes, categories and identify patterns and variations there are a number of comparisons to be made. Firstly, the researcher compares incident to incident to establish uniformity and variety. Secondly, she compares concepts to other incidents, thirdly she compares concepts to concepts (Glaser, 1978).

Theoretical sampling involves both inductive and deductive processes. CGT is primarily inductive in that the theory emerges or is induced once data collection commences. Yet deduction is required to decide where to go next to further develop the theory from the data collection and analysis. So for Glaser (1978, p. 38) *“deduction is in the service of induction and the source of derivations are the codes generated from comparing the data, not deductions from pre-existing theories in the extant literature.”* In this way, according to Glaser inductive-deductive interplay differs from those of other research methodologies. Another matter for consideration was when I should begin theoretical sampling. I was conscious that theoretical sampling should not begin too soon as to be too narrow in terms of generating theory and identifying the main concern, or too late as to overwhelm myself with too much data that does not add to the emerging theory. After the first five interviews, I began to focus my interview schedule to better elaborate and add dimension to the emerging categories, looking for variation and whether emergent concepts would stick. This proved very useful in seeing if something that I thought was

emerging/important to the participants actually was. I also continued to use my broad question, used throughout the interviews, allowing participants an opportunity to say what they wanted to say and possibly identify new codes. Whilst exploring any new emerging codes, I also focused on other codes and categories emerging from existing data. This allowed me to delimit my data but also remain open to the possibility of new concerns emerging, particularly in the earlier stages of theoretical sampling.

The process of theoretical sampling not only directed subsequent interviews but also I went back to previous transcripts, field notes and memos and applied the same focused questions to identify incidents that aided in the further development of the categories (Glaser and Strauss, 1967). There were a number of codes and categories emerging from the data and I wanted to see if these would aid in the development of the theory by identifying variations and connections.

In grounded theory, this sometimes requires selecting a different sample group to test this (theoretical sampling). However this is not always possible, for example in this study the participants were people living with dementia and this would remain the population. In order to test hypotheses, develop categories and identify problems, I changed the interview schedule, so whereas my population remained the same, the focus of the conversation was a little different. I started with my initial broad question and then became more vigilant for certain topics and targeted questions to explore these issues.

Additionally, the analysis of autobiographies allowed for the exploration of emergent variations of codes and categories. Indeed, this was beneficial as within the autobiographies, the people living with dementia were often younger than the interview participants and were more involved in national advocacy groups. Furthermore, they had the benefit of time to think about what they wanted to say. Therefore, they offered a different variation to inform the emergent codes, categories and subsequently the theory.

Throughout this process I was cognisant of the need to remain open to whatever emerged from the data and ensure that I was not leading participants with questions. Moreover, I wanted to ensure that the categories, and therefore the subsequent theory was not vulnerable to my own assumptions and biases. This I tried to achieve through supervision, DRAT PPI meetings and memo writing. However, this is not an unusual concern and has also been highlighted by Glaser (1978) in his book "*Theoretical Sensitivity*". A key feature of

grounded theory is an openness to discovery, however this does not equate to an empty mind, when approaching the field of inquiry.

3.7.9 Conceptualisation

A central tenet of grounded theory is conceptualisation but it is something which both seasoned researchers and novices to grounded theory can struggle with (Glaser, 2002). Glaser (1998, p.197) highlights two key rules of conceptualisation. Firstly, think theory and write substance and secondly, relate concept to concept, rather than concept to people. Additionally, conceptualisation should contain the properties of being abstract of time, place and people. Moreover, there must be grab, in that the concepts and ultimately the theory should be interesting and understandable to the layperson and professional alike (Glaser 1998).

3.7.10 Conceptual Versus Logical Elaboration

Glaser (1978, p. 78) refers to deductive elaboration as conceptual elaboration, stating that it involves “*systematic deduction from the emerging data of the theoretical possibilities and probabilities for elaborating the theory as to explanations and interpretations*”. This helps to guard against forcing interpretations on the data as the data check deductions/interpretations that lead nowhere or do not fit with the data do not “earn” a place within the emerging theory. In contrast logical deduction according to Glaser (1978) can happen when the researcher is drawn toward “fitting” extant theory to the emerging data. Although initially grounded in data, this type of deductive process can result in the researcher deviating outside the boundaries of the data (Glaser, 1978). This was true of certain points of this project, when given my knowledge of dementia and care processes related to it, whilst memo writing I was drawn to elements of extant theory that could, I felt, fit or explain concepts and categories emerging from the data. Glaser speaks about limiting memo writing to within the realms of the data and once spotted, I was able to discard ideas that were arrived at deductively and not grounded in the data (Glaser 1998). Glaser (1978) also warns against racing ahead with conceptualisation until theoretical sampling has corrected for fit, workability and relevance. Again this was a process I struggled with on occasion, in terms of allowing the data to speak for itself and finding the balance between being too descriptive, where there was no conceptualisation at all, and too conceptual, to the point where it was vulnerable to not being grounded in the data at all. Memo writing, discussions with my supervisors and using in vivo codes helped me to address these issues.

3.7.11 Theoretical Saturation

Theoretical saturation refers to a point in the study, where categories are sufficiently conceptualised, scrutinised and scoped so that it is unlikely that collecting further data will aid the further development of the theory (Gibson and Hartman, 2014; Foley and Timonen, 2015). However, despite theoretical saturation being a goal of all grounded theory researchers (Dey, 2007) suggests that theoretical saturation may have to be claimed rather than proved as it may not be possible to be sure it has been achieved. Additionally, Glaser and Strauss (1967, p. 40) argue that there is always a chance that additional data or theories will emerge and that there is a “*never-ending process of generating theory*”.

3.7.11 Memo Sorting

According to Glaser and Holton (2004) once theoretical saturation has been achieved, the research proceeds to sort the myriad of memos that have captured the emergent ideas from the substantive and theoretical categories. Sorting helps to generate a framework for articulating a grounded theory and is essential in putting “*fractured data back together*” resulting in a rich, multivariate, and parsimonious theory (Glaser and Holton 2004, p. 18).

Sorting is an essential element of theoretical coding, yet within the literature, it is often ill defined (Gibson and Hartman, 2014). Glaser (1978) offers nine analytical rules for sorting in classic grounded theory. Glaser’s rules provide guidance on getting the process started, including sorting in relation to the core category, promotion and demotion of core variables, continued memo writing and awareness of when to stop sorting (Glaser 1978, 1998, 2005; Gibson and Hartman 2014). Gibson and Hartman (2014) recommend further consideration, when sorting for a PhD thesis be given to questions relating to implications for research, policy and practice as well as public understanding in the subject area. I initially started sorting using a large board and cut outs of printed and handwritten memos. I took frequent photos to mark changes I made as I sorted the memos (Appendix 13). I also continued memo writing as I sorted existing memos and this helped to clarify my thoughts. I liked the freedom of being able to move memos around, promoting some and demoting others and I added two other large cork boards to provide the space I needed to sort all the memos.

I was also initially concerned as I had many hundreds of memos, but having attended a Grounded Theory Troubleshooting seminar and discussing my concerns with my supervisors, I was able to combine some memos and start with the most recent as these

memos were more refined and focused. Despite Glaser's warning that the theory generated through adhering to the grounded theory process is only one theory (Glaser 1998), I found myself going down multiple rabbit holes whilst sorting my memos. Leading me away from the categories that had already emerged. Frequent memoing and supervision helped me to address this and remain on track.

3.7.12 Theoretical Coding

Glaser (1998) distinguishes between two types of codes. Firstly, substantive codes, which start to emerge in the open coding phase and relate directly to the empirical data within the substantive area (Kelle, 2007). Secondly theoretical codes are needed to conceptualise how *"the substantive codes will relate to each other as interrelated, multivariate hypotheses in accounting for resolving the main concern"* (Glaser, 1998, p. 163). He concedes that it is particularly hard to stay open to the *"earned relevance"* of theoretical codes (Glaser, 2005, p. 3). Glaser (2005 p.2) argues that *"Staying open to theoretical codes will help maintain the substantively conceptual level required by grounded theory and increase its power"*. He ascertains that whereas theoretical codes are not necessary, a grounded theory is more integrated, enhanced, relevant and plausible when theoretical codes have emerged (not forced or preconceived) in the developing theory (Glaser 1998).

Glaser (2005) acknowledges that this stage of the grounded theory process can be the hardest and urges the researcher to remain patient, open and comfortable with confusion. Hernandez (2009) agrees, stating that it is particularly challenging for novice grounded theorists. This certainly was the case in this study, when not only was I becoming impatient with the process, but also, as discussed in earlier stages of coding, I was anxious not to "force" the theoretical codes. Additionally, I found much of the guidance from the literature, particularly *"The Grounded Theory Perspective III: Theoretical Coding"* (Glaser, 2005) challenging at best. Attending a Grounded Theory Troubleshooting Workshop and having discussions with supervisors helped provide some clarity on the process (see appendix 6)²

Integral elements of the theoretical coding process are on-going sorting and memo writing (Gibson and Hartman, 2014). Glaser (1978, p. 72) states *"Theoretical codes conceptualise*

² Appendix 6 contains reference to my additional learning in grounded theory, particularly classic grounded theory. It also references additional learning in PPI and academic and research processes to advance my skills in these areas throughout my PhD.

how the substantive codes of a research may relate to each other as hypotheses to be integrated into a theory. They, like substantive codes are emergent. They weave the fractured story back together again. Without substantive codes they are empty abstractions.” So, although theoretical codes allow for a greater level of abstraction and conceptualisation it is essential that they remain grounded in the substantive data (Glaser, 2005). Hernandez (2009, p.56) also suggests a number of ways in which researchers can enhance their ability to “see” the emergence of theoretical codes including theoretical sensitivity, in vivo codes, sorting and memo writing and increasing awareness of theoretical coding families (Hernandez, 2009).

Hernandez (2009) states that substantive codes break down or fracture the data whereas theoretical codes, which can be either implicit or explicit, knit the story back together into an organised, multivariate theory. Glaser (1978, 1998, 2005) identifies a number of theoretical coding families, which he added to and refined over the years, and urges researchers to be theoretically sensitive to the emergence of theoretical codes. Theoretical codes are “*not mutually exclusive, they overlap considerably*” and in addition “one family can spawn another” (Glaser 1978, p. 73). It is also essential that the codes emerge and are not forced. Being theoretically sensitive is essential to the emergence of theoretical codes (Hernandez, 2009). To this end I endeavoured to become familiar with as many theoretical coding families as possible through extensive reading of Glaser’s seminal texts (Glaser 1978, 1998, 2005). This helped me to become more theoretically sensitive to the emergence of possible theoretical codes that could have earned relevance for this study. I worried about unconsciously “forcing” extant theory in terms of identifying emerging theoretical codes. Continued memoing and discussions with my supervisors assisted me in acknowledging my thinking in relation to any preconceived ideas and extant theory. Additionally, continued memo sorting and further memoing aided the emergence of the theoretical code (Glaser 1978, 1998, 2005). I began to try out different theoretical codes to analyse possible relationships between the different categories. I initially thought of the possibility of the Identity-Self or Basic Social Processes families or even the Strategies family of theoretical codes. Although some elements of these families seemed to fit theoretically, I did not feel they would fit as an overarching theoretical code for the grounded theory. I then looked again at the 6 Cs theoretical coding family consisting of context, conditions, cause, consequence, covariance and contingent (Glaser 1978, p.74).

There are several different models within the 6 C's family, causal model, consequences model and conditions model (Glaser 1978). This is not to say that other theoretical codes could not be appropriate. Indeed, Glaser (2005) argues that a number of theoretical codes could be relevant. However, for this theory, the 6 Cs was deemed to be the most appropriate in terms of organising and integrating the properties of the theory and achieving a greater level of conceptualisation. Of particular relevance to the theory *Holding on to Me* is the causal family, identified by Glaser (Glaser 1978) and elaborated upon in further works (Glaser 2005; Hernandez 2009). This family contains such elements as conjunctural causation (reflecting a multiplicity and complexity of causes) and the social arena. Glaser (2005, p.83) states that “*In writing the grounded theorist should talk substantive codes and think theoretical codes*”. Although the writing up of the properties of the theory (Chapters Six-Eight) “talks” in terms of substantive codes, the impact of the six C's theoretical code will be evident.

Note: Criteria and issues relating to judging the theory are explored in Chapter Ten

3.8 Summary

This chapter provides a comprehensive overview of the aims, objectives and methods to provide clarity as to how this study successfully stayed true to classic grounded theory methodology. Of particular importance to this study, given that people living with dementia are often excluded from research due to perceived additional difficulties ethical issues such as consent and balancing the rights of the person to take part with beneficence and safeguarding are examined. Methodological issues and areas of debate within the literature such as audiotaping, transcribing and use of literature are also explored, with reference to adhering to the CGT methodology. As stated, the criteria for judging the theory are discussed in detail in Chapter Ten.

The next chapter explores another key aspect of the study in terms of the approach taken, that is the use of public and patient involvement (PPI).

Chapter 4

Person and Public Involvement

4.1 Introduction

Engaging service users in research processes has become the next evolution in healthcare research (Manafa *et al.*, 2018; Marjanovic *et al.* 2019). Engaged research and in particular, Person and Public Involvement (PPI) has become a common element of healthcare research in recent years, with advocacy groups and funders emphasising the involvement of individuals and groups impacted by the research in the research process (Baines and Regan de Bere, 2018; Modigh *et al.*, 2021; Gilfoyle *et al.*, 2022). Additionally, combining PPI with qualitative research can assist with accessing harder to reach groups (Morgan *et al.*, 2016). Alzheimer Europe's position paper on Person and Public Involvement (PPI) in dementia research underscores the importance of including people living with dementia, not only as participants but also as contributors in the research process (Gove *et al.*, 2018).

This chapter examines what is meant by PPI and the imperative for its use in research and specifically dementia research. Furthermore, the appropriateness of using of PPI in classic grounded theory is explored. Additionally, how PPI was incorporated into the study is discussed. Finally, using the GRIPP 2 reporting guidelines for PPI, the use of PPI in this study is detailed. First what is meant by engaged research to understand its relevance in this study is examined.

4.2 Engaged Research

Consensus as to what constitutes engaged research varies and in particular the role of service users in the process can be unclear (Manafa *et al.*, 2018). This lack of a clear definition can in itself pose challenges for those wishing to engage in this type of research (Modigh *et al.*, 2021). Moreover, not having a clear definition makes it difficult to evaluate its use and understand its impact on the research process (Holliman, 2017; Modigh *et al.*, 2021). Holliman *et al.* (2015, p. 3) offers this definition:

“Engaged research encompasses the different ways that researchers meaningfully interact with various stakeholders over any or all stages of a research process, from issue formulation, the production or co-creation of new knowledge, to knowledge evaluation and dissemination.”

So, in essence, engaged research encourages a shift from traditional research methods to a more community and citizen-based approach. In doing so, the aim is to enhance the relevancy and translation of research for the benefit of society (Gove *et al.*, 2018). Moreover, Duncan and Oliver (2017) assert that this type of research is needed as it is the right thing to do arguing that there are a number of imperatives as to why engaged research be undertaken, namely:

Substantive Imperatives - Engaging with experts by experience to increase the quality and richness of a study.

Normative Imperatives - Given that studies are funded, often by Government agencies, citizens in those countries should have opportunities to be involved in such research. Additionally, comprehensive reporting on the use and impact of engaged research is essential (Staniszewska *et al.*, 2017; Price *et al.*, 2018).

Instrumental Imperative - Research must be utilised in effective ways to benefit individuals, groups and society. Despite research evidence being seen as beneficial, there can be lengthy delays in translating research to practice (Morris, Wooding and Grant, 2011; Finney Rutten, Ridgeway and Griffin, 2024).

Holliman (2017, p. 5/6) goes even further stating that “*engaged research through superior academic practices should have a moral imperative*”. Holliman (2017) makes an important point here for not only a moral imperative but also relating to the quality of the research and that engaged research must be done well to result in the meaningful co-production of research. Engaged research, through its direct engagement with communities can enhance the translation of research into real life practice (Han *et al.*, 2021). Engaged research encompasses various approaches such as community-based research, participatory research and PPI, each with pros and cons. Choosing the right approach for particular research studies is crucial for success and relevance and ensuring it is not vulnerable to being a tick box exercise or an aspiration for which there has been insufficient planning. This study aims to explore the perspectives of people living with dementia and so PPI is deemed the most suitable.

4.3 Person and Public Involvement (PPI) in Dementia Research

NOTE: In line with the wishes of the Dementia Research Advisory Team (DRAT PPI) involved in this study, Patient and Public involvement will be termed throughout this thesis

as Person and Public Involvement (PPI). This is an important distinction and consideration as healthcare labels can impact not only how the person sees themselves but also on how others, including healthcare professionals view them (Sims *et al.*, 2020). Additionally, the distinction is central to this study as it will be shown that how people living with dementia view themselves and how others view them relates directly on their sense of self. Furthermore, promotion and maintenance of personhood, inclusivity and active partnership are central tenets of person-centred dementia care, which is the ethos that underpins this thesis.

PPI is defined as research that is carried out “with” or “by” persons or members of the public rather than “about” or “for” (Health Service Executive: Research and Development, 2021). PPI methods can range from informal discussions to actively carrying out research and co production (Hoddinott *et al.*, 2018). Importantly for this study, PPI can happen at any, or all points of the research cycle. The most important factor is to ensure the appropriateness of use in terms of the methodology and methods of the study. Fundamentally it is about exploring how PPI can be incorporated as much as possible into the research cycle and then choosing the most appropriate method, to ensure engagement is meaningful (Holliman, 2015; Hoddinott *et al.*, 2018). Yet there is little consensus on how PPI can be optimised (Baines and Regan de Bere, 2018) or evaluated. In spite of this lack of consensus regarding its optimisation, there is general agreement that where possible, PPI should be incorporated into research initiatives (Health Service Executive: Research and Development, 2021).

There is an expanding acknowledgement that people living with dementia must be included in research that impacts their lives (Baldwin *et al.*, 2018; Gove *et al.*, 2018; Miah *et al.*, 2020, IPOSSI, 2021). There is a growing body of research on dementia care, however, despite a general move toward more inclusive research processes, dementia research, until recently largely overlooked the involvement of people living with dementia (Gove *et al.*, 2018). Gove *et al.* (2018) in their paper reflecting the position of Alzheimer Europe on PPI in the context of dementia research advocates that people living with dementia should be involved in research that impacts their lives. However, they posit that involvement should not be confined to participation but also incorporate generating ideas for research, consulting and involvement in research activities. People with dementia can provide unique experiential knowledge and there are distinct differences between participation, engagement and true involvement.

In 2016 the Alzheimer Society of Ireland developed a Charter of Rights for people living with dementia (Alzheimer Society of Ireland, 2016), advocating that as citizens, people living with dementia must be afforded the same rights as other citizens, including in relation to inclusion in and access to research. Going further, Alzheimer Europe released a position paper on involving people living with dementia in research (Gove *et al.*, 2018), stating that the rights of people living with dementia are underpinned by the United Nations (UN) Convention on the Rights of People Living with Disabilities (United Nations, 2006). and that this affords them the rights to be involved in research (Gove *et al.*, 2018). Additionally, it means researchers have a moral imperative to uphold these rights (Gove *et al.*, 2018).

The Alzheimer Society of Ireland “*Team Up for Dementia Research*” (Alzheimer Society of Ireland, 2025a) service has a main goal of making research more accessible for people with dementia and their families/carers. The premise is to connect people impacted by dementia with researchers in the field to ensure that the person’s voice is heard. There are benefits to both researchers and participants in this scenario. Researchers benefit from accessing contributors for their study and having a supportive network through which to facilitate PPI. Participants may benefit through having their voice heard, participating in something that may make a difference to others with dementia and being a part of a research network for dementia care and innovation. The Team Up for Dementia Research team provide support for not only the researcher but the person living with dementia and their supporters throughout the process.

4.3.1 Benefits and Challenges of Involving People Living with Dementia in PPI

Miah and colleagues (Miah *et al.*, 2020), in their qualitative study exploring the impact of involving people living with dementia and their caregivers in research, found that in addition to strengthening the robustness of the study, PPI contributors felt it gave them a sense of purpose and satisfaction. Additionally, researchers felt that it gave them insight into the impact of their work on people living with dementia and a new way of thinking and approach to their work (Miah *et al.*, 2020). The Alzheimer Society of Ireland (Alzheimer Society of Ireland, 2025a) also highlights the benefits of PPI for people living with dementia, saying that it can boost their confidence if done in a thoughtful, meaningful way.

The Health Service Executive (HSE) in their guide to patient and public involvement in HSE research highlight that PPI in research is important for three main reasons (Health Service Executive: Research and Development, 2021). Firstly, in improving the quality and relevance of the study. Secondly, in asking the research questions that are important to people and designing and using methodologies that people can engage with. Thirdly, PPI representatives can help to inform all parts of the research process to ensure that it is relevant and applicable to the area being studied. This can be beneficial in terms of translating the study into practice. PPI has also been seen to improve recruitment processes and participation, particularly in ‘hard to reach’ groups, due to the expert knowledge of those with lived experience of the studied health condition but also the communities with which potential participants live (Smith, Baillie and Gill, 2024). Moreover, when community engaged research enhances the translatability of the research into practice, particularly if they are involved in the co production of community initiatives (Han *et al.*, 2021). This is beneficial as it often takes many years for research to be translated into practice (Rubin, 2023).

Notwithstanding the benefits of PPI in dementia research, highlighted previously, challenges such as communication difficulties, obstacles to interviewing, obtaining ethical approval, recruitment and securing consent (Di Lorito *et al.*, 2020). Cognisance also needs to be given to the fact that dementia is a progressive illness and so the ability of some PPI contributors to be involved could change over time (Gove *et al.*, 2018). Furthermore, PPI can add expense to a project and be time consuming, so to justify its use and show its impact accurate reporting is essential (Staniszewska *et al.*, 2017; Price *et al.*, 2018; Miah *et al.*, 2020). These considerations are particularly relevant in relation to early career researchers and doctoral studies, who often shy away from using PPI in their dementia research, mainly due to a perception of additional workload, complexity and challenges with ethical approval (Smith, Baillie and Gill, 2024). Furthermore, inclusive meaningful PPI does not simply happen, but must be meticulously planned and thought out (Pollard *et al.*, 2015; Miah *et al.*, 2020; Smith, Baillie and Gill, 2024). Additionally, training and education is also essential for the researcher to mitigate against potential difficulties such as losing control over the research process, conflict resolution and issues with communication (INVOLVE, 2012). Furthermore, it is equally important to ensure that PPI contributors have access to training and support to maximise their opportunities for meaningful and purposeful involvement (IPPOSI: Education, 2025).

Despite these challenges, it is widely recognised as best practice to involve people living with dementia in research that directly impacts their lives (Gove *et al.*, 2018; Roberts *et al.*, 2020; Alzheimer Society of Ireland, 2025a). This acknowledgement underscores the imperative of overcoming barriers and finding innovative ways to incorporate the perspectives and experiences of individuals with dementia in research endeavours.

It has been established that PPI involvement of people living with dementia in research that impacts their lives should be considered as an imperative by researchers. Additionally, PPI used appropriately is beneficial to the quality, relevancy and translatability of the study. However, prior to discussing how PPI was incorporated into this study, there is another point of consideration, namely the compatibility of PPI with Classic Grounded Theory (CGT).

4.4 PPI and CGT

The value and importance of combining PPI with qualitative research is widely acknowledged in the literature (Morgan *et al.*, 2016; Hoddinott *et al.*, 2018; Muller *et al.*, 2019) in terms of all the benefits explored above. Additionally, Glaser (1992, 1998) argues that GT is neither a qualitative nor quantitative research method but rather a systematic, inductive, conceptual theory generating research method. As such, GT is regarded as one of the most systematic, rigorous and widely used qualitative research methods (Bryant and Charmaz, 2007; Holton and Walsh, 2017). It would therefore seem beneficial to marry both research approaches. Yet there is a paucity of literature relating to the use of PPI in CGT (Gove *et al.*, 2018). An important consideration in using PPI in this study was that of compatibility with classic grounded theory, and at which point in the research cycle it was appropriate to use it. The latter will be discussed later in this chapter. This section will examine the former, the appropriate use of PPI in CGT.

One Canadian study explored the differences and similarities between patient-oriented research (POR) and CGT (Smith-MacDonald *et al.*, 2019). Patient-oriented research aims to create evidence that addresses what matters to patients, in a robust way through engaging with patients throughout the research process (Smith-MacDonald *et al.*, 2019). There are several elements required to ensure a study is person oriented. Firstly, patients are seen as expert. Secondly, patients are equal contributors to the research process. Thirdly, research

focuses on addressing patient need (Canadian Institute for Health Research, 2011). As such, patient-oriented research, particularly in relation to patient engagement can be closely aligned to PPI and is therefore relevant in terms of reviewing the content of the article relating to patient-oriented research and CGT.

Smith-MacDonald *et al.* (2019), noted a number of areas of convergence and divergence between POR and CGT. In terms of convergence, they noted person-centredness, rigorous data analysis and robust data sources. In terms of the use of PPI in CGT, within this study, it helped to discover what was most important to participants in a rich and meaningful way. Through flexible approaches, that recognised the communication preferences of participants, those who might otherwise have been excluded, for example those with significant communication difficulties could have a voice in the study. Additionally, the DRAT PPI team gave advice on interview techniques that would make the participant more comfortable during encounters. Through the DRAT PPI teams work in reviewing participant documents the recruitment process, and understanding what was being asked of them was more accessible for potential participants. Additionally, as will be discussed in greater detail later in this chapter, a key role of the DRAT PPI team was one that I had not originally expected. Through the trusting and open relationship that developed between us, the team were able to challenge preconceived ideas and assumptions I had not realised I possessed. In doing so, it significantly aided my ability to, as Glaser (1978, p. 2-3) states, engage with participants with as *“few predetermined ideas as possible...his mandate (the researcher) is to remain open to what is actually happening”*. This ensures that the codes and categories emerge from the data, essentially ‘fit’ with the data rather than being forced to ‘fit’ by the researcher.

However, despite the obvious benefits there are several considerations in order to ensure compatibility between PPI and CGT. Glaser (1978, 1998) argues that the researcher must maintain researcher autonomy, in order to ensure that they do not fall into the trap of allowing pet theories or preconceived ideas and assumptions, theirs or others to impact on the data. At first glance, this would seem to be a point of divergence with the use of PPI. However, the DRAT PPI team was not involved directly in data collection or analysis. Additionally, Glaser (1978, 1998), suggests that trust in grounded theory studies can be judged by the following criteria: fit, workability, relevancy and modifiability. Through the DRAT PPI group acting as “critical friends”, they were continuously giving feedback as to the judging criteria from their perspective. This helped, in adding an additional layer to judging the

trustworthiness of the study, in terms of Glaser's criteria (Glaser, 1998). Additionally, through confronting my assumptions and preconceived ideas, the DRAT PPI team helped me stay open to what was actually happening in the field and enhance theoretical sensitivity, as advocated by Glaser (1978).

Another consideration in using PPI in CGT is Glaser's insistence that the CGT research method must be adhered to with no change or modification to the process. Yet PPI does not impact the CGT process, which remains the same, but rather compliments and enhances it. At the core of CGT is generating theory to explain how people in a substantive area resolve or process their main concern. In relation to POR Smith-MacDonald *et al* (2019) agree stating that if the researcher's approach adheres diligently to the CGT method in relation to data collection and analysis, use of CGT in POR can add to the robustness of the study. Given the similarities between POR and PPI, this line of thinking could also be used to support the appropriateness of using PPI in CGT, particularly in supporting meaningful engagement with participants.

Whereas there may be some methodological divergence in the use of CGT in POR, this can be mitigated with appropriate use of PPI in CGT. Indeed, the use of PPI in grounded theory, as seen in this study, can be particularly helpful in enhancing meaningful engagement with populations, often deemed hard to reach and understanding what matters to them. Given that this is a central aim of both PPI and CGT this seems to be an advantageous pairing for PPI and CGT and consequently meaningful, person-centred dementia research.

In summary, arguably, CGT could be considered ideally suited to the use of PPI, given its focus on person-centred involvement in research, understanding the concerns of the person, and theory generated from empirical data grounded in the substantive area. However, careful memo writing and reflection was needed to ensure that the appropriate use of PPI enhances but does not modify the CGT method. Having established the imperative and appropriateness of using PPI in this CGT study, the remainder of this chapter will focus on how PPI involvement formed a crucial element of this study.

4.5 Use of PPI in this Study

The PPI contributors were recruited through an application process from the Alzheimer Society of Ireland (ASI), Team up for Dementia Research (Alzheimer Society of Ireland,

2025a). The team consisted of one person living with dementia and one caregiver of a person living with dementia. An initial meeting was held between the ASI, DRAT PPI team and I, early in the research project, to discuss expectations and to help to build a relationship. ASI staff were available to both the DRAT PPI team or I should any difficulties arise. Furthermore, they acted as a support for the DRAT PPI team, thus providing a safeguard for them should they need it. Initial meetings took place monthly, this helped to build the relationship.

In planning my work with the DRAT PPI team I was aware that PPI must be tailored to the individual, ensuring they are supported for meaningful engagement through exploring communication methods and providing relevant training (Gove *et al.*, 2018; Roberts *et al.*, 2020; Smith, Baillie and Gill, 2024). Given that dementia is a progressive condition, contributor's cognitive and functional abilities may change over time, requiring additional supports or the option to withdraw. If appropriate I would discuss this with the individual or ensure they received the support, they needed through the ASI.

There are several different ways in which people with dementia can be contributors in the research process, but it is crucial to plan meticulously to ensure that the expectations of all stakeholders, including contributors and researchers, are clearly defined and that the engagement process is mutually beneficial (Bethell *et al.*, 2018; Di Lorito *et al.*, 2020). To enhance role clarity for stakeholders for this study, the DRAT PPI group jointly discussed a role description and this was agreed at our initial meetings and amended as needed.

Gove *et al.* (2018) recommends safeguarding the wellbeing of people living with dementia in PPI by ensuring they understand the study, receive regular updates, feel no pressure to contribute and are given tasks suitable to their ability or supported as needed. As part of the ASI application process, potential contributors received a lay summary of the study, a brief outline of what could be their role (this was then decided by the group), and the project timeline. DRAT PPI team members were also given the option to have a trusted friend or carer with them. Although the team members did not take up this option, I had given consideration to ensuring that the input of the person living with dementia would not be overridden by their carer as advocated by (Gove *et al.*, 2018). Bird *et al.* (2020) also caution about the possibilities of power imbalance in the researcher-contributor relationship but state that developing clear roles and responsibilities can help to mitigate against this. As

previously indicated, this was discussed with the DRAT PPI team in our initial meetings. Additionally, the DRAT PPI team were very experienced and so did not seem to have any issues with making their opinions known.

It was in the earlier stages of the study that the DRAT PPI team had the most input in terms of reviewing and giving feedback on participant documents, advising on recruitment and reviewing the interview schedule/techniques. This was essential in creating opportunities for meaningful encounters with participants and their supporters. As the study progressed the DRAT PPI meetings were necessary to give updates about the study and also during this period the DRAT PPI team acted as ‘critical friends’ in giving their opinions as to the initial codes and categories emerging from the study. Although this did not influence the data analysis process, it helped me to enhance my theoretical sensitivity. Additionally, their opinions and perspectives helped in the consideration of the fit and workability of emerging codes and categories.

To ensure meaningful involvement, all materials for review by the DRAT PPI team were provided in accessible formats and sent two weeks in advance to allow time for review and feedback. One contributor required information in 14-point bold font, which was accommodated. The group also had time to review materials on the day. Contact details for the researcher were shared for any clarification or concerns. At the request of the DRAT PPI team reminders were sent two days prior to meetings. All meetings were held on zoom. Initially, this was to adhere to COVID 19 restrictions, but subsequently the DRAT PPI team found them easier given their geographical spread. Check in meetings were held with the ASI to keep them informed of the progress of the study and the work of the DRAT PPI team. Memo writing and discussions with supervisors ensured the emerging codes, categories and subsequently the theory remained firmly grounded in the data.

PPI contributed to the study in several ways:

- Reviewing participant documents, including the format, wording and language used in the participant documentation and amendments were made in accordance with their guidance.
- Reviewing the interview schedule and interview technique
- Reviewing and advising on recruitment processes
- Challenging preconceived ideas and assumptions

- Contributing to the preparation of presentations for an ethics symposium in Copenhagen and a research conference in Ireland. PPI contributors to dementia research have indicated that acknowledging their work as essential in articles and conferences is not only good practice but also recognises their valuable work as contributors (Roberts *et al.*, 2020).
- Acting as “critical friends” throughout the research study

While facilitating the DRAT PPI meetings it was important to recognise and acknowledge where people were at, personally, in the group as, I felt, this could influence their thinking. Whereas all their opinions and recommendations were valid and important, it may not necessarily have relevance for the study. For example, if a member of the DRAT PPI team had or was having a bad care experience, or simply having a bad day, they may be reacting to that situation rather than what was happening in the study. I wanted to ensure their participation was meaningful and purposeful and would not in any way be vulnerable to tokenism. It was important for me to listen to what they had to say and acknowledge it, even though it did not always have relevance for the study. Similarly, it was important to remember that their opinion is exactly that, their opinion. Wendy Mitchell’s book (Mitchell, 2022) “*What I wish people knew about dementia; from someone who knows*” refers to the well-known adage, in highlighting the uniqueness of each individual living with dementia: “*when you know one person with dementia, you know one person with dementia*”. Although not necessarily a challenge, this was something that required careful consideration in terms of the role of the DRAT PPI team as “critical friends”, and in particular to ensure that I was staying true to the codes and categories that were grounded in the data and had earned their way into the theory.

4.6 Reporting PPI Use in this Study

Reporting PPI processes is an essential element to highlighting the role, robustness and impact of PPI in the study. The failure to do so means the impact of PPI in research is often not evaluated. Additionally, the process can be structured by the use of recognised guidelines (Price *et al.*, 2018). Using the EQUATOR method Staniszewska *et al.* (2017) developed a consensus document, the GRIPP 2 reporting guidelines for use of PPI in research. The aim of the guidelines are to improve the quality, consistency and transparency of PPI in research (Staniszewska *et al.*, 2017). There is a long form and short for which can be used depending on the type of study and the requirements of the researcher and the study. The short form is

used in this study, to report on the processes for PPI, as it is more user friendly (Jones *et al.*, 2021)(Appendix 2).

4.7 Protecting the Wellbeing of PPI Contributors

Although ethical approval is not generally required for PPI, it is essential that measures are put in place to provide practical support for contributors (Health Service Executive: Research and Development, 2021). In particular relation to dementia, it also requires that there is meaningful, inclusive engagement (Roberts *et al.*, 2020). Moreover, researchers need to be aware of the societal context within which research. Gove *et al.* (2018) suggests ways to protect the wellbeing of people with dementia in PPI including, ensuring that contributors have read and understand what the study is about and are given frequent updates on the study and their involvement in it. Additionally, participation is voluntary, and contributors should not feel pressure to take part, and they should be given tasks based on their ability or support if required. It was useful to develop a role descriptor for PPI contributors that clearly outlined the PPI contribution, and this was discussed and amended as needed at the initial meeting with the DRAT group.

In addition to the above I needed to ensure the safety and wellbeing of PPI contributors living with dementia by conducting meetings at the person's pace and allowing time for breaks. The DRAT team was recruited through the Alzheimer Society of Ireland and there was a named contact that any of the group, including the researcher could contact should any concerns arise. In the initial meeting I offered group members that trusted family member or friend was permitted to attend with the person if they wish (Pickering *et al.*, 2021). Furthermore, contact numbers for the researcher and the Alzheimer Society of Ireland were made available in case of concerns or queries. It was made clear that the PPI contributors could withdraw from the group at any time. Given the global COVID 19 pandemic there were other safety issues to be considered. The DRAT PPI meetings were held on Zoom as this ensured the safeguarding of the group as well as being convenient as members hailed from different geographical locations throughout the country.

Finally, as people with dementia are considered a vulnerable group safeguarding considerations needed to be addressed. In Ireland there are guidelines underpinned by legislation for the protection of vulnerable adults from the risk of abuse. I was cognisant of the fact that in engaging with people with dementia, concerns might arise in terms of the

safety of the person, either through the person saying something during conversation or the researchers own observations. It is essential researchers know how to act in such instances, including ensuring the immediate safety of the person and reporting to relevant authorities (Health Service Executive: Research and Development, 2021).

4.8 Summary

This chapter examined the imperatives and benefits of involving people living with dementia in research as contributors (PPI) as well as participants. It has been shown that PPI can, if planned and facilitated properly, adds to the relevancy, translatability and richness of research. Moreover, it is well recognised in the literature that evaluating the impact of PPI presents a challenge, largely due to the limited reporting of PPI processes in research studies. To address this issue, the GRIPP 2 reporting guidelines for PPI have been used to comprehensively detail the use of PPI in this study. It is generally agreed, within the literature, that PPI in combination with qualitative research add to the robustness of the study and assists in accessing hard to reach groups. Yet, there is a paucity of evidence relating to the use of PPI in grounded theory studies, particularly CGT. The use of PPI in this study highlights that, if used appropriately PPI can enhance the CGT methodology rather than weaken it. As such there is a clear opportunity to further integrate and adopt PPI in future CGT studies, with a focus on comprehensive reporting to assess its impact. This study, by reporting on the use of PPI in CGT, can pave the way for future research opportunities.

So, in summary, while it must be acknowledged that there were challenges in involving people living with dementia in research, it is important to acknowledge their significant impact on this study, both as participants and contributors. Their engagement not only supports the study's aims but also enriches the research by enhancing its depth, relevance, translatability and robustness. Ultimately, the benefits of using PPI in this study far outweigh the challenges.

Chapter Five, examines the concept of self in dementia and introduces the theory, *Holding on to Me*.

Chapter 5

Persistence or Loss of Self in the Context of Dementia

5.1 Introduction

In grounded theory a central tenet is to identify the main concern of people in the substantive area and subsequently to identify patterns of behaviour for how they resolve or process their main concern. As a brief reminder, in Chapter One, *losing me*, is identified as the main concern of participants in this study. *Losing me* refers to any loss or potential loss associated with the individual's sense of self in the context of the diagnosis of dementia. This concept emerged as the main concern when the participants spoke about the loss and potential future loss of things that could impact their sense of self. Essentially, the impact and changes associated with dementia, both as seen by themselves and others, that can mean their sense of self, of who they are, is vulnerable to being lost and thus emerges as their main concern of *losing me*.

This chapter examines the extant literature relating to loss or persistence of self in the context of dementia, as a means of positioning the emergent theory *Holding on to Me*. Finally, an overview of the grounded theory, *Holding on to Me* is given as an introduction to how participants resolve or process their main concern, *losing me*. The theory is discussed in greater detail in Chapters Six, Seven and Eight. Firstly, the literature relating to self and dementia is explored, with particular focus on the preservation of self, essentially *Holding on to Me*, in the context of dementia.

5.2 The Persistence or Loss of Self and Dementia

Much debate exists within the literature regarding the degree to which self, diminishes or persists in dementia (Caddell and Clare, 2010). Some authors argue that self persists over the course of dementia, at least to some degree (Kitwood, 1997; Kontos, 2005; Surr, 2006; Millett, 2011; Schweda and Jongsma, 2022). Others argue that self in dementia diminishes over time until it is completely lost, the “*unbecoming*” of the self until only “*emptiness*” is left (Fontana and Smith, 1989, p. 45). Davis (2004, p. 375) suggests that “*what is so devastating about the relentless nature of dementia is the very splintering of the sedimented layers of Being... (until)...there is nothing left*”. However, Fuchs (2020) argues that theories of selfhood based on cognitive processes alone are in danger of excluding those with severe dementia from the status of persons. Millett (2011) concurs stating that there are significant

reasons why a perspective of self that relies on a separation of mind and body and cognitive capacity is problematic. This primarily relates to the person being seen by others as a non-person and the subsequent impact on their wellbeing and autonomy.

The question of persistence or loss of self in dementia is not made any clearer by the lack of general consensus regarding the meaning of the concept of self (Millett, 2011). Millett (2011) suggests that one of the issues in exploring self in dementia is that there are so many variations in understanding the concepts. Indeed, with particular relevance to the field of dementia the terms self, selfhood, identity and personhood are often used interchangeably (Millett, 2011; Norberg, 2019), thus adding to the confusion. In addition, Millett (2011) states that people often take their view of dementia from a medicalised standpoint of pathological decline, and that this has fundamentally led to the prevailing view of loss of self. So it would seem that there is no simple answer to providing an all-encompassing explanation of the concept of self (Millett, 2011). To better understand the persistence (or lack thereof) of the self in dementia, several perspectives are explored and conclusions drawn based on these insights.

Caddell and Clare (2010) in their systematic review examining research related to the impact of dementia on the persistence of self and identity, analysed qualitative and quantitative research literature. The literature examined self from several perspectives, including social constructionist, interactionist, embodied selfhood and self as narrative. However, Caddell and Clare (2010) caution that the methodologies used and even the perspectives of self adopted varied considerably between the studies, making the results somewhat limited. Within the qualitative studies reviewed, the emphasis was on a unitary construct of self. Caddell and Clare (2010) suggest a limitation to these studies was that they often focused on verbal communication, which could exclude people with later stages of dementia. Within the quantitative studies there was more emphasis on measuring specific aspects of self, such as self-recognition or self-concept. Additionally, they warn that small sample sizes particularly in many of the quantitative studies, could impact the validity and reliability of the results. Despite this, they posit that all studies with the exception of one (Fontana and Smith, 1989), argue for the persistence of self at some level throughout the course of dementia.

Bomilcar *et al.* (2021) argues that the concept of self is multifaceted and involves a variety of cognitive processes and psychological influences. To offer a framework to explain the

multiple facets of self in the context of dementia, they propose seven selves. The first, is embodied self, which they suggest is present even in severe dementia and relates to corporal expression and non-verbal communication, such as facial expressions, dancing or drawing. The agentic self relates to self-reflection and decision-making capabilities, preserved in dementia through behavioural and emotional responses. Implicit self refers to implicit emotional responses, attitudes and behaviours such as use of humour. Autobiographical memory is a crucial element of the critical self and refers to memories about past incidents and facts about oneself. Surrogate self involves perspective taking from a third person point of view, essentially seeing themselves as they perceive others see them. Extended self they suggest results from the interaction between embodied and social processes and involves use of external supports to enhance cognition and sense of self for example family and community supports. Lastly, the emergent self provides a unifying process for the experience of a unified self, a unitary concept that encompasses the other self-processes (Bomilcar *et al.*, 2021). Through the emergent, unified self they argue that some of the self-processes can compensate for impairments in others, thus allowing for the preservation of self throughout the course of dementia (Bomilcar *et al.*, 2021).

From a social constructionist perspective, the self is constructed in and through interactions with others and as such the use of language is fundamentally important (Caddell and Clare, 2010). Within the study of self and dementia the social constructionist model suggests that there are multiple selves. Kelly (2010) states that the idea of a self's framework evolved with the work of Sabat and Harré (1992). Sabat and Harré (1992, p. 443) had embarked upon their exploration of self in dementia in response to what was, they term, their “*puzzlement*” of a book entitled ‘*Loss of Self*’ (Cohen and Eisdorfer, 1986). Their confusion, they state, stemmed from wondering how someone could lose their self. This had previously been a widespread notion and widely stated in the literature (Millett, 2011). Sabat and Harré (1992) posit a multiplicity of selves, Self 1, Self 2, and Self 3, arguing against the notion of the totality of loss of self in dementia. They argue that some self-processes are more vulnerable to dementia than others, but that despite this there is a persistence, at least to some extent, of self even in the advanced stages of dementia.

Self 1 refers to the person's use of first-person pronouns when speaking about themselves or acting towards themselves. This includes the use of ‘I’, ‘Me’, ‘Myself’ and ‘Mine’. People participating in this study frequently referred to themselves. Particularly when telling the

stories of their lives. Sabat (2018) argues that Self 1 remains intact even into very advanced dementia. Studies have shown that use of personal pronouns, used as evidence of sense of self, can persist even in advanced dementia (Sabat and Harré, 1992; Small *et al.*, 1998; Sabat, 2002; Fazio and Mitchell, 2009). However, it is acknowledged that the use of personal pronouns could be resulting from habit. Additionally, Small *et al.* (1998) in their study examining the use of person pronouns as an expression of self, found that personal pronouns were only used half of the time. Despite this, it is generally thought to be evidence of the persistence of self (Caddell and Clare, 2010; Sabat, 2018).

Self 2 refers to such things as one's physical, mental or emotional characteristics and past achievements and experiences. Sabat argues that Self 2 remains largely intact even as dementia progresses (Sabat and Harré, 1992; Sabat, 2002, 2018, 2019). In a study examining the persistence of self in people with Alzheimer's disease by Fazio and Mitchell (2009), people with cognitive impairment were asked to identify themselves in photographs, which they successfully did, thus indicating a preservation of self (Fazio *et al.*, 2018).

Self 3 refers to the publicly presented part of ourselves, the roles we take on and the way we present ourselves in public social situations. There are many versions of Self 3, expression of which is varied in different social settings (Sabat, 2018). Self 3 is constructed, sustained, nurtured or changed through interaction with others (Norberg, 2019). Social context also plays a role and the rules within the social context can impact different ways of behaving within those contexts, influencing different manifestations of Self 3. Surr (2006) argues that selfhood should be considered as the complex interplay between several social and biographical factors, including interpersonal relationships, the social context, opportunities for and abilities to communicate aspects of self and individual coping styles and strategies. From a research viewpoint, Caddell and Clare (2010) argue that, whereas this perspective can be analysed more readily due to its focus on verbal communication, that is also its flaw. It is reliant on at least some level on language skills, which may not be present in more advanced dementia.

In a similar vein to Sabat and Harré (1992), and also recognising the multidimensional nature of self, Mentzou *et al.* (2023) in their scoping review of the changes in the psychological self in people living with dementia argue that the concept of self is not all or nothing. They maintain that self consists of several related elements that might not all be impacted by the

course of dementia. Given the multidimensional nature of the self, they argue, the person's sense of self can be retained, at least to some extent as dementia progresses and autobiographical memory declines. Findings from their review were organised into three main types of manifestations of psychological self, which they termed self-related functions. Firstly, higher order manifestation, autobiographical memory, sense of having a life knowledge and life narrative (Mentzou *et al.*, 2023 p. 2). Secondly, functional aspects of self exist in between higher order manifestations (self-awareness) and foundational manifestations (selfhood) and involve the cognitive processing of self-related information. Thirdly, foundational manifestations can be thought of in relation to a sense of awareness of one's own body. They argue that failure to understand these manifestations of psychological self can lead to the person experiencing psychological symptoms such as disconnection and reduced agency. Further they argue that failure to understand changes in selfhood can impact care practices (Mentzou *et al.*, 2023).

5.3 Personhood

The promotion and maintenance of personhood is a prerequisite for person-centred care provision (Dewing, 2008a). Additionally, it underpins policy documents such as the Irish National Dementia Strategy (Department of Health, 2014) and the Model of Care for Dementia in Ireland (Begley *et al.*, 2023). The philosophical concept of personhood, essentially how we define ourselves as persons, has been a source of debate for many years, with many perspectives having associated criteria as to what constitutes personhood (Hampson and Morris, 2016; Higgs and Gilleard, 2016; Sofronas, Wright and Carnevale, 2018).

There are several drawbacks associated with the criteria associated with personhood, specifically that they were often arbitrary, linked to specific cultural and historical perspectives and were difficult to evaluate and use (Sofronas, Wright and Carnevale, 2018). Additionally, many of the criteria are related to cognitive abilities such as language, understanding, planning, consciousness, rationality, autonomy and reason (Sofronas, Wright and Carnevale, 2018). This creates another important consideration in terms of the personhood, or lack thereof for people who may have alterations in their cognitive and language abilities (Sofronas, Wright and Carnevale, 2018). Kitwood (1997, p. 9) warns that in following this line of thinking, there is room to argue for the exclusion of people living with dementia and severe disabilities from the "*personhood club*".

Kitwood (1997) states that there are three main discourses associated with personhood namely, theology and spiritual, ethics and social psychology, each with different perspectives and weightings applied to aspects of personhood. Additionally, in a similar vein to the concept of self, a consistently agreed upon definition of personhood can be difficult to ascertain (Kitwood, 1997; Dewing, 2008a). Adding to the confusion, as already stated the concepts of self, personhood and identity can often be used interchangeably within the literature (Norberg, 2019). Indeed, given the many connotations of personhood within the literature the term itself can be an unhelpful concept (Higgs and Gilleard, 2016). Higgs and Gilleard (2016) suggest a more beneficial standpoint would be to cast aside ambiguous concepts and concentrate on maximising people's capabilities and minimising incapacities (Higgs and Gilleard, 2016). Whereas there is benefit to maximising capabilities and minimising deficits, there is a particular danger involved in care that does not promote and nurture the self in dementia. Where there is a perception that the person living with dementia is devoid of self this can have a detrimental impact on the attitudes, behaviours and care practices of healthcare staff (Schweda and Jongsma, 2022).

The social environment within which the person resides has a vital impact on the preservation of self (Sabat, 2019). Within social relationships, interpersonal processes can result in an erosion of personhood, rendering the person living with dementia invisible whilst increasing the visibility of the impact of dementia (Kitwood, 1997; Dewing, 2008a). This is what Kitwood (1997, p. 45-49) calls "*malignant social psychology*" and it consists of such interpersonal processes such as ignoring, labelling, infantilism and outpacing. The impact of such interactions results in the erosion of the personhood of the person (Kitwood, 1997; Dewing, 2008a). Sabat (1994) concurs stating that the social environment and interpersonal interactions can lead to excess disability for people living with dementia, through the erosion of their sense of self. In contrast to malignant social psychology, Kitwood (1997) details how the preservation of personhood is possible through meeting the psychological needs of people living with dementia. These psychological needs are identified as love, attachment, comfort, identity, inclusion and occupation (Kitwood, 1997, p. 82).

Kelly (2010) integrated Kitwood's personhood and person-centred care (Kitwood, 1997) and Sabat's selfhood approaches (Sabat, 2001) to explore how the self in dementia can be supported through person-centred approaches. She used observation, dementia care

mapping, and video recordings with residents in three continuing care wards in a psychogeriatric facility. Participant's responses to their interactions with caregivers were recorded and documented in terms of illbeing or wellbeing. She found that whilst staff working in the wards generally recognised Self 1, they were less able to recognise Self 2 and Self 3. This inability to recognise the self of the person was directly linked to staff behaviours associated with Kitwood's malignant social psychology (Kitwood, 1997). This often led to feelings of illbeing amongst the participants and subsequently "*problematic behaviours*" (Kelly, 2010 p. 120). In contrast they found the Occupational Therapy staff recognised and supported Selves 1-3 in creative sessions and this raised their levels of wellbeing (Kelly, 2010). Based on her findings she argues for a shift in focus to a care approach that recognises and supports the self of the person living with dementia, thus enhancing their wellbeing (Kelly, 2010).

Whilst acknowledging Kitwood's work, Kontos argues that there is a need to shift our perspectives of personhood and subsequently person-centred care to incorporate the embodied self, in order to recognise the persistence of self, beyond conventional relationships, particularly in the later stages of dementia (Kontos, 2005; Kontos and Martin, 2013) (This is discussed in greater detail in the section on Embodied Self: page 81). Despite this, the work and ideas of Kitwood (Kitwood, 1997) in advancing the recognition and maintenance of personhood in dementia care remain widely cited and used in dementia care practice (Brooker, 2007; Dewing, 2008; Mitchell and Agnelli, 2015; Fazio *et al.*, 2018).

5.4 Narrative Self

The perspective of a narrative self, focusses on the suggestion that self is constructed through the person's ability to generate and communicate a life narrative (Caddell and Clare, 2010). Hutmacher (2021) argues that an essential element of humanness is the ability to create and maintain a life narrative. Additionally, Surr (2006) argues that biopsychosocial perspectives of dementia, such as advocated by Kitwood advocate for the preservation of self and identity and that there is a role for individual narratives to achieve such preservation. Kitwood (1993) suggests that "*To have an identity is to know who one is, in cognition and in feeling. It means having a sense of continuity with the past; and hence a 'narrative', a story to present to others*". However, Hutmacher (2021) argues that having continuity and narrative requires a certain level of memory and language. In recognition that people with advancing cognitive decline in dementia may not be able to communicate their narrative, Kitwood highlights the role of others in holding their story in order to ensure that their

uniqueness continues to be respected and cherished (Kitwood, 1997; Dewing, 2008a; Fazio *et al.*, 2018). However, it is acknowledged that this might prove more difficult in healthcare settings (Kitwood, 1997).

Surr (2006) contends that the sense of self is particularly at risk in healthcare settings such as Long-Term Care (LTC) and the narrative of the person is essential to understanding what is important to the person and so in preserving their sense of self and identity. To counter this, in her qualitative study exploring the preservation of self of people living with dementia in LTC, she offers a socio-biographical theory of self. This theory posits that relationships with others, the broader social context and narrative have a crucial role in preservation, or not, of self. Mead (1934) also recognises the importance of relationships and the broader social context, contending that the self is constructed through social responses from interpersonal relationships and the attitudes of society and communities of which the person is a member. Although Mead's work (Mead, 1934), did not directly focus on dementia, it has particular relevance given that people living with dementia in modern society continue to be vulnerable to stigma and discrimination (Olwage, 2024).

Indeed, these difficulties can be exacerbated and influenced by common discourses surrounding dementia, particularly advanced dementia, as 'a second childhood' or a 'living death' (Schweda and Jongsma, 2022). In their critique of the "Zombification" of people with dementia, Schweda and Jongsma (2022) criticise the impact that such metaphors have on the person with dementia's sense of self in terms of how they see themselves but also how others see them. They reference the work of Pia Kontos (Kontos, 2014; Kontos *et al.*, 2017) in challenging this rhetoric and highlighting the response of people, even with advanced dementia, to music and theatre (Schweda and Jongsma, 2022). Surr (2006) suggests that in addition to a socio-biographical approach there may also be a role for embodied factors in the preservation of self. Indeed, Norberg (2019, p.3) argues that people with advanced dementia show clear unique reactions to stimuli such as music and experience "*moments of lucidity*" that support the persistence of self throughout the life course of the person living with dementia. Additionally, for participants in Surr's study, relationships and belonging with family, friends and healthcare staff was an important element of their storytelling, showing the importance of interpersonal relationships on the preservation of self (Surr, 2006). This also has relevance for Kitwood's claim of the importance of others in supporting the person to hold on to their narrative (Kitwood, 1997). However, this also makes the person

and their narrative vulnerable to malignant social psychology (Kitwood, 1997) as discussed above.

5.4.1 Memory and Narrative

Whilst acknowledging the significant variations in presentation in the different subtypes of dementia, to some extent they all have issues with memory and language (Hutmacher, 2021). There has been a long association between memory and self (Strikwerda-Brown *et al.*, 2019). In his exploration of the psychological and philosophical understandings of the self of people living with dementia, Hutmacher (2021, p. 161) starts with an interesting and valid question: *“If the notion of having a self is intimately linked with being able to create and maintain a life narrative, and if people with dementia tend to lose this ability, what kind of self do people with dementia still possess?”*. In countering the notion of a narrative self, as the only self, and when gone, the person is devoid of self, Hutmacher (2021) suggests as an alternative the work of Kahneman (Kahneman, 2011). Although not specific to the field of dementia, Kahneman posits that there are two selves. Firstly, the remembering (narrative) self and secondly the experiencing (minimal) self (Kahneman, 2011). Kahneman (2011) suggests that while the remembering self is impaired in dementia the experiencing self persists. Additionally, he posits that the experiencing self, in essence, mirrors the life story of the person. Subsequently, when the person has difficulty expressing their narrative verbally, they can continue to do so through their behaviour (Hutmacher, 2021).

5.5 Embodied Selfhood

Kontos (Kontos, 2004, 2005) argues that any discussion on dementia and self must include that of the embodied self. Originating in the work of Bourdieu and Merleau-Ponty, embodied selfhood posits that selfhood exists in the body itself (Kontos and Martin, 2013). Whilst acknowledging the importance of the work of Kitwood (Kitwood, 1997) in broadening the scope of personhood away from a primarily neuropathological and cognitive focus, Kontos (2005) argues that a socio interactive perspective of selfhood fails to recognise the significance of humans as embodied beings. She argues that in the work of Kitwood (Kitwood, 1997) and Sabat and Harré (Sabat and Harré, 1992), the body takes on a symbolic role and there is a failure to recognise the body as a significant means by which people with severe dementia engage with the world (Kontos, 2004).

To bring the body into what she calls a “ *theoretical revisioning of selfhood in Alzheimer’s disease*”, Kontos (2005, p. 558) conducted an ethnographic study in a long term facility, she called Chai Village in Canada (Kontos, 2004). Most residents were Jewish and had dementia that ranged from moderately severe to very severe (as judged by Mini Mental State Examination [MMSE] scores). There was a diverse range of social activities available at Chai Village, for example sing songs, dancing, bingo, to name but a few. Additionally, all major Jewish holidays were observed and celebrated. Observations were conducted over an eight-month period, for eight hours per day, three days per week. From her work, Kontos (2005, p. 559) posits that embodied selfhood “*speaks of a complex interrelationship between primordial and sociocultural characteristics of the body, all of which reside below the threshold of cognition, grounded in the pre-reflective level of experience, existing primarily in corporeal ways.*”. As such she draws on the work of Merleau-Ponty (1962), in arguing that the pre-reflective self is intentional by the virtue that it is directed towards the world, despite this being at an unconscious level. Kontos (2005, p. 561) references numerous occasions when residents of Chai Village illustrate the fundamental ability of the body to pre-reflectively perform claiming that “*selfhood emanates from the body’s power of natural expression, manifesting in the actual movements of the body.*”. These illustrations included when residents sang to comfort each other, clapped and danced to music and took pride in their appearance (Kontos, 2005, p. 561). Kontos also draws on the work of Bourdieu (1977, 1990) and the concept of Habitus, introducing the notion of learned sociocultural aspects of pre-reflection (Kontos and Martin, 2013). This could be seen in the habits, routines and rituals of residents but also in a level of class status amongst the residents in Chai Village, that was long gone but still adhered to (Kontos, 2005).

In a similar vein to Kontos (2005), Baird and Thompson (2018) in their review examining the impact of music on the self in dementia suggest that music can stimulate autobiographical or personal memories in people living with dementia. Furthermore, they suggest, even when memory function is impaired, there is a growing body of evidence that to some extent, musical memory remains, even for non-musicians (Baird and Samson, 2015; Baird and Thompson, 2018). Although in saying that they do concede that there is a lack of empirical research on the topic.

Pickles and Jones (2006) offer the notion of a ‘musical self’ arguing in their study that even in the absence of higher cognitive function the musical self endures. There has been much

interest in recent times in the impact of music for people living with dementia. In 2014, a documentary called *Alive Inside: A Story of Music and Memory* (2014) explored the impact of music in dementia. The documentary showed a gentleman, Henry, who had been largely uncommunicative, but when listening to his favourite music would become animated and could articulate why the music was important to him. This would seem to confirm Baird and Thompson's claim that even if the premise of music's ability to preserve the self is disputed, there is at least anecdotal evidence of music eliciting emotion and relational responses in people living with dementia, including advanced dementia (Baird and Thompson, 2018).

Using the framework for researching the self, proposed by Caddell and Clare (2013), Baird and Thompson (2018) studied the impact of music on the self in dementia. The framework proposes using Neisser's framework of the self (Caddell and Clare, 2013). Neisser's framework of the self includes five elements, ecological self, interpersonal self, extended self, private self and conceptual self. They looked at two case studies, one non-musician and one musician to identify the impact of music on the five elements of Neisser's self-framework. Baird and Thompson (2018) concluded that music impacted on multiple elements of self and surmised that music can enhance and preserve a sense of self in dementia. This would seem to add another layer to our discussion, both in terms of preservation of the self in dementia but also in terms of the need for a shift in care delivery. Furthermore, Kontos (2005) argues that the concept of an embodied self must be considered to enhance the delivery of person-centred care.

5.6 Concluding Comments on the Self in Dementia

In describing these perspectives of self, it is evident that there are several differences, but it would seem a greater number of similarities in terms of perspectives of self. Multi-dimensional perspectives of self appear to include some elements of cognitive, relational and corporeal processes that can persist over time. This would seem to suggest that even in the absence of one self-process, there are remaining other self-processes that are expressed by people living with dementia at all stages of dementia. So perhaps, like every aspect of dementia care, one size does not fit all, and the most important thing is that the self of the person living with dementia is respected, supported and effectively seen for their wellbeing to be enhanced and person-centred care to be realised.

However, in drawing conclusions, it is important to be cognisant of the difficulties associated with identifying (consensus as to what self is) and researching the self in dementia (Cohen-Mansfield, Golander and Arnhem, 2000; Caddell and Clare, 2010, 2013). Additionally, Cohen-Mansfield, Golander and Arnhem (2000) caution that research and subsequent arguments in terms of the persistence of self in dementia may be influenced by the researcher's own beliefs and perspectives in relation to the persistence of self, even in severe dementia. This has been a particular point of reflection for me, given my own often dogged belief in the persistence of self throughout dementia. In a similar vein to Sabat and Harré (1992), I am puzzled by the concept that someone can lose their self. Yet, I also believe that as dementia progresses, people living with the condition may require more support to express their self and ensure it is seen. As such the social context within which the person is situated has a bearing on their sense of self. This has implications for care practices and is discussed in detail in Chapter Nine.

With reference to all the above, this thesis is underpinned by a multidimensional perspective of self, acknowledging the role and impact of interpersonal relationships but also embracing the inherent selfhood of the person that persists outside of these relationships. As stated previously, my perspective is particularly influenced by the work of Sabat (Sabat and Harré, 1992; Sabat, 2002, 2018, 2019), Kitwood (Kitwood, 1997) and Mead (Mead, 1934).

5.7 Overview of the Theory: *Holding on to Me*

The main concern of participants in this study is *losing me*. The core category, or way in which the main concern of participants is resolved or processed by participants is *Holding on to Me*. *Holding on to Me* refers to ways in which participants hold onto their sense of self, who they are, and what is meaningful to them. Although the concept of self has been explored in the literature above, there is little known about the perspectives of people living with dementia in relation to holding on to their sense of self. The grounded theory, *Holding on to Me*, generated in this study addresses this gap.

Within the context of living with dementia there are three modes of action people engage in in terms of *Holding on to Me*. These are conceptualised as *holding tighter*, *letting go* and *relational grappling*. Each of these modes are explored in the following three chapters but a brief introduction is warranted in this chapter. A graphic of the theory is available on page 87.

5.7.1 *Holding Tighter*

People with dementia in the study engage in *Holding on to Me* behaviours when there is a perceived threat of losing their sense of self. Situations within which the person experiences the threat, can relate to, for example a diagnosis of dementia, a change in functioning/cognition or change in living circumstances. However, it can also relate to the person having a bad day or experiencing something that upset them. Where the loss or potential loss is very meaningful to the person, in terms of their sense of self, they are more likely to *hold tighter* and resist the loss. The social context significantly influences how a person with dementia experiences their situation in terms of *holding tighter*. When they are involved in decision-making, supported to maintain independence, have opportunities for learning and are treated with respect, they can hold on to their sense of self. In contrast, in social environments that are restrictive and paternalistic, the person can resist threats to their sense of self, leading to feelings of mistrust and isolation. *Holding tighter* has several properties, Me not dementia (who I am, who will I be, meaning/purpose, past experience), adaptive actions (Practical, health optimising, emotional, relational) and resistance (what I believe, what others believe, what I'm told/not told).

5.7.2 Letting Go

Within the context of a diagnosis of dementia, for people living with the condition to hold on to their sense of self, they sometimes have to let go of things that they cannot control, or that no longer hold meaning for them. In *letting go* there is a vital difference between them letting go of something and it being taken from them (by dementia or others) in terms of how they then act. Essentially, letting go involves patterns of action where participants in this study let go of certain things, to preserve the people and aspects of their lives that are important to them and their sense of self. To maintain these important connections, they sometimes must let go of things, even when this is hard for them. By *letting go* they can strengthen and maintain key relationships, lessen fear and uncertainty and/or maintain something important to their sense of self. *Letting go* has several properties, acceptance (learning, social context), simplifying life (adopting/adjusting, simplifying life versus a shrinking life) and living in the present (control, dealing with uncertainty and opportunities for learning).

5.7.3 Relational Grappling

Relational grappling refers to the social interactions that either assist or hinder the person's ability to hold on to their sense of self in the context of a dementia diagnosis. In the context of dementia, *relational grappling* involves several key aspects that are essential to the person's ability to hold on to their sense of self, that essentially involve getting along with others and getting along with themselves. It is interconnected with how others see the person and how they in turn see themselves. Therefore, in terms of their sense of self, the social context, for example stigma and paternalism can have a significant impact. People with dementia in this study are not passive, but rather actively involved in balancing and reframing relationships with themselves and others to hold on to their sense of self. *Relational grappling* has several properties, getting along with others (connecting, belonging and social context), getting along with me (sorting in my head), balancing (support versus smothering) and learning (dementia awareness and making mistakes).

Figure 2, page 87, gives a graphic illustration of the grounded theory *Holding on to Me*.

5.8 Summary

The concept of self, and more particularly, the concept of self in the context of dementia is complex. Despite definite vulnerabilities associated with sense of self for people with dementia (how they see themselves and how others see them) it is clear that the concept of self is more intricate and complex than the ability to remember facts or the changes in neuronal pathways in the brain. The persistence of self in those living with dementia has been the focus of much debate for many years. There are several extant theories and suppositions endeavouring to explain the concept and argue for persistence or loss of self in dementia. From a multiple self's perspective, it can be argued that the self persists to some degree in dementia, even at end of life. Additionally, whilst acknowledging the role of others in the construction of self, the person living with dementia is an active partner in the persistence and expression of self, albeit that additional supports may be required in the later stages of the condition. This has significant implications for person-centred care practices (Discussed in detail in Chapter Nine).

Moreover, in adopting a multidimensional perspective of self, it is important to understand how people living with dementia preserve their sense of self and the supporting and inhibiting factors in this process. Yet there is a paucity of research literature relating to the perspectives of people living with dementia in relation to holding on to their sense of self. *Holding on to Me* provides a multivariate grounded theory to explain how people living with dementia maintain their sense of self in their everyday lives. This has implications for their wellbeing, relationships and for their care and support.

The completion of this chapter consists of an overview of the theory, *Holding on to Me* and its several properties, *Holding Tighter, Letting Go and Relational Grappling*. There are other considerations that must be borne in mind when explaining the theory in terms of the person's ability to *Hold on to Me* in the face of a threat to their sense of self. These are the meanings assigned to the loss/potential loss and the social context.

The following Chapters Six, Seven and Eight give a detailed explanation of the three sub core categories, *Holding Tighter, Letting Go and Relational Grappling*.

Holding on to Me:
A Classic Grounded Theory

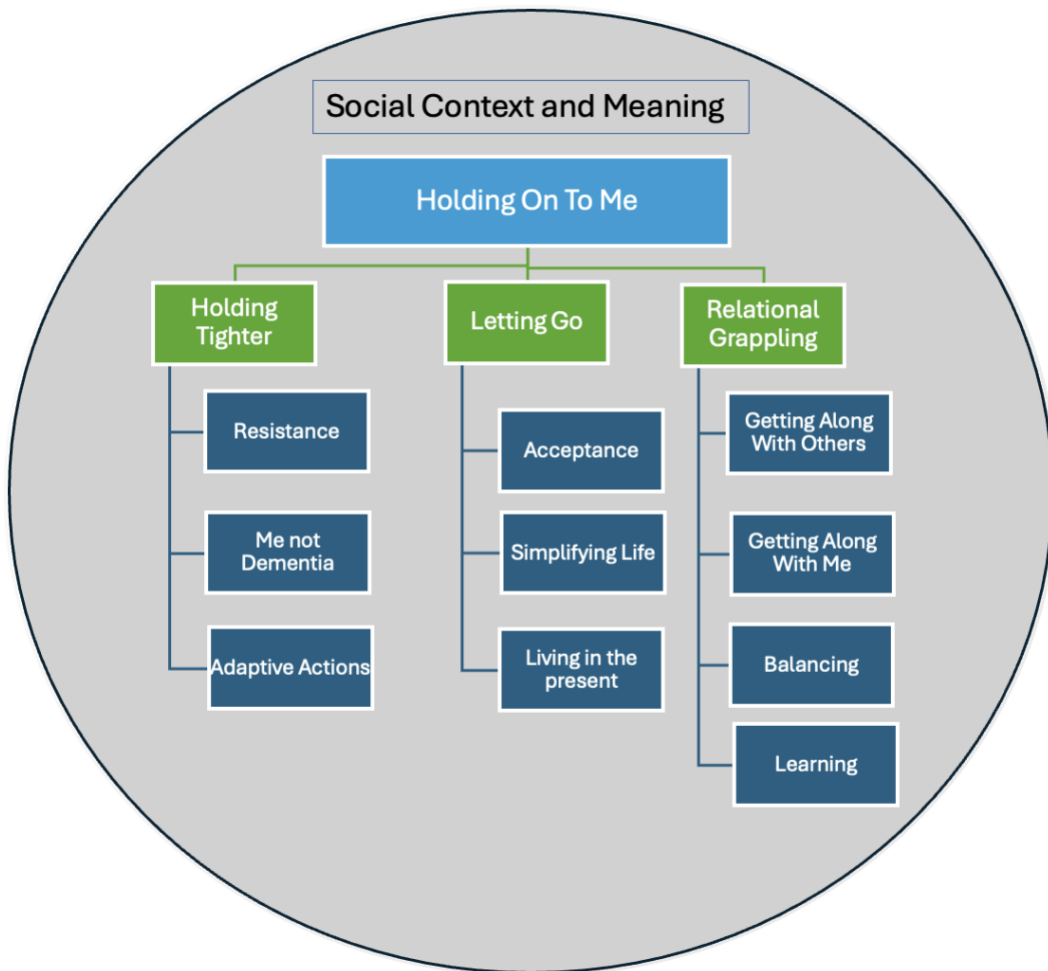


Figure 2: *Holding on to Me*: A Classic Grounded Theory

Although the graph may appear linear the person's decision in terms of holding tighter, letting go or relational grappling are influenced by social context and meaning. Additionally, this process is not static but is a dynamic process. If the person's perspective of the social context or meaning change this can influence the action that the person takes and ultimately the person's perception of success or otherwise in *Holding on to Me*.

Chapter 6

Holding Tighter

6.1 Introduction

As a reminder, the main concern of participants in this study is *losing me* in the context of a diagnosis of dementia. This seems reflective of a basic human need to preserve their sense of identity and personal significance in the light of threats to their sense of self. The theory of *Holding on to Me* was generated to explain how people living with dementia in this study resolve or process this concern. *Holding onto me* through *holding tighter* refers to participants resisting losing what they see as being core to their sense of self, and what matters to them. In essence, the things that they perceive as making them, them. *Holding tighter* has several properties, *Resistance*, *Me not dementia*, and *Adaptive actions*. What follows is an in-depth exploration of the sub core category *holding tighter* and its properties.

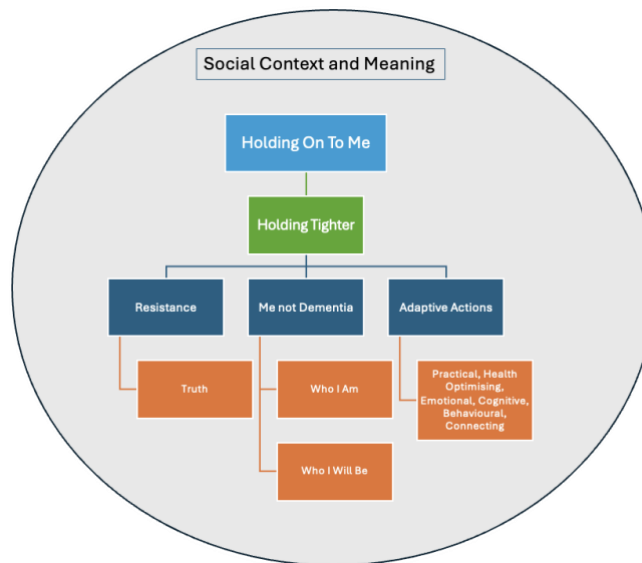


Figure 3: *Holding Tighter*

6.2 Holding Tighter through Resistance

In order to resist the loss of their sense of self in the context of a diagnosis of dementia participants must manage their own thoughts and perceptions and those of others. They often refer to having good and bad days, although good and bad can even vary within the same day depending on the situation or the impact of dementia at that moment. On the “*good days*” participants feel “...*the same*...” as they usually do and this impacts on how they view themselves. On “*bad days*” there is a need to *hold tighter* to the things that matter in terms

of sense of self. Participants voice their resistance to dementia, saying “...*I won't let it beat me...*” and “...*I'll never give up...*”. Molly says “*I'm in the early stages... I'll keep going as long as I can...I won't let it define me... that that's who I am a dementia patient... that's not me...*”. Furthermore, at times dementia is referred to as an entity itself, “...*the beast*” or “...*the fog...*” and is viewed as something to overcome.

A key factor in resistance is the meaning assigned by the participant to the loss/potential loss. For example, Jim, who's sense of self, and importantly for Jim his perception of being “*successful*” in life is as the “*taxi driver*” of the family, holds such meaning in his ability to drive that he resists being able to drive being taken from him. He tries to bargain, rationalise and look for solutions to try to get back his ability to drive. He asks multiple questions regarding how he could start driving again. Others within the family now drive Jim wherever he wants to go. Yet it is what driving symbolises for Jim, being independent, being the “*taxi driver*”, being successful and allowing him to care for his family that is important. The impact of his dementia is more pronounced in terms of his losing his sense of self, because his ability to drive was so much a part of it.

Similarly, Nora has difficulty going to her local group to play cards due to safety concerns of her family. This impacts directly on Nora's sense of self and belonging within the community. She says “...*I would rather die... if I cannot go out...*”. The loss or potential loss has so much meaning in terms of the person's sense of self that they cannot see how it can be resolved aside from being able to drive (Jim) or go out (Nora). This is particularly frustrating for the person living with dementia as from their perspective there is no valid reason they cannot do what they want to. They resist these important elements of their lives that are integral to who they feel they are being taken from them through striving to find ways to continue to do them. This can bring them into conflict with their families. Additionally, this can sometimes mean that the person feels they are being “...*hoodwinked...*” by their family in decisions that impact their lives, but which they feel they have little influence over. Jim feels that driving was “*just taken from him*” and resists that the decision was made for him without any consultation, even though he is the one impacted by the decision. He tries to hold on to his sense of self through *holding tighter* to his ability to drive as it has meaning for him in terms of how he views himself and how he perceives others see him. Consequently, he becomes frustrated and mistrustful of his family, who he feels have stopped him from driving.

In contrast Mary, willingly gives up driving as she worries she could hurt other people. Driving is not an essential element of her sense of self but ensuring that she does not hurt others is. Again, individuality in terms of meaning and sense of self is evident. Interestingly, when Mary is faced with another potential loss, that of her past memories, and knowing who her children are, she reacts differently. Unlike her ability to drive, this potential loss holds meaning for her in terms of her sense of self and so, like Jim, she resists through seeking ways she can *hold onto me* through *holding tighter* to her memories. She speaks extensively about her life, looks at photos, has a room full of old pictures and books and asks for ways she can hold tighter to her memories for as long as possible.

Whereas the meaning assigned to the loss or potential loss plays an important role in terms of the person's ability to hold onto their sense of self, so too does the level of control the person perceives they have in relation to influencing their own lives. For example, Jean says "... *when I'm told you can't... and one part of your brain says you can... you have to try... you have to learn from yourself... ..*". She has linked this directly to her having a diagnosis of dementia and making some mistakes in the kitchen saying, "*The things you do...and then I'm in trouble... before I'd do it and it wouldn't even be noticed...but not now...*". She feels her dementia diagnosis has changed how her family act towards her and she resists this to *hold tighter* to her sense of self. She says "... *I know there'll come a time when I won't even try to do it.... but for now ...I won't admit I can't do it...*". This makes her feel as if she is no longer part of the family unit, despite feeling she is the same person as she was prior to her diagnosis of dementia. She says, "*Some of them here [her family] could be chatting... and I'm not involved...and I know how they are...*". Consequently, Jean relates that she does not feel seen by her family.

There is another form of resistance that is a result of fear of the future. Jean recounts a story of having never held her grandchildren/great grandchildren (since her diagnosis of dementia) as she is afraid not only of the loss to her, but also of the impact on her grandchildren, who would only know her when she has dementia. She says, "... *I feel very empty, I have one little grandchild who is 1 year old, and I never held her... I have another great grandchild, can't hold him..... I don't trust myself.... I'm afraid of getting too close.... Will I see them for their confirmation [regarding other grandchildren] ... when these other ones [younger grandchildren] came along... you're afraid to look forward...but that's the circle of life...*".

Jean has a deep fear of what the future might hold in terms of her sense of who she will be. She fears this not only for herself but also the hurt she could potentially cause her loved ones and so resists allowing herself to get close to her newest grandchild. Even though this resistance is painful for Jean.

6.2.1 Truth as Resistance

Truth, whether in relation to interactions with others or interactions with themselves, plays a valuable role in *holding tighter* to the person's sense of self. Ronan Smith (Smith, 2021) in his autobiography speaks about initially hiding the truth of not only his own dementia but also his father's dementia. He speaks about doing extra work to compensate for the fact that his father was unable to work to the same level as he used to due to his dementia. His work in the theatre seems a defining element of Ronan's sense of self and when he was diagnosed with younger onset dementia, he initially denied to himself the truth of his difficulties and the possibility of a diagnosis of dementia. He speaks about seeing his father deteriorate and how he felt this impacted on who his father was.

Ronan Smith remembers being very careful about who he told regarding his diagnosis of dementia due to the impact on how others would see him. Similarly, Linda speaks about "...*keeping up appearances for the neighbours and family members...*". She is very cautious about who she tells about her diagnosis and has learned this lesson the hard way. She relates a story where she told her sister, with whom she was very close about her diagnosis. As a result of learning about Linda's diagnosis her sister refused to visit her and indicated to Linda that she was not comfortable and would not speak about the diagnosis of dementia. Therefore, she feels she has lost a family member who was very important to her. The learning from this situation leads Linda to be very cautious in who she tells about her diagnosis.

Participants also hide the extent of the impact of their dementia, in terms of their ability to function independently, as the possible consequences of allowing the truth to be known are too great. Nelly is a sixty-two-year-old recently retired lady, with a form of dementia that has rapidly impacted her language and movement. She hides the truth of the level of impairment caused by her diagnosis from some members of her family for fear of their reaction and consequently having to leave her home. Remaining within her home is extremely important to Nelly and her sense of self. However, in recognising that she needs

support, she shares the truth of her impairment with other family who she knows will support her to stay in her home. Nelly fears having no control over where she will live and that the decision could be taken from her. In essence she fears that others will do what they feel is best for her, even if it is at odds with what she feels is best for her.

Families can also play a role in supporting the person's truth. Luke denies he has any memory loss and says the only thing that's holding him back is physical complaints. Truth can be different for participants and their loved ones and although his wife would say otherwise, when Luke is there, she does not argue with him or challenge his belief in this truth. Similarly, Olive says on a number of occasions that she is ok, fine, and that she only has "*a very slight form of it*" [relating to her dementia]. She goes on to say that she has not even noticed any changes in her cognition, but that it was her family who had noticed. She goes into town (with family) and goes to play cards and goes dancing/singing on a Saturday night. Olive's truth is that "*...things are much the same as they were...*". Her family have put in supports and "*systems*" to ensure that her truth remains her reality. For these participants, maintaining their truth albeit with support allows them to *hold tighter* to their sense of self through them continuing to believe what is important to them.

6.3 Holding Tighter to Me not Dementia

Another way in which participants *hold tighter* to their sense of self is through telling their story. Participants want to be seen as themselves and not in terms of their dementia. In telling their stories, it is important for participants to distinguish themselves from their diagnosis of dementia. Interestingly, when participants were telling me about themselves, they became animated and were at their most comfortable. They delighted in telling their stories, even when times had been hard for them, as often the hardships of the past help them *hold tighter* to their sense of self in the context of dementia in the present. Essentially, experiential learning from the past is used to help in learning to adapt to a diagnosis of dementia.

In Kevin Quaid's book, entitled "*I am KEVIN! Not Lewy!*" (Quaid, 2021) he cites a poem written by an American gentleman William Cramer called "Who Am I". William lives with Dementia Lewy Body. His question is reflected by many other participants in that they all speak at length about who they were, house builder, cyclist, dancer, dentist, the driver of the family, the helper, the musician. Whilst in the natural course of a life roles change, it seems to be more difficult to accept when the person's identity and what matters to them, how they

see themselves or how others perceive them is threatened in the context of dementia. The participants generally accept that life changes, feeling it does for everyone and several participants state that the changes they are experiencing are part of growing older. The changes that are more difficult to accept are threats to who they are. For example, Janice becomes tearful when she says that the thing that matters most to her is *holding on* to her humour as this is a central part of who she sees herself as being.

6.3.1 Who I Am

Material objects often hold meaning for participants in terms of their sense of self. In each of the interviews, participants introduced me to themselves through photos, favourite books, their pets, their knitting, cards, musical instruments, family members and a multitude of things that add meaning for them to the stories of their life. The same objects can have totally different meanings or outcomes for people in terms of *holding tighter* to their sense of self. For Linda, her sitting room is her haven, important to her as a symbol of what she has achieved. She has meaningful mementos, furniture and photos and delights in telling the story of each item. Additionally, as she is the main caregiver of her husband who also has dementia, this room signifies space and rest for just her. She can see the road from her window and says she still feels she is a part of the community, as even when not out as she can see the comings and goings from her chair. Therefore, the room, for Linda, helps her to *hold tighter* to her sense of self. In contrast, Jean has a very pleasant, comfortable room at the back of her house, but it has little meaning for her. The main hub of the house is her kitchen, but she doesn't really go in there anymore as her family fear that she would "*burn something*". She feels she is in a part of the house where her family "*...don't see her*". Although the material object is the same, the meaning of it to the person and subsequently the consequences for losing it in terms of sense of self are different for each person.

Participant's sense of self is introduced through the telling of their stories, illustrating who they are outside of a diagnosis of dementia. For example, Tom talks about his memories as if they are his old friends saying he spends hours happily remembering his past adventures and all the places he has travelled to. He sits in a house that he has built, surrounded by people and things that are important to him. Telling his stories allows Tom to hold onto his sense of self, who he sees himself as and also who he was. By *holding on to me* through his story, he feels the same as he always has and says he feels content and happy. In this instance Tom *holds tighter* to his memories as they are important to him and allow him to influence

how he spends his day. Tom also spoke about a situation where he was in respite and tried to make suggestions about activities that they could do, however this was quickly rejected by the staff working in the care facility. As a result, Tom withdrew, said very little for the rest of his time there and has made it very clear that he will not go back there. In essence, his sense of self was undermined by the staff in the care facility. He felt he had no control or influence in the care facility and was not seen by the staff there. In this instance, *holding tighter* to sense of self through storytelling and influencing one's life seems even more important in the context of the diagnosis of dementia.

It is important for the people with dementia in the study to be seen for who they are and not solely in terms of their diagnosis of dementia. All participants related their story; they consistently used pronouns such as “I” and “Me” and “...I was always...” in their stories that had meaning to them in their lives. As discussed in Chapter Five, according to (Sabat, 2018) “self” can be thought of as having three different aspects, Self 1, 2 and 3. He states that Self 1 is expressed through the use of personal pronouns and is integral to the person's expression of self. By using these personal pronouns in their stories participants are expressing their sense of self. The stories vary but all relate to things that are important to the person and their sense of self. This includes their roles, inside and outside the home, their relationships, hobbies, work and adventures. Participants are generally proud of the lives they have made for themselves, and their story frames not only the things that are important to them but also what continues to be important to them in the context of a diagnosis of dementia. Telling their story helps give narrative to what they want to hold tighter to in the context of dementia. Invariably this relates, to some extent, to maintaining their independence and influence over decisions that impact their lives. Where people feel they can affect their story, they do not feel that dementia has impacted them to any great extent. This is also influenced by their relationships and the social environment within which they live. Telling their story helps them to *hold tighter* to their sense of self as the focus is on them and not their diagnosis of dementia.

For participants, the diagnosis of dementia can mean a certain level of relief, for others it is met with shock. For example, Tim, a sixty-nine-year-old gentleman, living with his spouse greeted the diagnosis with a certain relief. He had noticed changes in terms of his memory but now felt he had an answer as to what was happening to him. It is not that the diagnosis is welcome, but importantly, for Tim, he felt he now “...knew what he was dealing with...”

and could proactively make changes in this life to accommodate his diagnosis. Janice, a 75-year-old lady, with a recent diagnosis of Alzheimer's disease was shocked by her diagnosis and initially wondered if she had been given the correct diagnosis as she didn't feel any different. For Janice this leads to uncertainty, and she questions, "... *do I really have it...*" (diagnosis of dementia) and in relation to her treatment "...*doctors differ, patients die...*".

Distinguishing themselves from their diagnosis is important for participants. Janice says she "...*doesn't forget what's important to her... I know I can do it ...*". Essentially that she can still be herself and do things that matter to her, even in the context of a diagnosis of dementia. Tim says "*it's the disease, it's not me.... for the moment I can do it myself...*" and holds on to his ability to remain independent in this life. Nora says that if she can continue to do things (her daily routines) around the house, she's happy. Mary refers specifically to her cognition and decision-making capacity saying, "*I think I'm still capable of making a decision...I know good and bad. I know I can do it...*". For all participants, there is experience of dealing with varying levels of uncertainty in relation to not only their future self but also distinguishing between what is me and what is dementia. This is difficult at times as due to their diagnosis they sometimes doubt their ability to accurately judge their levels of ability. Janice questions her ability to trust herself in the context of dementia, saying "...*I don't know is that part of dementia...*" and "... *but am I thinking right...*". Making mistakes and doing "*stupid*" things is something that participants worry about in terms of benchmarking the impact of dementia.

Holding tighter to purpose and meaning is important, particularly if it involves routines or tasks associated with sense of self and is often linked with maintaining independence. For example, Tom says once he can continue doing things about the house, he'll be ok. This can take the form of maintaining routines, such as going to mass or cleaning the house. Nora was frustrated when she could not clean the house as she always did and Daphne became upset as she had to wait for her grandson to put up the Christmas decorations, a job that she always prided herself in doing. Learning what she could and couldn't do herself was important to Jean. When Jean felt this was being taken from her and she could not control this, she felt as if she was unseen within her family, "...I need to learn myself... I hear them talking about me... but they don't see me, but I know...". However, having an optimistic outlook is seen by Jean and other participants as important to getting on with it in the face of dementia and an uncertain future.

6.3.2 Who Will I Be

Whereas story telling relates who I am and who I was, there is also an element of imagining who I will be in the future in the context of dementia. Participants relate their worries about not being able to do the things that they want to in the future, which leads to uncertainty and a level of fear. They speak about not wanting to be a burden for their families by being totally reliant on them. They do not want to lose their independence and their ability to influence their own lives. But more so they want to *hold tighter* to what they perceive as being essential to their sense of self and their identity. This varies depending on what is important to the person. For some, it is elements of their personality such as humour. For others, it is their ability to live in their own home, even if that entails negotiating extra supports. Continuing to do something that is important, such as driving or going out with friends is particularly important to maintaining a sense of self for some participants. Ronan Smith (Smith, 2021) in his autobiography, speaks about an experience of making coffee, a task he has done with little thought most of his life, yet since his diagnosis of dementia, this task, which requires a sequence of events has become more challenging and confusing. He feels the frustration not only for himself but also for his wife, who he feels also must live with the condition. He speaks about finding a new normality, a way of living with himself and retaining his sense of self in the context of dementia. To an extent he does this by holding onto what matters to him, for Ronan this is his work, his advocacy work and his writing. Although retaining what has meaning is a constant in all the interviews and autobiographies, it differs for everyone. For some it relates to personality traits such as kindness and humour, for others it is the ability to retain meaningful connections with family and friends, for others influence over where they live or doing daily tasks. However, there is one constant and that is maintenance of independence and influence over one's life. For participants maintaining independence is important to holding onto their sense of self, although again what that looks like is different for everyone.

Within the context of dementia for participants to *hold tighter* to their sense of self, they must come to terms with the old me (who I was) and come up with ways to adapt to being a new me (who I am with dementia and who I will be). This can be challenging as the new me might not be the “...*the one people expect...*” (Joe). People's experiences of being themselves are often intertwined with how others perceive them. Blanaid says she was always known as the “boss” in the family. Jim explains that he was always known as the taxi

driver of the family. This is complicated when the participant can no longer be the person others expect them to be, particularly if they themselves have a lot of meaning in that perceived sense of me. It is not solely the “me” others expect, but the “me” the participants expect of themselves.

Ronan (Smith, 2021) and Kevin (Quaid, 2021) in their autobiographies, express feelings of uselessness that also features in the participant interviews. For participants, finding a sense of purpose and meaning in their diagnosis helps them *hold tighter* to their sense of self through finding a new perception of what “me” is for them. Participants speak about finding new meaning in life and “*something to get up for...*”. Wendy (Mitchell, 2022), in her autobiography stresses the importance for her in developing a different outlook, and making her life meaningful by grasping new opportunities, ones that may not have been available to her had she not received a diagnosis of dementia. To hold on to her sense of self, she has *held tighter* to what is meaningful and purposeful for her and she has created a new me.

There can also be a fear of the new me and this stems from uncertainty about the future, as discussed above but also lived experience of supporting or knowing others living with dementia. Molly differentiates her father, who was a “*lovely father*” from her father who required increased support as his dementia progressed. This worries her as she is very independent and fears not being able to remain in her home as dementia progresses as her wish is to “*...be carried out in a box...*”. Similarly, Janice says “*I said to [daughter]... if there’s one thing, I want to hold onto is my sense of humour... not throwing pots and pans... even downtown the other day.... I’d be witty.... I saw my sister-in-law [who has dementia], ...she’d throw her shoes...or she wouldn’t talk to you really...*”. Janice wants to hold onto her sense of self, who she perceives herself to be and who she perceives others see her as. Janice says “*... I kinda got the feeling, are people not going to want me.... maybe something that I’m telling them that’s genuine, that they might think I’m making it up...or not thinking right... but I am thinking right... but it’s just to know when to do things... I have notes everywhere...*”. She feels she has always been known as being an independent, kind, thoughtful person and would like to continue to be into the future. Although, she acknowledges that you “*...cannot see into the future...*”.

6.4 Holding Tighter through Adaptive Actions

When faced with the loss or potential loss of self in the context of dementia, participants engage in several adaptive actions to try to hold on to their sense of self. These are now discussed in terms of practical actions, health optimising actions, emotional, cognitive and behavioural actions.

6.4.1 Practical Actions

Participants actively sought strategies to help slow down the progression of the disease and stay the same for as long as possible. By engaging in practical actions, the participant tries to maintain something important to them, mitigate against or delay the progression of dementia. Often the person uses them to maintain their independence for as long as possible. Practical strategies include use of reminders, prompts, assistive technology, and future planning. Molly, like several participants, does puzzles and uses memory boards and her phone to help her compensate for her memory issues.

6.4.2 Health Optimising Actions

These actions refer to behaviours that the person with dementia engages in to try to slow down the progression of dementia and remain as functionally and cognitively able as they can for as long as they can. These behaviours include physical exercise, eating healthily, doing puzzles, reading, managing stress and engaging in activity that are meaningful. For example, Tim has joined an active retirement group, and the local keep fit classes saying “...if I can just stay where I’m at for as long as possible...”. For Michael, finding out information about his condition was a “*turning point*” in realising that he could live well with dementia and that he could still hold on to his sense of what is important to him.

6.4.3 Emotional Actions

These actions include the use of humour, gratitude, positivity, hope and living in the moment. All participants speak about others who are worse off than them and about being grateful for what they have. Blanaid speaks about “*having a little cry...*” to help her feel better when things are not going well for her. Tom says, “*but sure look, I’m still alive...there’s always someone worse than yourself...*” but despite this he does “*...pray to slow it down*”.

6.4.4 Cognitive Actions

To help maintain their sense of self people use self-talk. They speak about how they use positive self-talk but also how they admonish themselves in order to *hold tighter* to self in the face of “*bad days*”. They admonish themselves to get on with it, and use positive mantras such as “*I’m grand*”, “*I’m doing ok*”. They use self-talk to help them accept what is happening and move forward with their lives. They use phrases such as “*that’s life*” and “*you have to get on with it*” as a means of living their lives to the best of their ability in the context of a life altering diagnosis. Participants use these phrases almost as a reminder to themselves that they will be ok and that even when there is a threat to their sense of self, they will overcome it and be “*grand*”. Olive speaks about going to the bottom of her garden and giving out to herself for letting things get on top of her, she laughed as she remembered her neighbour commenting on her admonishing herself. Additionally, they count their blessings, think of others worse than them, and try to be grateful for what they have.

6.4.5 Behavioural Actions

Engaging in rituals and routines that have meaning such as mass, distraction through books, photos, music, going for walks, chatting with friends and helping others is important in terms of “staying the same”. But this is not the same for everyone and not without complexity, Alan speaks about the difficulty of reliance on others and having to “...*sit and wait for something to happen...*”. This is particularly difficult for him as he was always the organiser, the one who supported others. In this regard the deficits associated with dementia present unique problems for *holding onto me* such as apathy and diminished initiation skills. The unique presentation of the illness for each individual can vary what people do or are able to do to *hold tighter*. Additionally, it can also be that people living with dementia doubt themselves, as people in the context of a diagnosis of dementia can lose trust in themselves. Relationships become essential to maintaining control and adapting in that there is more reliance on others to support and maintain sense of self. In tandem with this there is also a recognition of the family member’s need for control and to adapt also to support the person to maintain familiar routines and hold tighter to their sense of self.

6.4.6 Connecting

All participants acknowledge the importance of family in supporting them to *hold tighter* to their sense of self. Yet conversely, this reliance has to be balanced with *holding tighter* to their independence and who they are. Blanaid has to balance *holding tighter* to her independence with not worrying her family members. She says “...yes, he does worry, but I’m capable and I’m very independent which is good. I don’t give into things...”. Yet this is tempered with a realisation that she may not be able to do everything that she used to do, “I wouldn’t go anywhere on my own in case I kinda take a wrong turn and all that jazz and I don’t want to be worrying [her family] and that, so that they’re not saying she was supposed to be here half an hour ago, so you have to kind of consider S and E, they’re worried about me and yeah so I don’t do things on the spur of the moment without telling someone where I’m going or what I’m doing yeah.”.

Luke, although he acknowledges his reliance on others, does not want this reliance encroaching on his sense of self. He becomes angry when questioned by his wife saying, “I know where I’m going...I know what I’m doing... do you think I’m mental”. However, Luke acknowledges his being “grand” is often reliant on the support of others. He says, “I’m grand as long as she gives me my tablets...”. Luke worked as a mechanic, but for him, this role did not define him. He was a talented musician with a showband, travelling around the country performing. In time his son accompanied him in performing and is himself a talented musician. The loss of his ability to play music as he used to is deeply felt by Luke and he made a “solemn vow” never to pick up his guitar again, despite encouragement from his family. Luke becomes animated when he speaks about this period of his life, and we even sang songs during our conversation, and his sense of grief and loss was palpable. However, to *hold tighter* to his music, essential to his sense of self, he goes to his son’s performances and listens to his son’s music. Whereas he *let go* (discussed in the next chapter) of his music he was also able to *hold tighter* to it through his son.

Another way in which families support the person to *hold tighter* to the person’s sense of self is by helping them to *hold tighter* to people that are important to them. Martin’s, Ciara’s and Blanaid’s families support them in maintaining lifelong friendships by arranging visits and supporting phone calls. They also support their beliefs, when they say they can do things that are now too difficult for them, helping them to *hold tighter* to the belief that they remain essentially the same. For example, Mary, does not feel that dementia has impacted her at the

moment as she has a supportive family saying, “*I don’t think it’s changed me...I don’t feel it has affected my life...I’m not missing out on things... not making bad judgements...*”. Her ability to *hold tighter* to what matters to her, with family support, allows her life to feel much the same as before.

6.5 Summary

Holding Tighter allows participants to hold onto their sense of self by holding onto what matters to them and gives their life meaning. They resist being seen by themselves or others in terms of their dementia diagnosis. They do this by telling their story and always became animated when speaking about their lives, their achievements and things that were important to them. They engage in rituals and routines that are important such as going to mass, saying prayers and going for walks. They also *hold tight* to people who are important to them and who help them to continue doing things that are meaningful to them and give their lives purpose. A sense of connection and belonging is important to all participants, and this extends from the family to the community and friends. They also engage in adaptive actions such as healthy eating, exercise and brain training to keep them “*the same*”, independent and *holding tighter* to their sense of self for as long as possible. To this end they *hold tight* to hope that they can continue to live their lives in a meaningful way.

There are factors that influence how people act in *holding tighter*. Firstly, the meaning associated with the loss/potential loss in terms of impact on sense of self. Secondly, the social context in terms of relationships, the person’s input into decision-making and opportunities for learning and adapting. This has consequences for their ability to feel seen both by themselves and others. It also has implications for the level of impact of the diagnosis of dementia on their lives and whether they feel the same or not. There is also a balancing act with family and others that the person living with dementia must navigate in recognising their reliance on others as dementia progresses but also maintaining their own sense of self and independence. Balance also needs to be considered in terms of ensuring the person can maintain their independence, when there is a safety concern. Participants tend to resist when decisions are made for them or when important aspects of their life, for example driving are just taken without consultation. However, where changes are negotiated with the person there seems to be better acceptance even if it is not something they would have wanted. The influence of relationships on *Holding on to Me* is discussed in greater detail in Chapter Eight. The next chapter explores another sub core category of *Holding on to Me, letting go*.

Chapter 7

Letting Go

7.1 Introduction

As already discussed in previous chapters, participants in this study experience varying levels of loss associated with their diagnosis of dementia. However, their main concern is conceptualised as *losing me*. This refers to their concerns relating to the loss of their sense of self, in essence what matters to them and gives meaning and purpose to their lives. How they resolve or process this is by *Holding on to Me*. The theory of *Holding on to Me* has three central properties, *holding tighter*, which was discussed in detail in the previous chapter, *relational grappling*, which is discussed in detail in the next chapter and *letting go*, which is explored in this chapter.

Essentially, *letting go* refers to a pattern of actions whereby participants in the study let go of things they cannot control, or no longer have the ability to do, to hold onto the things and people that are important to them and their sense of self. Essentially, to hold on, they sometimes must *let go*. Additionally, sometimes they *let go* of being able to do certain things they would have done, mostly due to their perceived impact on others. By *letting go* of these often contentious behaviours, for example going out alone or driving they can ensure that they hold onto key relationships with family members. *Letting go* is discussed in relation to its properties, *acceptance*, *simplifying life* and *living in the present*.

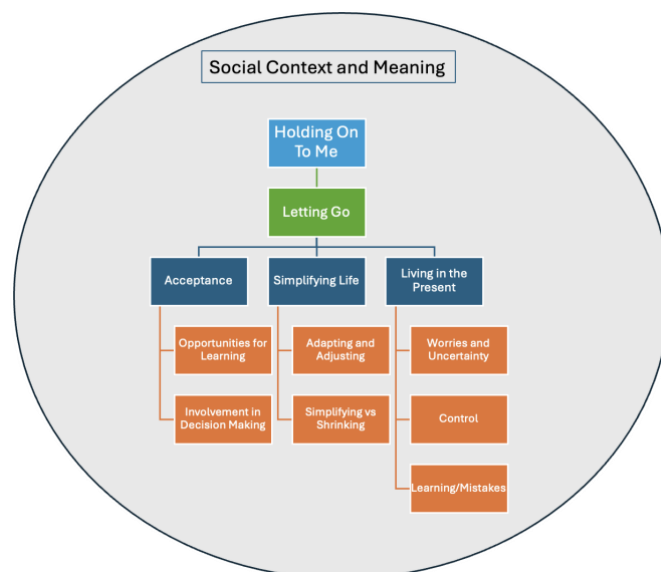


Figure 4: Letting Go

7.2 Acceptance

A central element of *letting go* to *hold on to me* is acceptance of the diagnosis of dementia but also as it progresses, acceptance of what the person can and cannot do. Tom is accepting of his diagnosis of dementia, saying you must be open to “...*taking the rough with the smooth...*”. He speaks about “*playing with the hand you’re dealt...*”. Frank is still working, but to keep doing something he has always done, he has made adaptations and does not take on as much work as he would have previously. Martin is philosophical about his life now, in the context of dementia. He says “*You accept what’s thrown at you...I suppose I’m philosophical to know, every dog has its day and my day has passed.....I don’t want to die.... but I realise it might not be far off... ..take life as it comes...*”. John says, “*I know it’s there; I know where I’m blocked with it but I’m in my 80’s...I go out walking... it helps my body and my mind...*”. He accepts that he cannot do everything he used to do and this allows him to move forward and live his life as best he can. In relation to dementia, Molly says, “... *if I have it I have it... I get on with it... my memory is bad... but I do remember things... for the age I’m at it’s good...*”. She feels she is good for her age and is grateful for what she can still do.

The meaning held by the person in relation to the loss or potential loss and the impact on their sense of self, significantly influences acceptance. Additionally, acknowledgement needs to be given to the grief associated with *letting go* and that acceptance often comes at a price for the person. Blanaid had to give up some of her caring role related to her son who has special needs. She says “...*so I don't do the medicines now in case I make a mistake so I give that to [her husband] you have to be very, very .. you have to check, and then you kind of feel, “Oh God is this the stage I'm at?... and you just sit down you have a good cry and then you get on with it “cause I love doing everything and I found that very difficult to kind of have to give that to somebody else yeah but then it just, just wait it's about safety like having somebody like (her son) and that like he has special needs..”*. Despite the grief associated with *letting go* of this task, Blanaid uses adaptive actions, such as having “*a good cry*” and self-talk to accept what she can no longer do and *let go* of it. In accepting what she can no longer do, Blanaid is able to *let go* to hold on to other things important to her sense of self, such as her relationship with her family. Additionally, *letting go* allows her to continue with her mothering role, which is important to her sense of self, as despite the grief

associated with the loss of being able to do certain tasks, she continues to put her son's safety first.

So, by *letting go* of these tasks she has held onto something that is an important part of who she is and her sense of self, her role as a mother. It also allows her to hold on to another important characteristic for her sense of self, she sees herself as a coping person. Blanaid says she was always optimistic, and she must accept what she cannot do, to hold onto this personality trait, which she feels is important to who she is. An important enabler for Blanaid in holding on to her sense of self is her supportive family. She says “...*it's how you deal with it, but I mean they're very good [her family], they would know if I was kinda sitting there, I'm not one for house hatching, sure I'm not [asks her daughter], now I love going out I love to be out but now I can't go into town on my own and I miss that then I thought you just have to deal with it love you can't change it...*”. The importance of relationships is discussed in greater detail in Chapter Eight, *Relational Grappling*.

7.2.1 Opportunities for Learning

As illustrated by Blanaid's story, acceptance is not without difficulty. As with all the other ways in which people solve/resolve *losing me*, learning and being afforded the support and opportunities to learn are essential elements of acceptance. Jean makes this point very succinctly saying “*I have to learn myself what I can and cannot do... I don't want to be told...*”. In a similar vein, Nora says “*I am woman... I never stop... I get fed up, when I can't do things... I do not accept it.... I did this job and that, and now I can't do my own job...*”. But despite this, there is also an acceptance of the fact that she must find some way of continuing to live her life and hold on to her sense of self by being grateful for what she has and so she says “... *but that's life. Now for the moment I am independent.... I have a good family...*”. Mary says that getting the diagnosis of dementia was “...*just awful...*”. However, she is “*just getting used to it*”. She has accepted that dementia impacts her life and is learning ways to continue to live her life as best she can and hold on to her sense of self. She says, “*it's just a learning things all over again... learning to cope with your limitations...*”. She is learning to adapt to a life with dementia and how to keep her sense of self in the context of a dementia diagnosis.

There are several contributory factors in considering whether people living with dementia are afforded, or avail of, opportunities to learn. Factors include the social environment,

including stigma, the caregivers' coping styles and dementia awareness. This will be explored in greater detail in the next chapter whilst discussing the sub core category of *Relational Grappling*. Another element is the person themselves, their life experience and their personality. In thinking about this, it is important to differentiate between new learning and adaptation and past experiential learning. John says his past life experience helps him cope with dementia. Participants use the coping skills they learned from past life experience to help adapt and cope with life in the context of dementia. Participants relate quite traumatic events that occurred in their lives, which they also had to let go of to hold on to their sense of self. Molly speaks about significant traumas that her family have endured and that although she didn't have direct influence over the outcome she says, "*I said lots of prayers...I did what I could do...*". Even though she cannot directly influence the situation, she does what she can to make the situation better for her family.

Acceptance does not mean that the person is not trying to make the best of the life they currently have. They want to learn to live the best life they can in the context of their diagnosis. Michael speaks about "*...looking for the best you can get...*". Despite this, participants worry about making mistakes that they would attribute, or they felt others would attribute to their dementia. David says, "*I don't make any hilarious mistakes or wonder where the hell I am or anything like that so, no problem, but I do realise that that can happen yeah and my age that I want to know you know is there any way that I can prevent me doing anything like losing myself somewhere*". David is a seventy-five-year-old gentleman, who loves to go out walking. He recognises that this could cause him difficulties as his dementia progresses and actively seeks solutions to try to deal with this concern. Similarly, Daphne doesn't think "*...she is too bad at the moment...*". She, like several participants, try to learn how to slow the progression of dementia and engage in several adaptive activities such as optimising their health and using using cognitive strategies to remain the same as they are now for as long as possible. These adaptive strategies are discussed in Chapter Six *holding tighter* but are worth noting in this chapter as acceptance is often a precursor to adaptive actions.

Being proactive allows people living with dementia in this study to hold onto their sense of who they are now whilst also trying to influence who they will be in the future. Participants adapt to maintain routines or activities, important to their sense of self. John, an eighty-year-old retired teacher, finds joy in reading, particularly Irish language books. This is proving

more difficult for him as he forgets where he left off or the storyline. He accepts that reading full books is too difficult for him now but has learned that he could let go of this old skill but gain as much joy through reading poetry. He delighted in showing me his poems and telling me how he finds it easier to keep track when the text is only one or two pages. By *letting go* of something he accepts he can no longer do, he can learn to adapt and continue to hold on to something that is important to his sense of self.

7.2.2 Involvement in Decision Making

Another consideration for acceptance is the person's involvement in, or control over, the *letting go* process. Involvement in decision making is important to participants in terms of what they let go and what they hold on to. This is particularly relevant if the loss or potential loss is of something they deem important to their sense of self. Although Alan acknowledges that he cannot drive, he finds it difficult to accept, saying “...*I've never had a crash...*” and “*terrible to get rid of the car... bad for your mental health...*”. His car is important to Alan in terms of how he sees himself, how he feels other people see him and his sense of self. He was always one to help others (often using his car in the process) and also liked to be independent, in terms of getting about, both of which he feels he cannot do, due to his inability to drive. Although feeling that it is unfair that he cannot drive, he has let it go, mainly because he feels he has little influence over whether or not he can drive. Despite all these changes, Alan does not feel that dementia has impacted his day-to-day life. This could be because he has maintained the relationships that are important to his sense of self. These people fulfil the role of driver for Alan, so although not quite the same, Alan can still do things important to him and hold onto his sense of self. Additionally, he had involvement in the decision to stop driving. Involvement in decisions impacting their lives, and more particularly in *letting go*, is important for participants and is often the influencing factor between simplifying life and a life that is shrinking.

7.3 Simplifying Life

Several participants speak about *letting go* to simplify their lives in the context of their dementia diagnosis and things they can no longer control.

7.3.1 Adapting and Adjusting

Frank speaks about his life being much the same “...*I've cut down... otherwise life is normal... just less to do... the same only smaller...*”. He has let go of areas in his life that he

cannot control, to hold onto the things that are important to his sense of self. In explaining how and why participants in the study *let go* to simplify life, consideration must be given to what the person chooses to *let go* and what they *let go* of due to other factors such as the impact of dementia, or in consideration for their relationships with others. For example, the person may decide to let go of driving outside of their locality, due to fear of getting lost, or they may decide to give it up altogether as they do not want to add additional stress to their lives or the lives of their families. Michael puts it very succinctly, when he speaks about changes in his life when he says, “*You need to simplify things... you cannot avoid stress if you’re being pulled in all different directions*”. *Letting go* to simplify their lives allows people living with dementia to hold on to what was important to their sense of self.

Martin does not really go out anymore, even though this is something he misses, as he is afraid of what others who knew him would think of him now. Yet, he does not feel his life has shrunk in a negative sense and says he is “*...doing very well, the only thing I’d like is a bit of physiotherapy... don’t go out now.... don’t want to wobble outside.... miss going out.....people looking at me... look at your man he used to go around... look at him now....*”. Yet despite this, he does not feel that life has changed significantly for him. He says “*...nothing has really changed with me.... One of my little tricks ... to walk up and down the hall and do this over my head [his exercises] ...*”. Martin feels that once he holds on to his personality and has his family, essentially the things that are integral to his sense of self, he can continue to feel that life is much the same as it has been. He has also adapted to be able to go for a small walk without having to go out. Additionally, Martin takes pride in the fact that he has devised this “*little trick*” himself and so retains an element of influence over his life, something that is important to him and his sense of self. Another element of this could be that Martin has numerous medical ailments that also make it difficult for him to get about. This has resulted in Martin deciding to *let go* of something he felt he could not control, going out, and living his life the best he could from inside his house.

In another variation on *letting go*, Molly had to give up driving due to her dementia and dizzy spells. This is not an easy change for her and even though she has accepted that she cannot drive, she feels that the impact on her is greater as the decision was not hers to give up driving. She says “*they thought I wasn’t fit enough mentally... they em...I was very disappointed when they said I couldn’t drive anymore.... So anyway, I’m getting used to not driving..... it was very difficult... then when I thought about it, I said they’re right, but I had*

to get it straight in my head... I found it very difficult to begin with". Molly had to *let go* of the disappointment of not being allowed to drive. Driving was very important to Molly as it was linked to her independence which is an integral element of her sense of self. Although Molly is unhappy about not being able to drive, she *let go* and finds new ways to remain independent, for example being proactive about asking others to bring her places. She says *"I want to be as I was... I was independent when I had the car... but I suppose I'm independent now as I have the others"*. Molly says that although she can be accepting of this now, this was not always the case, and it was initially very difficult. She says *"It's not nice when your independence is gone... but you work around it... that's the way I do it...talk to myself and sort it in my head...I do have a lot in my life and a lot of people in my life..."* Because the people in her life are important to her sense of self, Molly can reframe how she thinks about independence and this can mean that life is almost the same as it had been. She says, *"you have to get on with it"*.

Similarly, other participants also simplify their lives through adaptation. When they can no longer do an activity they enjoy or has meaning for them, they adapt it so they could continue to do it. They let go of elements of the activity they cannot do to continue to do the activity, albeit in an adapted version. For example, Luke found it very difficult when being told he could no longer use his car, restricting his ability to go to the local shop for his newspaper, which was his daily ritual. With the support of his family, he purchased a mobility scooter, and this allows him to maintain his independence and continue to complete his daily ritual. This could have been a very different outcome for Luke had he not been involved in deciding on a solution to the driving issue, one which could have resulted in a diminished sense of self.

7.3.2 Simplifying Life versus a Shrinking Life

It is important to distinguish between simplifying life and when the person's life is shrinking, beyond what they want. This seems to relate to the influence the participants feel they have in relation to what they *let go*, the meaning of the thing and if it feels to them that it has been taken rather than *let go*. Jean is a 69-year-old lady, who was very much the matriarch of the family. Her kitchen was her haven and the hub of all the activity in the household. Jean's life has been reduced to a single room at the front of her house. It is a beautiful room, with an open fire, comfortable seating, a TV and a view to the front garden. Jean appears content and relaxed in the room, yet she speaks about not being seen by her family *"...I can hear*

them...they don't see me...". The kitchen, which is where all family life happens, in Jean's house, is in the back of the house and Jean does not feel she can spend time in there as her husband is busy, doing what Jean would normally have done. Her husband, she says, is afraid she would burn something. People come and go through the back door, but Jean cannot see them as she is in the front of the house and does not feel she can go into the kitchen. She fears she'll just be in the way. She feels that due to her diagnosis of dementia her family have made assumptions about what she is or is not capable of doing. She says she needs to "*learn for myself*" what she can and cannot do, not only for herself, but also to prove to others. Jean feels that decisions are made on her behalf due to her diagnosis of dementia and this has resulted in her keenly feeling the impact of her diagnosis. The impact of relationships on decision making is discussed in greater detail in Chapter Eight, *Relational Grappling*.

Sometimes participants have little control over what or who they lose in their lives. Several participants and authors (biographies) speak about their dwindling group of friends. Although this saddens them, they can *let go* as they can still hold onto important relationships in their lives, ones that are important to maintain their sense of self. Michael speaks about friends who he rarely sees due to his diagnosis of dementia "*they take me for what I am now... if they're not interested in that...I'm not interested...*". Alan has a diagnosis of Alzheimer Disease. He speaks about having to *let go* of being the one to initiate activities in his family and friend group. Alan has worked since he was 15 years old and loved his work and the comradery it afforded him with his workmates. Since his diagnosis of dementia and particularly since he lost the ability to drive, he feels that rather than being the initiator and having control over what is happening in his life, he must wait for things to happen. He speaks about it being "*...terrible just sitting watching the TV... sitting and waiting for someone to do something...*". He is philosophical about this saying "*Everything has to end...you don't know what's going to happen...just grin and bear it...*". He does not like to have to wait on his friends to bring him places but cannot seem to see any other way to live his life outside of the support of others. This annoys him as he was always seen as the "*problem solver*" and "*provider*" for his family. He finishes our conversation by looking out the window and saying "*...looks like I'll be sitting here for ages...*". In a similar vein, Jim speaks not only about the feeling of having to sit and wait for things to happen, but his disappointment in himself because he cannot change it. Yet he feels there is little he can do about it and feels it is just part of having a diagnosis of dementia. He says "*...I suppose it's more disappointing and annoying than anything else that I can't, I have to sit and wait for*

something to happen, yeah but I, I wouldn't be, I wouldn't be annoyed I wouldn't be I would just take it as part of what's happening and not happening...".

7.4 Living in the Present

Participants also speak about life changing naturally as one grows older. This, particularly if they have led what they believe to be a full and good life, helps them to live in the present. Many participants speak about the shock of the diagnosis but also about having to *let go* of this to begin living their life again. In the context of a dementia diagnosis, feeling of lack of control over the future can impact participants' ability to *let go*. Participants' preconceived ideas about dementia and how it could impact their life also has a part to play in their ability to *let go*. Daphne says she worries about what she can and cannot do much more than she did prior to her diagnosis. She says, "*I just have to get on with it...*" and says this is a mantra that she has always lived by. She talks about several worries, since her diagnosis of dementia. She particularly worries about a time where she might not recognise her family, especially her grandchildren. Her past experiences influence her concerns regarding her diagnosis of dementia and subsequently her ability to *let go* of her overwhelming worries about being diagnosed with dementia. She tells the story of her sister who had dementia and was living in a nursing home. Her sister's husband had recently died, and Daphne was upset that her sister did not know. As a result, Daphne says she worries that what she can and cannot do is due to dementia, rather than what she would have thought before, that her difficulties were simply a part of growing older. Yet inspiringly, despite these significant concerns Daphne can still *let go* of them enough to be hopeful that she will not have the same path as her sister. She says the medication she is on, her determination to keep going, going for walks, mixing with people and the support of her family will help to keep her as well as she can be for as long as possible.

Letting go can also be about protection for some participants. For some individuals, the imagining of the potential loss associated with particularly meaningful parts of their lives in terms of their sense of self is so great that they let go of it even before they need to. Luke had been in a show band, and this was a huge part of his identity as a younger man. He likes to talk about this time but now refuses to pick up his guitar, saying that he has made a "*solemn vow*" not to. It seems to be that he still has his memories of good times with the band and the reality of maybe not being able to play the guitar would almost be another loss, in terms of his identity as a very accomplished musician.

Me: “*you were saying that you don't really get out the guitar anymore 'cause it upsets you?*”

L: *It does, very very bad, I have a brand-new guitar in the house, I won't even take it up,*

Me: *why is that?*

L: *no, no I made a solemn vow, I wouldn't go near it again [He then went on to say how good his son was and that he had a band and was an excellent musician... but it was still a loss for him]*

Me: *yeah, but your big love was the music*

L: *oh, Jesus yeah, yeah yeah big, big time, big marvellous time, I have books in there now...*

Me: *and you missed it*

L: *yeah, miss it terrible and I tell you what's wrong with me now lately, is me breathing. I can't, I used to have a strong voice, you wanna hear me, I used to have, you know people waiting out there an all, [sings a song], I loved it... ”*

Me: *what was the thing you love most about it ... ”*

L: *everything yeah, everything about it, getting out, setting up all the gear, getting it going, yeah and watching the crowd, you know what I mean, and boy Jesus, I could tell you some stories... ”.*

By *letting go* of playing music Luke can continue to be an accomplished musician and hold on to a very important part of his sense of self.

Similarly, Jean has several grandchildren but does not allow herself to hold her newest grandchild. She explains that she feels her other grandchildren know her for who she was and is, but that this newest grandchild would only ever know her as the person she worries she would become as her dementia progressed. Additionally, she also feels that *letting go* of her grandchild now would protect her from the hurt of not remembering him in the future. Both Luke and Jean *let go* of something that was very important to them in terms of their sense of self to protect their past identity, but also their interpretation of it in the present and future.

Sometimes for participants, *letting go* of the truth helps them to protect their sense of self by holding on to a belief in the present. However, in this regard the person's family also play a role in maintaining the person's truth. Blanaid takes pride in her home and is a keen baker and cook. This role has now been taken over by her husband and to hold onto something important to her sense of self, she says “... *but sure I let him do it, he likes doing it, so I let him...*”. This allows Blanaid to continue to feel she had influence in her life and this is

important to her sense of self as she says she was “*..always the boss..*”. Similarly, Ciara, says she likes to keep the house clean and tidy. In explaining her day she says “*..Yeah no, then clean up before I go to mass.... I don't like leaving it... Well, I like to have the house tidy*”. Her husband says, “*Cleaning is an obsession I think would be the word for it, wouldn't it?*”. Despite this role largely falling to Ciara's husband now, he does not correct Ciara and allows her to continue to believe something that is important to her sense of self. There is an unsaid collusion with other family members to allow Blanaid and Ciara to believe they still hold a role or are giving it up to suit others, thus holding on to their sense of self. This is discussed in greater detail in the next chapter, *Relational Grappling*.

7.4.1 Letting Go of Worries and Uncertainty

An important element of living in the present is *letting go* to manage worries and uncertainty. Several participants speak about how, due to the diagnosis of dementia, additional uncertainty has been introduced into their lives. This relates to their everyday life as it is now, and what life could become in the future. David speaks about a “*...constant half expectancy... I'm sure I shouldn't be just sitting like this with nothing to do and not, not being able to think of anything I have to do...*”. David speaks about the importance of relying on others to *let go* of worries and uncertainty. He says “*...well it stops me from worrying, ...asking the question am I supposed to be doing something? Just that I'm sure I shouldn't be just sitting like this with nothing to do and not not being able to think of anything I have to doso that's it, it's a source of anxiety, but the phone is a great a great resource and I do remember how to work it...*”. David makes the decision to rely on others, who he would contact if he was worried or unsure about what he should be doing. This is important for his sense of self, in that he can continue doing what matters to him without the worry of thinking he should be doing something else. For David, *letting go* of worries means *letting go* of control for things he feels are now outside of his influence. This allows him to hold onto the things that are important to him. David has lived in his house for 32 years. A daily routine for him is to go out onto the road in front of his house, go for a walk and collect sticks for the fire. This is something David enjoys doing and it is important to him to continue doing this. It is a part of his independence and his sense of self. Of late, David has been getting lost when he is out, and neighbours and the local shop keeper have found David and contacted his family members to take him home. Although David says getting lost is the “*ultimate disaster..*” he does not want to stop going for his walks and collecting his sticks. It is important to his sense of self and to hold onto it, he *let go* of something he feels he can

no longer control, his getting lost. David talks about handing control of his getting lost over to his team “...*I have a team for that... for finding me...*”. By *letting go* of something he can no longer control, he holds onto something that is important to his sense of self.

As with the subcategory of *holding tighter*, the meaning that participants place on the loss or potential loss on sense of self influences whether they *let go* or *hold tighter* to hold onto their sense of self. In the *holding tighter* chapter, I introduced Jim who was asked not to drive due to the impact of dementia, however, due to the meaning he placed on driving in relation to his sense of self (he is the taxi driver of the family and sees maintaining his independence as being a part of having a “successful life” and caring for his family), he cannot let go of driving and resists and *holds tighter* to his ability to drive. In contrast, for Mary the meaning of driving in terms of her sense of self is something she feels she can let go of. Mary worried about the impact of dementia on her driving and says she could not live with herself if she hurt someone on the road. She describes herself as a kind and thoughtful person and felt she was able to hold onto this persona and its meaning for her sense of self through *letting go* of her driving even though she had not been asked to abstain from driving due to her diagnosis of dementia. For Mary, the consideration was one of balancing. The meaning of driving for Mary in terms of impact on the sense of self of hurting another person and acting outside of her personality outweighed her *letting go* of her ability to drive. So sometimes, even when the loss/potential loss has meaning for the person, they must balance this with losses or potential losses that may have even greater impact on their sense of self. Similarly, Alan says he gets stressed when he forgets where his keys are, gets lost when going to the post office and regarding not being able to drive. He says “*Yeah, it’s [the car] still there because I’m scared to drive, or anything like that, because of the Alzheimer’s, and that causes me a fair bit of grief, you know, whereas [his daughter] can drive*”. He lets go of the stress of driving, by *letting go* of driving and allowing his daughter to take up this task.

Uncertainty and fear about the future for participants are often influenced by their experience of others living with dementia. Jerry tells a story about his mother who had a diagnosis of dementia. He becomes quite upset as he relates how she “...*ended up in a kip...where she just wandered around...*”. He says that if this happened to him in the future he would prefer to “...*check out.... that life is not worth living...*”. Yet Jerry says he chooses “...*not to dwell...*” on this. Essentially, he has *let go* of concerns about the future to live his life in the

present. Similarly, John speaks about *letting go* of worries and concerns relating to his diagnosis of dementia stating, “*what’s the point in getting bogged down and worrying...*”. Yet this could fluctuate and even though this is his usual stance he does admit to sometimes worrying about the future. However, by *letting go* of his worries, he can concentrate on living his life as it is and holding onto his sense of self. Learning to live in the present, John says “*I can tell you what life was... but what’s the point... it’s about how life is... that’s the key to it...*”. By *letting go* of worries about the future, participants are not denying that they exist, but that to hold onto what is important and their sense of self they need to, even for a short time, let them go. Michael says this very eloquently “*...I understand that there is a point, I won’t be able to do things, and die, but I don’t think like that...*” He goes on to say “*...I have a good life, and I intend to continue as long as I can...*”. For Michael and his wife, hope is a feature of *letting go*. By *letting go* of worries and living in the present they can hold onto what is important, hope. Michael describes himself as an optimist, that is part of his sense of self and who he sees himself as. By *letting go* he can hold onto this sense of himself. He says that he is “*hopeful that I will be able to get through it, I feel so good at the moment and that’s down to everyone in the group that looks after us... we’re going to guide ourselves... get through it.... not thinking too far into the future...*”. Similarly, Martin says “*... get over today and see what tomorrow brings.... you can’t just turn off and live in a state of depression... worry about what will happen...*”. By *letting go* of the worries about the future and living in the present, Martin can maintain the parts of his life important for his sense of self, his belonging in his family, his feeling he has influence in his life and his humour.

7.4.2 Control

There is a flip side to *letting go* of control and that is that, particularly when *letting go* for protection, *letting go* is taking control. Wendy Mitchell (1956-2024) was diagnosed with young onset dementia at the age of 58 years. She was an avid campaigner for rights-based dementia supports, writing three books and a blog entitled “*Which me am I today? One person’s experience of living with dementia*”. She worried about losing her sense of self to dementia, of not being able to control who she might become. In her books, she talks about her fear of not recognising her daughters or becoming someone, she and they would not recognise. Wendy ended her life through Voluntary Stopping Eating and Drinking and sought to hold on to her sense of self, and control through ending her life on her terms, essentially *letting go*. In her last blog she said “*If assisted dying was available in this country, I would have chosen it in a heartbeat, but it isn’t. I didn’t want dementia to take me into the later*

stages; that stage where I'm reliant on others for my daily needs; others deciding for me when I shower or maybe insisting, I had a bath, which I hate; or when and what I eat and drink. Or what they believe to be 'entertainment'. Yes, I may be happy but that's irrelevant. The Wendy that was didn't want to be the Wendy dementia will dictate for me. I wouldn't want my daughters to see the Wendy I'd become either... This was all MY CHOICE, my decision.... dementia didn't play the winning card – I did". This sentiment is shared with several other participants, although they have chosen other ways to *let go* to hold onto their sense of self and control. Both Jerry and Nora relate that they would rather die than lose what is important to their sense of self, their independence and their connections to others. They have learned other ways to *let go* of these concerns, such as looking for ways to slow down the progression of the condition and making adaptations in their lives. However as with all aspects of dementia care, how people act to *hold on to me* is different for everyone and can change over time.

The level of influence the person feels they have over the decision to *let go* is an important consideration for participants. Martin feels he still can make decisions for himself, and this is important to his holding on to his sense of self. Yet despite *letting go* of fears of the future to live in the present, he says that he “... *would like to be prepared...*”. He asks [people with advanced dementia] “...*can they talk... can they talk... not gobily gook.... Can they be clear?.....so you can still survive?*” Martin is illustrating what is important to him in terms of his sense of self and links this with his survival. In essence, holding on to his sense of self is as important to his survival, if not more so, to the person he is, as being physically alive. Although his family play a central role in helping him to plan and support him to continue to live his life in the present, he is very clear that he wants to have as much control over his own life as possible. Consequently, he feels he is “... *not changing into someone he wasn't before...*”. In contrast, Nelly feels the consequence of revealing the impact of her dementia is too great and so shrinks her ability to do things and her relationships with others. She feels that if her family finds out the extent of the impact of her dementia, she will lose her home and have to move to long term care. Therefore, even though she understands that she requires extra support and environmental adaptations to her home she is reluctant to do this as she says “...*in case they find out...*”, even though she would be able to be more independent with these supports. Nelly is essentially grappling with what to tell and what not to tell to maintain her relationship with her family and maintain her independence.

For Nora, going out and meeting her friends, and the sense of belonging that brings her is so important to her sense of self that she would “...rather be dead...” than not be able to do this. In understanding why this sense of belonging has so much meaning for Nora’s sense of self, it is important to take into consideration her past experience. Nora was born outside of Ireland. She moved here as a young woman and built a life for herself. She married, had a family and forged a network of friends and family that were important to her. She frequently visited her mother in her home country. Her husband is now dead, and she misses him greatly. She is no longer able to visit her home country, so her friendships she has built here in her community are really important to her. Another consideration is how Nora’s ability to go out to play cards and meet her friends is linked to her independence, something vital to her sense of self. She says “*I am not really invalid yet.... I am very independent...I manage myself.... for the moment I can do it myself...*”. When asked if this is important, she says “*very, very, very important...if I don’t manage myself, I don’t want to live*”. The two illustrations of Nelly and Nora, show that they want to have more influence over how they live their lives, but that this brings them into conflict with their families who they feel are restricting, or would restrict them due to concerns for their wellbeing. This results in Nora’s illbeing and Nelly not receiving the support she needs. In essence, the fear of making mistakes, and their potential consequences, whilst learning what they can and cannot do, prohibits opportunities for them to learn for themselves and seek the support they need.

7.4.3 Learning and Mistake Making

The importance of learning was highlighted by all participants as essential to accepting and adapting to their diagnosis. Essentially, participants must learn to live well with dementia. Sometimes this involves more formal learning and signposting, such as post diagnostic support. Michael talks about a “*turning point as I could understand what is happening*” after he attended a post diagnostic support session. This was important for him as he says “*you adapt as you go on...small little bites.... I want to continue as I am now.. I don’t want to get worse... and that keeps me going.... It gives you more confidence...*”. Sometimes it is more informal, with the person and their families learning to live and adapt, through trial and error and as they go along.

By living in the present, participants can let go of worries about the future and not dwell on their diagnosis of dementia. Tom speaks about “*...taking things as they come...*” and even though he has concerns about the future, he says he prefers to “*...live in the now...*”. Mary

speaks about “...*playing with what you’re dealt.... I’m not sitting here pondering...*”. Despite her diagnosis of dementia, she is getting on with it and despite the impact of dementia diagnosis, she still feels the same as she used to. John says he “... *has let go of fear... there’s no point...*”. Although he does have concerns about the future and in particular how the progression of dementia will impact his wife, he says that there is no point in worrying about it. By *letting go* of his fear of the future he can hold onto his present and the things that are important to maintain his sense of self. The ability to live in the present, and let go of worries for the future, is for some participants made easier if they are older and feel they has lived a good life. John says “... *I’ve lived a good life... I’m in my 80’s.... I’m living everyday as it comes now...*”. However, staying the same does not refer to being the same as before, but rather that in the context of dementia, where the person is able to hold on to their sense of self, they can feel the same as prior to their diagnosis. This is a fluid process that involves learning. Making mistakes is an important part of learning, yet participants feared making mistakes and saw it, or worried that, mistakes would be seen as a benchmark of their progressing dementia.

If you do a web search for the word mistake, you are sure to find numerous websites, detailing inspirational phrases regarding the certainty and reassurance that we as humans all make mistakes, the importance of learning from mistakes and a myriad of other motivational and encouraging thoughts. Whether or not you subscribe to this line of thought, does not lessen the certitude that humans regularly make mistakes. Also, that generally, they are seen for what they are, mistakes. Yet for people living with dementia making mistakes is often intertwined with conversations about risk (Clarke *et al.*, 2009; Department of Health (UK), 2010). For some participants in this study, mistakes were feared and seen almost as a benchmark for the progression of their condition. For David, the mistake of getting lost is the “*ultimate disaster*”. Blanaid stops herself from doing certain things she likes doing as she says, “*I’m afraid I’d make a mistake*”. Frank says his dementia is not having much of an impact as “...*I’m still capable of making a decision. I know good and bad...I’m not doing anything stupid...*”. Bridget speaks about not doing anything “...*disastrous...*”. The language used by participants when they talk about making mistakes illustrates the fear they have in terms of the consequences of making mistakes. Making mistakes is closely linked to how they view the impact of dementia on their ability to continue to do things that are important to them. Due to their diagnosis of dementia, there can be a tendency to mistrust themselves and making mistakes can be seen as a benchmark for them in terms of the progression of

their dementia. For these participants, making mistakes is a threat to their sense of self in terms not only how they see themselves, but also how they feel others see them. For them, the consequence of making mistakes is far greater, in terms of holding on to their sense of self. This would appear to put them in a catch 22 situation where they fear making mistakes, yet making mistakes is a part of learning and adapting to life in the context of a diagnosis of dementia. As previously illustrated, participants such as David would *let go* to manage this fear and continue to do what mattered to him and was important to his sense of self.

7.5 Summary

Letting go refers to a pattern of actions, acceptance, simplifying life, and living in the present that people living with dementia in this study engage in to *hold on to me*. In the context of a diagnosis of dementia, participants are faced with uncertainty. Their ability to accept and make adaptations in their lives is often influenced by opportunities for learning and the social context. *Letting go* of what they cannot control or do not have the ability to do can help them to continue to hold on to what matters to them in terms of their sense of self. Rather than being passive, participants are actively involved in determining the course of their actions to hold on to their sense of self, including in the decision to *let go*. Participants want to be involved in decisions that impact their lives, including what to *let go* of, rather than the decision being made for them. This can sometimes put them in conflict with their families, particularly where participants want to learn for themselves what they can and cannot do.

Within this chapter, the importance of learning and making mistakes is highlighted in *letting go* to manage the fear and uncertainty associated with progression of dementia and allow the person to continue to do what matters to them and hold on to their sense of self in the present. Yet it is acknowledged that this is more complex in the context of a diagnosis of dementia and can often be intertwined with the notion of risk and decision making. As with all aspects of dementia care, one size does not fit all and even within *letting go* there exists variations that are reflective of the person, meaning and the social context. Additionally, relationships play a role in the person's ability to *let go* to *hold onto me*. This will be discussed in greater detail in the Chapter Eight, exploring *Relational Grappling*.

Chapter 8

Relational Grappling

8.1 Introduction

As a reminder, the main concern of participants in this study is conceptualised as *losing me*. In examining how participants resolve or process their main concern, the theory of *Holding on to Me* emerged. *Holding on to Me* has several sub core categories. The sub core categories of *holding tighter* and *letting go* have been explained in Chapter Six and Chapter Seven. The sub core category of *relational grappling* is explained in this chapter. *Relational grappling* refers to participants *Holding on to Me*, their sense of self through navigating, negotiating and at times rebalancing or reframing their social relationships and interactions. For the most part, this involves family and close friends. Some participants made connections with community groups and healthcare professionals who could help them remain well and independent, have a sense of belonging or find meaning and purpose, for example the Irish Working Dementia Group, dementia advocacy work, exercise groups and memory cafés.

In the context of dementia, *relational grappling* involves not only the person’s relationship with others but also their relationship with themselves. In essence *relational grappling* explains how people living with dementia get along with themselves and others in order to hold on to their sense of self. *Relational grappling* has several properties, *getting along with others*, *getting along with me*, *balancing* and *learning*. What follows is a detailed explanation of the variations in patterns of action involved in *relational grappling*.

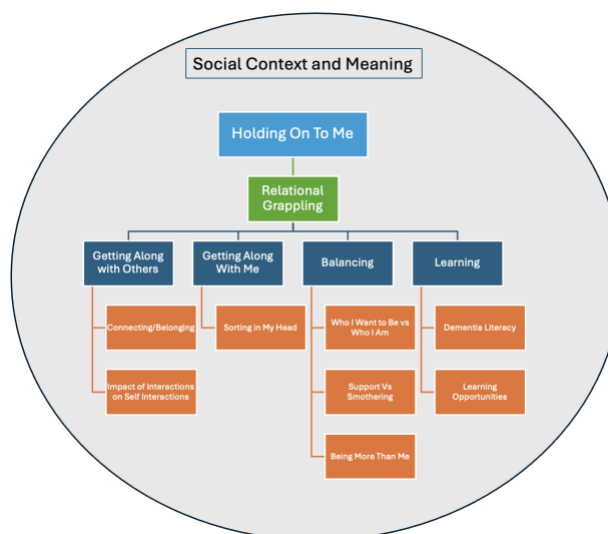


Figure 5: *Relational Grappling*

8.2 Getting Along with Others

Maintaining a sense of belonging and connecting with others is very important for people with dementia participating in this study.

8.2.1 Connecting and Belonging

In the context of the study, getting along with others relates to connecting and belonging, essentially, how others see them and the importance of being seen to their sense of self. As a reminder, Sabat (2018) drawing on social constructionist theory, posits a tripartite self. Of relevance to *relational grappling*, Self 3 refers to the “*socially presented aspect of us*” (Sabat, 2018 p. 141). Not only do we construct for ourselves multiple social personae, depending on the context, but these are reliant on the cooperation and support of at least one other person. Sabat (2018) suggests that Self 3 is the most vulnerable to dementia, in that it is reliant on others, and therefore can be influenced by the actions and attitudes of others. A possible vulnerability to Self 3, in the context of dementia, could be that reliance on what Christine Bryden (2018) terms the outsider view, may often be often contrary to how the person views themselves and indeed how they wish to be viewed by others. Without exception all participants refer to their family and friends, and their reliance on them to continue with the practicalities of everyday life such as attending appointments, cooking, cleaning, and attending to activities of daily living. These relationships are extremely important to all the people living with dementia in this study. It is not only in relation to the practicalities of daily living for which relationships are important to participants in the study, but also in their impact on their sense of self and their ability to *hold on to me*. Yet, with reference to Sabat (2018) and Bryden (2018) there is a vulnerability in that ability to *hold on to me* could be diminished where negative attitudes towards dementia exist.

Several participants use the term “*lost*” when referring to how they would feel if they did not have their families and friends support, for the most part saying phrases such as they would be “*lost without them*”. David, when speaking about his ability to manage from day to day, acknowledges his need for support from family and friends to allow him to continue to live the life he wants, saying “...*I’m quite happy and that, as long as they don’t cut me off or something, excuse me, so long as they don’t leave me standing there lost*”. For David, his relationships with family and friends allow him to continue to hold onto his sense of self in terms of supporting his ability to continue to do what matters to him.

Michael feels that if you didn't have support or if you didn't have a personality that was easy going, life would be very different. He says that the support of family and friends "*keep you going...when people have your back... it gives you confidence...*". In response to this, and recognising her role in supporting Michael to maintain his way of life, his wife says, "*I wonder does having family and friends around slow down the progression [of dementia] ... if you're on your own... what would that be like...*". There is a strong sense that Michael and his wife are working as a team to allow him to live the life he wants and have as much influence over his life as possible. Similarly, Blanaid recognises her need for support from her family to continue to live her life as best she can, she says "*...if you're living on your own and you had dementia, you could go downhill very very easily...*". Participants recognise their reliance on family in everyday life but equally as important in maintaining important relationships. Close family and friends help the person to maintain important relationships outside of the immediate family and friend circle, contributing to their sense of belonging.

Maintaining a sense of belonging is very important to all participants. This can be with family, friends or within the wider community. For several participants, family members play a central role in maintaining relationships that are important to the person. This includes facilitating visits, phone calls and supporting conversations. Connecting with others helps Blanaid to deal with having bad days. She says "*...but the most important thing is pick up the phone and chat to a friend and say, "how are you" even if it's only going to bingo or whatever it may be...*". Her family supports her to do this. Her daughter says "*...If my mam wanted to ring her friend say P, she lives in.... he [her father] would and he normally kind of does it every second week or whatever and he'd ring [her friend] maybe on our landline yeah be like is you know is it OK yeah yeah time to have a little chat with ... and yeah and then they'll be on the phone for about half an hour...*".

Similarly, Ciara has had a close friend for many years, with whom she went for walks and to clubs. This relationship has been proving more difficult for Ciara to maintain since her diagnosis of dementia, particularly in relation to planning the meetings and maintaining the conversations. Her husband contacts her friend to arrange visits and also says that he supports Ciara to maintain the conversation as it would otherwise "*...be silent pauses between them...*". Ciara's husband tries to protect Ciara, whilst endeavouring to maintain

what is important to her. Yet sometimes during the interview with Ciara, her husband's helpfulness meant that Ciara was not given enough time to answer and was vulnerable to being excluded from the conversation. This tended to annoy Ciara and shows the need for balance in terms of the levels of helpfulness and ensuring it does not impact on the person's ability to do things themselves, albeit a little slower than before. This will be discussed in greater detail later in this chapter.

Maintaining a sense of belonging is important to participants, not only in relation to the importance of connecting with others, but also in maintaining roles that are important to the person's sense of self. Olive, a seventy-seven-year-old lady and mother of seven, says it is important to have people around her. Indeed, it is one of the things she cites as central to her feeling good. She says, "*I'm fine anyhow...I'd go to town, plenty of visitors...*". Her family plays a very important role in maintaining Olive's ability to hold onto key relationships that are important to her and her sense of self. Her husband says they have a "...*very good system...*" to ensure there is family to support Olive with things she wants to do, but also just being there. This allows Olive to hold onto things that are important to her, namely, getting out and about, connecting with people and her role within the family. Ultimately, this contributes to her being able to say "...*things are much the same as they were...* [prior to the diagnosis of dementia]". However, there was a process of learning involved to get to this point, where, not only Olive, but her family were adjusting to her diagnosis of dementia. This will be discussed in greater detail later in the chapter.

Retaining relationships with his community is also important to John. John had worked in his local community for many years prior to retirement. One of his favourite routines is to go out walking in the locality. He reflects on occasions when he meets friends and former colleagues, and they tell him the local news and how he has positively impacted their lives. Through his connections in the community, he holds onto things that are important to his sense of self. John had been a member of a religious community in his past and says the sense of belonging this life brought him was important to him. His family and community are important in helping him maintain this sense of belonging and subsequently something that is important to his sense of self.

Olive and John's illustration can be contrasted with that of Nora. Nora doesn't like to stay in the house all the time, she wants to go out to meet her friends at cards. She says if she

cannot continue to do this she would rather die. Through her card games with her friends, she has built a sense of belonging with her community. She was born outside of Ireland and is proud of the relationships she has built up here. Doing this alone has become more difficult for Nora and it was no longer deemed safe for her to go out alone. This puts her in conflict with her family. She wants to maintain her independence and relationships with her friends and family. She says “...*for the moment I can do it myself*”. Yet this contrasts with what her daughter believes and she becomes quite frustrated with Nora and the situation saying “...*we had this out last weekend...she doesn't want to depend on anyone... she doesn't want to rely on anyone and if she does get to that stage she wants to die...*”. It is obvious that Nora's daughter wants to do the best for her mother. However, how Nora sees herself and how her daughter sees her are at odds, leading to tension between them and illbeing for Nora.

Participants could also feel they had little to contribute to relationships and shy away from connecting with others because of their diagnosis and the impact on their cognition. Linda speaks about how continuing to connect with people is more difficult in the context of dementia. She says “...*I was somebody who was interested in things, talking to people... the little important things... I thought I was curtailed in them, even last night I would normally do a bit of baking... but she did it [granddaughter]... but even having people over for food-seems a bigger deal to me now... that they're better than me now... I do the simple dinners I have to do that to get the better of it... even this [a family gathering she is going to] ... in the pit of my stomach... doing something, I don't really want to do ...it seems too much*”.

8.2.2 Impact of Interactions with Others on Self-Interaction

Within the context of dementia, how other people see themselves is essential to the person's ability to hold on to their sense of self. John speaks about his wife and how she supports him in his daily life. He calls her a “*marvellous woman*”. He acknowledges that his relationship with his wife has changed and that she makes decisions about his life that she would not have done prior to his diagnosis of dementia. He says “... *My wife said I was not to go into town on the bus... I said to her, that she doesn't have confidence in me... I know how to go into town... I can walk that in my head still...*”. Although he struggles to accept his wife's instruction not to go to town and feels he can still do it, in the context of his dementia diagnosis, he mistrusts himself and so accepts that his wife must be right. He says, “...*obviously she's right... as things could change and what I'm thinking in my head might be different than what it is like now...*”. Michael very eloquently illustrates the importance

of family after receiving his diagnosis of dementia in helping the person living with dementia live well. He says, *"They're looking out for you... don't be afraid..."*. Yet this is not always the case if the person with dementia and their family have differing views as to what the person should and should not be doing as in Nora's and John's illustrations. Additionally, there can be uncertainty and worry in connecting with people outside the family circle. The diagnosis of dementia can be a shock and make the person more cautious in their interactions with others. Carmel feels she is more vulnerable due to her diagnosis of dementia. She is more protective of herself now, due to her diagnosis of dementia she feels more vulnerable with others, especially those she doesn't know too well. She was always protective of others, now she feels, in the context of her dementia, that they need to protect her. How she sees herself and how she feels others see her has changed in the context of dementia.

Similarly, Linda says her son says she must do things for herself and be positive about her diagnosis and the possibility of living well with dementia.

Linda: *"I haven't done anything in a while- I started doing things for myself- going to the bank- getting the bills on direct debit- those kinds of things"*

Me: *Do you feel that getting from the shock stage [she had spoken about the shock of her diagnosis] to now, was through finding new ways to do things?*

Linda: *absolutely... to try get into town... trying on dresses... not very important things... but I'm trying to get out more... you don't really see people around now they're all working now a days, there used to be loads around here but not anymore..."*

Linda's son tries to support his mother to explore new ways of doing things to maintain her independence, something very important to her sense of self. Essentially, Linda is trying to find herself again in the context of a dementia diagnosis and her son is trying to help. Yet Linda did not always receive the support she felt she needed and later in the conversation related that she informed her sister of her diagnosis, and she now rarely speaks to her as her sister was uncomfortable and unsure what to say to her. Linda also speaks about her son, who, as detailed above, tries to help her remain independent. However, sometimes the help is what he feels Linda needs rather than what she feels herself. On one occasion, she indicates he had changed her relationship with her granddaughter by telling her to *"...help granny..."*. Linda says that she and her granddaughter enjoy many fun activities and that in that relationship, she does not want her granddaughter to become a "helper". This, she feels, would change the dynamic, how she is seen by her granddaughter and essentially how she

sees herself. She is not happy about this and says “...*I’m going to have words with him about that...*”. This illustration shows not only the complexity of social interactions, especially in the context of dementia, but also their impact on the person’s sense of self. It also shows that families and friends are also often trying to deal with uncertainty and figure out how to best support the person living with dementia.

Participants also spent time nurturing and building connections to garner information and find people who can help them *hold on to me*. They connect with others to help them to learn more about dementia, slow its progression and live well. They engage with clinical services to help them stay well and independent for as long as possible. These relationships included clinicians, but also voluntary agencies such as social clubs, exercise groups, Alzheimer Society of Ireland and memory cafés. However, this can also be perplexing for participants, particularly in non-dementia specific services and groups. Molly worries “...*are people not going to want me...even if I’m saying something that’s right will they think I’m wrong because I have dementia?*” Molly feels that people will see her differently due to her diagnosis and mistrust what she says even if she is right.

Relationships are important to participants in this study and as shown above they can support the person to hold on to their sense of self. Additionally shown above, the person with dementia’s perception of what they need is sometimes different than that of their loved ones. Bridget speaks about how she likes to have family around, but that maintaining her independence is equally as important. When speaking about tasks her family would prefer, she seek help she says “...*that’s my routine and I’m not going to change...I don’t think I’m any different, maybe someone would say that’s the label I’ll put on you [dementia] but I don’t think, at times I cannot remember something, but it’s no big deal- get over it... if I need to call support I will, but mostly I don’t, only shopping... I’m fine, sure we all have our days...*” When asked if she was concerned about the future, she says “...*whatever comes, comes and please God we’ll be able to cope with it, no I don’t know...no I just get on with it. My mam, when she was my age was in wheelchair, but she was still able to crack the whip, that’s what I see, I’ve two feet and a mind, that’s what I see*”. Bridget sees herself as independent and does not let her diagnosis of dementia interfere with that view. Although sometimes difficult for them, her family support Bridget in this. Her daughter says “...*well it ruffles her to have family around sometimes too. Yeah, cos you don’t want to take her independence, I’d try to do something, and she’d say “I can do that myself”- so I’d say feck it, do it so.... but you*

cannot blame her either... ”. Whilst Bridget’s daughter might not want her to do as much as she does, she recognises that Bridget’s independence is important to how she sees herself and how she gets along with herself in the context of her diagnosis of dementia.

8.3 Getting Along with Me

How people living with dementia participating in the study get along with themselves changes in the context of their diagnosis. This can be in terms of their confidence, trust in themselves, how they see themselves (now and in the future) and concerns about how others see the person living with dementia. Ultimately, this has the potential to impact on their sense of self. Tom says, *“I don’t care what others think, so long as I feel ok”*. This requires an acceptance of himself, of what he can and cannot do. Yet, this is not the same for everyone and the process of getting along with me can sometimes be challenging for the person, when faced with the changes associated with dementia. Wendy Mitchell (Mitchell, 2019, p. 8) talks about herself prior to the impact of dementia. She speaks of her former self in contrast to who she is now: *“I remember the frantic pace, the speed with which you tackled things. I secretly admired that...I couldn’t do that. Not now. We wouldn’t get on now, you and I...”*.

Similarly, Jim speaks about going for walks and the changes he has experienced due to the impact of dementia. Walking is an activity he previously took for granted, but it has taken on a new dimension, in terms of how he relates to himself since his diagnosis a few years ago. He says *“I mean obviously I know around here, this kind of area yeah, so I don't go outside of it walking or anything like that, I don't get panic and find myself saying “Oh my God where am I” but if I, I do feel, if I did you know just stroll along without thinking or without realising where I had been, and you know where I was going, then I, I would get a little scared, or I wouldn't panic or anything like that, it's kind of weird to find yourself like that, you feel like a baby, like a young child again, you know “Daddy, Daddy, where am I..... I know that yes I could get confused sometimes you know I go through all around here, and how do I get back to where I was, you know yeah, I think- just stay calm, be logical about it, don’t panic, you know, I do, there's no major, I mean I feel such an idiot I want to kick myself, [laughs] but yeah no I am careful and I I'm not going into any kind of situation, I hope anyway, that I might find myself completely lost you know, I won’t go into crowds or anything like that, or into places that are terribly unknown, “cos then I find sometimes that I'm walking around and oh gosh I haven’t remembered, you know to remember, and but then I can kind of turn around and think and I’ll be OK”*. Jim mocks himself and indeed is almost

derisory towards himself for not being able to do things he had previously done without much thought. He has to find some way to get along with himself and so he makes some adaptations to try and continue to do things that are important to him. Despite this, Jim says “...*I always feel slightly inadequate....*” when he compares himself to his wife who he feels has a perfect memory. This makes him unsure of who he is in the context of dementia.

Jim talks about being “wary” about himself now as he is unsure how to trust himself in the context of dementia. In part, his wariness seems to be influenced by his preconceived ideas about dementia. He speaks about the shock of receiving the diagnosis and having to come to terms with how this might impact him “... *definitely that shocked me, “Me, Demented” you know, but I don't think it's too bad, it's only a surprise I couldn't remember something, yeah that sort of thinghasn't encroached on me, at first the very word [dementia], you know, creeps , and now I say OK I'd better be careful not to get into trouble because of you know, if unplanned I find myself somewhere that I don't know or something like that, I've kind of gone wary, about how I go, how I travel, yeah I think I'm coping OK, I don't think I have any, (his wife) is terrific, the kids are too*”. Despite his family being supportive, his diagnosis of dementia has knocked how he sees himself. He wants to be as independent as possible and asks for ways in which he can maintain his independence, particularly in relation to going for walks, which was very important to him. In doing so, he is trying to find ways to get along with himself.

8.3.1 Sorting in my Head

Most participants speak about how they process what is happening in their lives through interactions with themselves (self-talk). How participants speak to themselves can impact on their sense of self, in terms of how they see themselves and also in helping them hold on to their sense of self when having bad days. Michael says “*You talk to yourself.. well Michael what are you going to do? ... you decide....*”. On days when he feels overwhelmed, Michael speaks to himself to change his thought processes to a more positive way of thinking. Similarly, Blanaid realises she cannot do some tasks she was able to do before and this impacts on how she sees herself and her sense of self. She tries to adjust saying “...*yeah it's how you deal with what life throws at you... you say to yourself, get on with it...*”. Bridget, speaks about when things frustrate her, going to the bottom of the garden and shouting to herself “...*that's the way it is, Get on with it ...*”. These illustrations show how participants use self-talk to not only work things out for themselves but also decide what to do next.

In terms of symbolic interactionism, Blumer (Blumer, 1969, p. 63) talks about self-interactions and how, due to people possessing a self, they engage in a “*reflexive process*” which involves the “*person making indications to himself, that is to say noting things and determining their significance for his line of action*”. Molly further illustrates this point and says that although she can be accepting of her limited independence now, this was not always the case, and it was initially very difficult. She says, “*It’s not nice when your independence is gone... but you work around it... that’s the way I do it...talk to myself and sort it in my head...I do have a lot in my life and a lot of people in my life...*”. Because these things are important to her sense of self, holding on to them can mean that life is almost the same as it had been, apart from physically not being as able as she used to be. To get to this stage is an active process that requires her being able to “*sort it*” in her head and decide a course of action.

Additionally, in speaking to themselves, many participants have phrases or mantras that they use often when speaking about their dementia. Phrases such as “*that’s life*”, “*you have to get on with it*”, “*I’m grand*”, “*We’re grand*”, “*I haven’t changed*”, “*I’m content*”, “*there are people worse off*” are used on multiple occasions by all participants in conversation. The use of these phrases seems to help the person change how they see themselves, but in saying them aloud it seems they also want to impact how others see them.

8.4 Balancing Relationships

Connecting with others and maintaining a sense of belonging often needs to be balanced with participants wanting to maintain their independence and not be “*smothered*” by others. For many participants, there is an uncertainty associated with their relationships in the context of dementia progression. They often wonder how relationships might change, particularly as the person with dementia may need more help and support as the condition progresses.

8.4.1 Who I Want to Be Versus Who I Am

Jim talks about his wife and how he does not want to be a burden to her. He says “*...yeah, I have a lovely wife who looks after me, I don’t put too much pressure on her, but we do get on very well.... I’m able to amuse myself, yeah and not get in the way too much [laugh], ah no, they’re good [his family] ...*”. Yet this is not without compromise for Jim and when

speaking about an imminent house move that he does not particularly want, he says “... *that's kinda upset me emotionally, I'm kinda over it now, you know yeah I would like to stay on, [his wife] gets the ideas and before I know where I am, I'm agreeing,...kinda hoodwinked... I would try to disagree, but she's the boss yeah, I don't mean that in a bad way, she looks after me, very, very well, yeah, there you are*”. And he says, in the end “...*my wife will win... it's the wise decision*”. So despite Jim feeling, at times, “*hoodwinked*” and as if he has little influence over decisions made regarding his life, he must balance this with his need for someone to support him, particularly as dementia progresses. It is important for Jim to feel he can still be involved in decisions that impact on his life despite his having dementia.

Blanaid says she loves to go into town, but she must balance this with not worrying her family. However, it's a balancing act also for Blanaid's family, who want to help her hold on to her sense of self, her independence, safety and wellbeing whilst also recognising that she may need help. Her daughter says “...*we try and suggest things, yeah to make moms life easier, that she's not getting stressed because if she's stressed about something in particular we notice that it just drains her and you know she's not sleeping ...and her anxiety is you know, my mam wouldn't have been an anxious person at all so if she's stressed over something if she thinks she's after misplacing something ...because obviously you know the short term memory might not be as good as what it was even two years ago, the stress just you know the mind is confused as it is, and then if the stress level goes up that's it, it's just like, no just so we just try and make little suggestions to make life easier*”. In making suggestions to Blanaid rather than making decisions for her, Blanaid can feel she is still a part of decision making in her life. She is then more accepting of not going to town on her own. She says “...*I don't feel safe anymore yeah I really don't and then if for some reason I got mixed up and we got off at the wrong stop, is not fair yeah so I've got to think they're worrying about me but I've got to consider they have their own lives to get on with as well and that's very important...*”. Both Blanaid and her family are trying to balance their needs with the needs of the other using dialogue and negotiation.

Nelly, whose dementia has impacted on her speech and mobility does not want to be a burden to her family. She wants to be able to contribute to the care of her mother with other family members. She says “...*I don't want to be a burden..., My mother is still alive...yeah, she's 90, yeah ..., I'm, she's bothering me as well ... yeah, she's 90 and she's bedridden.... I've got*

a huge affinity to my mother, and it worries me that, I can't go down to see her... I can't play my fair share of looking after her...and none of the others have dementia... ”. Nelly is trying to balance her need for support with her need to care for her mother by ensuring that her mother has the support and care she needs, even as it distresses her that she cannot care for her mother herself. Additionally, Nelly tries to balance how much to tell her family to get the support she requires but also still live with a level of independence. She has not told her family the extent of her difficulties as she is afraid that they would not allow her to have influence over where she would live. When asked about the impact of dementia on her life she says “... I can't do anything, I can't do anything, that affects my end of life... I just don't know what's going to be around the corner... my boys are grown up...I don't know what to say to them...it upsets me, because I didn't think I would live with dementia, I didn't think I would get dementia... yeah I'm worried about the future, once, once, I don't know what's going to be the end of me.... ”. When asked if she worries that she would have influence over her care in the future, she says “...I just think they'll put me into a home and forget about me... ”. When asked what kind of decisions Nelly would like to have influence over, she says “...em, what kinds of decisions, do I like to have influence on? I want to make sure the boys don't put me into a home.”. Nelly, acknowledging the difficulties she experiences due to her dementia, is reluctant to discuss her difficulties with her family as she is fearful that this will cause her to lose her influence over where she will live in the future, something extremely important to her. This can result in Nelly not receiving the support she needs. When speaking about some bathroom renovations that would allow her to be more independent, she says “...I'm worried about how the boys, would see that ...I don't know if I can have a say... ”. In this instance, Nelly withheld the truth about the extent of her issues as she was afraid of the consequences. Yet it means that she might not receive the support she needs to be more independent.

8.4.2 Support Versus Smothering

Balancing the level of support someone might require is a challenge for participants and families. Ciara's husband is aware of the things with which she struggles in the context of dementia. He tries to support her with these and make her life as easy and comfortable as possible. Yet, in contrast to Blanaid's situation (above), where her family made suggestions and included her in decision making, Ciara's husband's protection can mean that he tends to take over and do things for Ciara that she might be able to do herself. Throughout our encounter, Ciara's husband would as he put it “*help the conversation*” by answering for her.

Yet, when given time she was able to do this for herself. It was particularly evident when we were discussing her knitting, she became animated at this point and corrected her husband when he made wrong assumptions about the knitting. He says she was a “...*great knitter in her day...*”. When he says she is knitting a scarf, she is quick to correct him. “...*It’s not a scarf.... I decided that I was going to do gloves, make mittens...I’ll probably end up giving them to the kids...*”. Through her knitting, something she feels confident to speak about, Ciara is able to hold onto to her sense of who she is and asserts herself as an independent person.

Participants, whilst acknowledging the importance of having family in their lives to support them, try to balance this with maintaining their own sense of self and their independence. Michael says, “*a lot of people do things for you, that doesn’t help....*”. Others worry about being “*smothered*” by their loved ones. They worry that their need for additional support would mean a loss of their sense of self and that their individuality would be subsumed into the collective of the family. Blanaid says, “... *but they [her family] are actually great, well we give each other space and I think that is so important as well, you don’t want someone kind of smothering you...*”. Similarly, Janice speaks about family members calling and sometimes pretending not to be in. She says “... *family are great but sometimes you need to have a bit of time...one sister is really helpful, but she smothers me...I sometimes pretend I’m not in, when I see her car coming up the road...*”. Whilst Janice is appreciative of her family, she also wishes to remain independent and in charge of her own space.

8.4.3 Being More than Me

The previous chapter contained a detailed discussion of how participants *let go* of their worries of making mistakes to hold on to their sense of self. However, their ability to do this is often influenced by their social context and interactions. Jerry says that people often make assumptions about people with dementia, about what they can and cannot do. This can sometimes give rise to the person having to prove themselves. This can involve proving to themselves that they can continue to do something through a process of learning what they can and cannot do. Participants say that they must do this themselves. They must learn themselves what they can and cannot do, rather than having someone tell them.

When a diagnosis of dementia is given, there can be an element of circling the wagons. By this, I mean that the family/caregivers often surround the person to keep them safe, and to

do, what they feel is protecting the person. While this is important, it also entails an element of learning. Frank says that his wife has taken over certain things in the house and doesn't allow him to drive. He says "...but I know I can do it ...I would love to drive to the centre to prove to her that I am still capable". Similarly, Jim, who can no longer drive, cannot understand why. He says "...I have never had an issue...". Both Frank and Jim want to prove to others that they can still drive. This raises another issue, particularly in relation to driving, that of the safety of the person and others. This then presents a challenge for the person and those around them to balance the wishes of the person and a tendency to over protection with the person's safety and the safety of others. It requires an awareness of preconceived ideas and fears about dementia and its impact, or possible impact on the person.

This level of reflection can involve family, friends and even the wider community learning and understanding not only about dementia but also the importance of supporting opportunities to learn to overcome uncertainty and fear and hold on to what is important to the person. One of Olive's passions is playing bridge, and she is an avid and competent player. Prior to Olive joining our interview, I was sitting with her husband, and he asked numerous questions about dementia, about the information he had been given in the clinic and about how things would be in the future. He was trying to learn more about dementia, to learn how to support Olive. Her family had been the ones to notice changes in Olive that had prompted them to ask her to go for an assessment. Despite Olive feeling the same as always, her family did not bring her to bridge for a few weeks after her diagnosis as they were afraid that she would not be able for it. Her husband says "...we were all of the opinion that she couldn't [play bridge] ...but then she went and then she won... so that threw away all that fear..." ([the fear he spoke of related to her] "*dropping the cards and becoming distressed*"). The family themselves are working out what the dementia diagnosis means and balancing between keeping Olive safe and allowing her opportunities to do things for herself. Her husband says there are systems in place "*a very good system*" to help support Olive, with daily tasks, bringing her to her bridge and helping her to maintain her independence. This allows Olive to maintain her reality that "... *things are much the same as they were...*". But also, by Olive doing things for herself, her family begins to accept that she can do things. Although it was only when she won that she was supported to go back again. There could be a question that if she had lost or made mistakes, would further bridge trips have been facilitated. For some participants in the study, they need to be "more than me" to prove themselves to others as someone who did not make mistakes or forget things. In a world

where humans constantly make mistakes, it is impossible to imagine that anyone could meet this ideal. This has implications for how we support people living with dementia, but also in relation to dementia education that supports opportunities for learning and mistake making.

8.5 Importance of Learning

Most participants speak about learning. For participants, this encompasses several elements.

8.5.1 Dementia Literacy

Participants speak about learning to cope with the diagnosis of dementia, speaking about the post diagnostic supports given as helping them to understand what is happening to them and how they can live with a diagnosis of dementia. For some, this helps them to accept the diagnosis. They educate themselves on how to remain healthy and try to stop the progression of the disease, reading books, going to clubs and asking specific questions of the researcher. All participants relish their independence, and it is important for them to hold on to it for as long as they can. However, they have to learn what they can and cannot do for themselves rather than being told. Bridget highlights the need for time to learn how to live with dementia. She says “...*as time goes on you get used to the climate, you’re in..*”. Similarly, Tom speaks of how he is just “*getting used to having a diagnosis of dementia...*”.

Even in learning to live with the diagnosis of dementia, participants endeavour to learn what they can do to slow down the progression of the condition. Tim was recently diagnosed with Alzheimer Disease and wants to know how he can slow down the progression of his dementia. He says “...*I’ve read the books but was wondering if there is anything else I can do to stay the same as I am now*”. He has set out a plan for improving his health, including diet, puzzles and exercise. However, a little balance is also sometimes necessary, and Tim’s wife worries that he was becoming obsessive with his health, and using the books, almost as a benchmark for his own experience of his dementia. Staying the same as they are now, is a common theme with participants, and many request information and engage in activities that might help them to continue to live well in the context of their diagnosis of dementia. Despite the benefits of being proactive with their health and hoping that they can stay as they are now for as long as possible, participants are also aware of the course of dementia. Jerry says “...*I want to keep going for as long as I can...I don’t want to die...but I realise it might not be far off...take life as it comes...*”. Despite recognising that his dementia is progressive,

Jerry then asks about the new disease modifying dementia drugs and if they could help him stay as he is now.

Learning about dementia also helps people living with dementia and their loved ones in the study interpret differently, things that might have been important and held meaning for them. A central tenet of Blumer's symbolic interactionism argues that the meaning of things arises out of interaction, and further that the meanings of things are handled and modified through a process of interpretation that individuals engage in as they deal with the things they encounter (Blumer, 1969). So, in essence, what can be important and have meaning to the persons sense of self can be modified depending on the situation and interaction with themselves and others. Blanaid says "... *you've got to be practical, you have to deal with things how they are today, like I will hop on a bus with no bother, isn't that right? Would be in town an awful lot, but I'd be afraid I'm going to get off at the wrong stop, and I thought that's not fair worrying my family...*". In the past, one of Blanaid's favourite things to do was to go into town and was important to her sense of self in terms of her independence (she describes herself as very independent and the "boss" of the family). This has changed in the context of her dementia diagnosis and her interaction with those around her. She no longer goes into town to hold on to something with greater meaning to her sense of self, her relationship with her family and ensuring their wellbeing. Within the support of her family, she has learned what she can and cannot do and acts accordingly. Although family and friends play a valuable role in supporting the person to understand what they can and cannot do, at times this is not without its challenges.

8.5.2 Learning Opportunities

Dementia can sometimes offer opportunities for learning that are unexpected. Throughout the autobiographies, the authors almost come to a truce with the entity of dementia and detail experiences and a level of fulfilment they would not have had if they had not been diagnosed with dementia. This is not to say that having a diagnosis of dementia is to be welcomed, but more that, as Wendy Mitchell in her autobiography *Somebody I used to Know* (Mitchell, 2019) states it "*teaches harsh lessons*". According to Wendy, if you are willing to learn those lessons and embrace new opportunities it can result in a meaningful life. Wendy (Mitchell, 2019) talks about the opportunities that she may not have had, had she not been diagnosed with dementia. She must learn to identify and take those opportunities and not be defined by her diagnosis. This is also important for people living with dementia within this study as

they also want to be seen for themselves, as opposed to a focus on their diagnosis of dementia. They want to maintain their sense of self in the context of a diagnosis of dementia. This chapter has shown that this is not always an easy feat to accomplish and requires cognisance of the social context within which the person lives, their relationship with themselves, others and opportunities for learning.

8.6 Summary

Relational grappling explains how, in the context of dementia, participants in this study holding on to their relationships with others and themselves can be linked to their holding on to their sense of self. This is not without a level of complexity, and participants, often have to negotiate and balance their need for support with their need for independence. Additionally, this can lead to tensions in their relationships with others but also their relationships with themselves. Getting along with themselves and others also requires an openness to learning, not only in respect of dementia awareness, but also in relation to reframing relationships with themselves and others. Opportunities for learning are important for both participants and their supporters. The next chapter is an in-depth discussion of the theory, *Holding on to Me* and its sub core categories, with reference to the extant literature and in relation to implications for dementia practice, further research and education.

Chapter 9

Discussion

9.1 Introduction

Within the literature, there are a plethora of perspectives relating to the persistence or loss of self in the context of dementia. Indeed, a wide variety of methodologies and methods have been used to better understand the persistence, or not, of self in dementia (Caddell and Clare, 2010, 2013). Given this variation along with the complexity and lack of consensus in defining self, findings from the extant literature have been somewhat diverse. Despite this, tentative conclusions as to the persistence of self in dementia can be drawn (Caddell and Clare, 2010). The theory, *Holding on to Me*, explains how people hold on to their sense of self in the context of dementia from the perspective of their lived experience. It identifies the actions people take to mitigate potential threats to their sense of self, and the impact of factors such as relationships with self and others and the social context and environment.

This chapter explores key elements of the theory with reference to the extant literature. These elements are the self in the context of dementia; relationships and the social context; implications and recommendations for care practices; the importance of learning and recommendations for education and implications and recommendations for future research.

9.2 Self in the Context of Dementia

The loss or persistence of self in the context of dementia is explored in Chapter Five as an introduction to the theory. However, it is now examined with specific reference to the theory, *Holding on to Me*. As discussed in Chapter One, dementia is an umbrella term used to describe a range of conditions that cause changes in the brain (Begley *et al.*, 2023). In general, people living with dementia can experience deterioration in cognitive and functional abilities (Alzheimer Europe, 2016). Some may also experience neuropsychiatric and non-cognitive symptoms such as hallucinations, apathy, disinhibition and emotional lability (Cloak, Schoo and Al Khalili, 2025). Additionally, dementia's impact on the person's sense of self, and in particular the perception of loss or persistence of self in dementia has been debated extensively in the literature (Kitwood, 1997; Kontos, 2005; Caddell and Clare, 2010; Sabat, 2018; Norberg, 2019; Hutmacher, 2021).

The theory, *Holding on to Me*, supports the persistence of self in the context of dementia. Bryden (2018) in her book exploring self from her lived experience of dementia, argues that loss of self due to dementia is a misconception and one that is usually perpetuated by people not living with dementia. She refers to this as the outsider view and that from her insider view there is no loss of self. She further argues that a sense of self cannot be reduced to the ability to remember or the workings of the neurons in your brain. Stephen Post (2000) agrees, stating that the value of humans cannot be measured by their ability to remember. Further, Bryden (2018) to support the persistence of the self, from the perspective of her lived experience, suggests three aspects of self: an embodied self, a relational self and a narrative self. As discussed in previous chapters, this multidimensional perspective of self is in line with other perspectives advocating the persistence of self in dementia (Kitwood, 1997; Sabat, 2001, 2018; Kontos, 2005; Bomilcar *et al.*, 2021). An element of multidimensional perspectives of self and one way in which self is expressed in this study is through narratives.

9.2.1 Use of Narrative

In *Holding on to Me*, people living with dementia express their sense of self through their narrative (Self 1) and describe characteristics of themselves and the multiple roles that are important to them (Self 2 and Self 3). A more detailed exploration of the literature relating to narrative self can be found in Chapter Five. However further examination is warranted in relation to the theory, *Holding on to Me*.

People are narrative beings and their selves can be found in the stories they tell and the stories others tell about them (Baldwin, 2008). Baldwin (2008 p.222) begins his exploration of narrative citizenship in dementia with the line, “*Let me tell you a story*”. As he predicts, this immediately grabs the attention of the reader. *Holding on to Me* through narrative storytelling is important for distinguishing the person from their diagnosis of dementia. Through people living with dementia telling their story, they are not only distinguishing themselves from their dementia but also engaging the listener. One argument for evidence of the persistence of self in narrative is the use of first-person pronouns (Gallagher, 2000; Sabat, 2018). Gallagher (2000, p.15) further suggests that the use of first-person pronouns is subject to an “*immunity principle*”. This principle refers to the person not being able to make a mistake about whom they are alluding to when they are referring to themselves in the first-person. Another argument is naming particular personal characteristics for the expression of

Self 1 and Self 2 (Sabat, 2002). Essentially, people living with dementia are *Holding on to Me*, their sense of self, through the telling of their stories.

When words become difficult, this study highlights that the use of objects such as photos, books, and hobbies can assist in telling the person's story and express their sense of self. Therefore, it must be acknowledged that fluent, coherent verbal communication is not necessarily a requirement for storytelling, although, in these situations, there is a greater onus on others to understand what is being communicated. Kontos (2005) agrees and asserts that social interactionist perspectives of self, posited by Sabat and Harré (1992) and Kitwood (1997) reframed self away from a biomedical perspectives, thus challenging the loss of self, based on cognitive deficits. However, she states that a focus on social interaction fails to recognise the importance of the pre reflective body to selfhood (Kontos, 2005). In a similar vein, and in relation to the notion of a narrative self, Summa and Fuchs (2015) argue that there is very little consensus as to what a narrative perspective of self should involve. Indeed, they posit that whereas "coherent narrations" have a role in the self, there are also more fundamental aspects of self-experience that entail pre-reflective self-awareness and reflection (Summa and Fuchs, 2015). Additionally, self-narratives are intertwined with the narratives of others (Ricoeur, 1992). Moreover, Dennett (1988) argues that narratives are modifiable, depending on "*the way the world impinges on us*". This is important to note as caregivers play an increasing role in supporting or not supporting (impinging) the person's narrative as dementia progresses. They also play an important role in creating the narrative surrounding the person living with dementia, particularly when they might have difficulty verbally expressing their narrative as dementia progresses (Baldwin, 2008). Therefore, the social environment and the relationships within which these stories are constructed are central to, firstly, their being told, secondly, their content and thirdly, their being listened to and acted upon. So, there are important considerations in terms of narrative, particularly as dementia progresses, relating to the intention of others to listen and acknowledge the person through their story, although it might not be readily discernible at first. Additionally, the use of non-verbal communication in "telling" a story needs to be considered.

Norberg (2019) in her exploration of sense of self among persons with advanced dementia, argues that when individuals living with dementia hold on to their sense of self, they can feel as if they are the same as before their diagnosis of dementia. There are two ways in which this is explained in the theory, *Holding on to Me*. Firstly, in the present, that there is a

perception that life had not changed substantially since the diagnosis of dementia. In the sub core category *letting go* (Chapter Seven), participants speak about their lives being very much the same as always, despite their diagnosis of dementia. Essentially, through *letting go* of what they cannot control or do anymore, they can hold on to what matters to their sense of self, often resulting in them feeling much the same as before their diagnosis. Secondly, for the future, in wishing to remain the same for as long as possible, people living with dementia want to continue to do things or have relationships that are important to them to feel much the same as they always have. It was not that the person does not acknowledge that they have dementia, or that they do not recognise how it was impacting their lives, but that holding on to who and what matters to them, their sense of self, allows them to feel the same.

To stay the same for as long as possible, people living with dementia use health optimising behaviours, self-management and adaptive techniques (Chapter Six, *Holding Tighter*). They engage in various adaptive behaviours to hold on to their sense of self and stay the same, for as long as possible. They seek knowledge about dementia and engage in physical, cognitive, emotional and social activities to hold on to their sense of self and remain independent. As is later discussed in section 9.5: Implications and Recommendations for Education, increasing knowledge about dementia can strengthen the person's sense of self and agency (Hedman *et al.*, 2018). Therefore, through actively engaging in health optimising and adaptive activities to stay the same, people living with dementia are holding on to their sense of self. This is important to how they see themselves but also in how others see them. Hedman *et al.* (2018) in their study exploring the sense of self in Alzheimer's research participants, highlighted the importance of being recognised by others in terms of boosting sense of self. Although, it must be acknowledged that sometimes how the person is seen by others is outside the control of the person living with dementia and determined by relationships and the social context.

9.3 Relationships and the Social Context

Relationships are hugely important to people living with dementia in *Holding on to Me*, but there can be challenges in circumstances when there is a paternalistic approach or when their personhood is undermined. This section examines several perspectives central to *Holding on to Me* in relationships and the social context in terms of extant theories and literature.

The theoretical perspective of symbolic interactionism has relevance to *Holding on to Me* in terms of the meaning assigned to objects, but also in terms of an understanding the importance of social interactions in the formation of self. Mead (1934) places the self firmly in the realms of social interactions, stating that it can only become an object through the perspectives of others. Blumer (1969, p. 68) elaborates, stating that according to Mead (1934), an object refers to “...anything that can be designated or referred to”.

Mead (1934, p. 138) states “*The individual experiences himself as such, not directly, but only indirectly, from the particular standpoints of other individual members of the same social group, or from the generalised standpoint of the social group as a whole to which he belongs*”. Therefore, according to Mead (1934), the role of interactions with others must be acknowledged in the formation, support and maintenance of self. Similarly, the tripartite model of self proposed by Sabat and Harré (Sabat and Harré, 1992; Sabat, 2001, 2002, 2018) based on social constructionist thinking, places the role of interactions firmly intertwined with the formation of self. This is particularly relevant for Self 3, which refers to the multiple personae constructed by people which, Sabat contends, are dependent on the co-operation of at least one healthy other (Sabat, 2002). Moreover, Kitwood (1997, p. 9) argues that personhood is a value that is bestowed on the person by others. Both authors warn about the vulnerability of the self, to being diminished by the actions of others, when the focus is the characteristics of dementia and not the characteristics of the person. This is discussed in greater detail throughout this chapter, in relation to stigma, discrimination and, what Kitwood (1997) calls, malignant social psychology.

9.3.1 Self-relationships

In terms of *Holding on to Me*, it is also important to note that in symbolic interactionism, the self is not only social in terms of interactions with others but also in terms of interactions with themselves. Blumer (Blumer, 1969 p. 62) refers to this as “*self-indications*”. This has been mentioned in previous chapters but is worthy of mention here. Blumer (1969, p. 63) elaborates: “*As mentioned, the reflexive process takes the form of the person making indications to himself, that is to say noting things and determining their significance for his line of action*”.

Mograbi, Huntley and Critchley (2021, p. 68) define self-awareness as “*the capacity of becoming the object of one’s own awareness*”. They further suggest that there are multiple

dimensions to self-awareness, for example bodily self-awareness (representation of one's bodily state), metacognitive thinking (awareness and evaluation of own thoughts) and emotional regulation (Mograbi, Huntley and Critchley, 2021). Huntley *et al.* (2021) argue that self-awareness refers to multiple subjective experiences including ability to reflect on the self, self-evaluation and access to autobiographical memories, beliefs and knowledge. To *hold on to me*, people living with dementia engage in self-talk. This can take the form of "sorting things" in their head, positive self-talk, telling themselves to "get on with it" or using mantras such as "*I'm grand*". Self-talk is used in general but is particularly referred to in relation to when the person is having a bad day, to help them to think more positively about themselves and their situation. Latinjak *et al.* (2023) suggest that what we say to ourselves impacts on our actions and emotions. Self-talk is widely debated in the literature, particularly in the fields of sports and educational psychology in terms of its impact on performance and wellbeing (Latinjak *et al.*, 2023). Norberg (2019) argues that positive self-talk can reduce anxiety, boost confidence and coping and enhance relationships. Although there is a lack of research evidence relating to self-talk with specific reference to dementia, the Forward with Dementia, Australia (2025), website advises people living with dementia to "*practice positive self-talk to boost their self-image and challenge self-stigma*".

If we consider again Sabat and Harré's tripartite self, Norberg (2019, Ch. 13) states the "*How we display Self 3, depends on the situation, on how the other persons position us and how we position ourselves to them through actions or inner dialogues*". In engaging in self-talk, the person living with dementia is endeavouring to change their perspective to maintain their wellbeing and hold on to their sense of self. In terms of symbolic interactionism, Blumer (1969) argues that people are making self-indications in order to determine their course of action. This, he suggests, is evidence of the person possessing a self. In relation to *Holding on to Me*, these self-indications determine their actions in *holding tighter, letting go* and/or *relational grappling*, impacting how we should support people to engage in positive self-talk.

9.3.2 Meaning

Regarding symbolic interactionism, a further consideration in terms of *Holding on to Me* is the meaning assigned to the loss/potential loss by the person in terms of an object central to their sense of self, how they see themselves or how they perceive or want others to see them. People assign meaning to objects in their lives. As explained by Blumer (1969), this can

refer to anything. With reference to Mead (1934) he states: “...objects are human constructs and not self-existing entities with intrinsic natures. Their nature is dependent on the orientation and action of people toward them...In short, objects consist of whatever people indicate or refer to”. In relation to *Holding on to Me*, the actions taken by the person living with dementia to hold on to their sense of self are often determined by the meaning the object held for their sense of self. When something has great meaning for the person in terms of their sense of self, for example driving, they resist it being taken from them (*holding tighter*). They would try to find ways to continue driving. This could involve trying to negotiate with others how they could continue to drive (*relational grappling*). If this is unsuccessful it can lead to illbeing and diminished sense of self for the person and tension between them and their loved ones. If, on the other hand, driving has little meaning for the person in terms of their sense of self but ensuring they would not harm someone on the road (their perception of being a kind, caring person) does, they might *let go* of being able to drive to hold on to their sense of self and their view of themselves as a caring person. In both cases, their actions could also be important to their sense of self in terms of how they want others to view them (example 1, the driver of the family/looking after their family, example 2, the kind person, looking after others). Therefore, the meaning assigned by the person to the loss/potential loss can impact on their course of action in holding on to their sense of self.

In a further consideration of meaning, Blumer (1969, p. 63) distinguishes between non-symbolic and symbolic interactionism, noting that people respond, for the most part, to situations, people and interactions by choosing to act, rather than responding automatically. This is crucial for this study as people living with dementia are actively engaging in *Holding on to Me*, essentially holding on to their sense of self. Their responses, for the most part, are not automatic, they are deliberate, shaped by awareness of interactions with others and themselves. They are active agents in holding on to their sense of self, both in terms of how they see themselves, but also in responding to how others see them. *Holding on to Me* does not imply that people living with dementia do not act automatically at times, but a point needs to be made that they are, and are able to be, active participants in their lives and care, not passive role players. Active participation of people living with dementia is essential to enhancing person-centred approaches, although often not acknowledged or prioritised in many care settings (Bosco *et al.*, 2019). Additionally, the person’s ability to *hold on to me* could be challenged in settings where their active involvement is neither sought or supported, or paternalistic approaches prevail. As such, it is important to note that this theory

acknowledges that relationships for people living with dementia, both with themselves and others, and their assigned meaning, do not happen in a vacuum but are influenced significantly by the social context.

9.3.3 Impact of Relationships and the Social Context

The theory, *Holding on to Me*, highlights the impact of others, not only on how the person sees themselves, but also on how they feel others see them. This can mean they feel they have to prove themselves to others to continue doing things they would have done prior to their diagnosis. Additionally, people living with dementia might not be included in decisions impacting their lives due to a focus on dementia rather than the person and misconceptions regarding their ability to be involved. In Sabat and Harré's tripartite model of self, Self 2 relates to physical and mental characteristics and related beliefs (Sabat and Harré, 1992; Sabat, 2002). However, Self 2 consists of past attributes (for example, being a student), and newer attributes (having dementia). If we then take Self 3 into account, which relates to the multiple social personae of the person that require the cooperation of others to construct (for example being known as a diligent student), others' view of the characteristics of Self 2 matter in terms of preserving Self 3. For example, if the person is regarded by others in terms of their deficits associated with dementia (a dysfunctional Self 2), their Self 3 persona is restricted to the "patient" or "dementia sufferer". If however, the focus is on the person's healthy Self 2 characteristics (for example, humorous, kind, helpful), then the person can construct Self 3 personae they can enjoy and feel represents who they are (for example, a humorous, kind person, a beautiful dancer) (Sabat, 2002).

Where the person continues to be seen as a person, rather than in terms of their dementia, this can lead to an environment that promotes active partnership in decision making, and opportunities for learning to adapt to the diagnosis. The impact of the diagnosis of dementia is, therefore, minimal to the person's sense of self as they can continue to do, and be, what is important to them. However, this is not the case where the person is seen in terms of their dementia, they can feel excluded and "not seen", even within their own home. This can lead to a diminished sense of self and feelings of ill-being. It can also lead to tensions with other family members, adding to feelings of "them" and "me" for the person.

9.3.4 The Impact of Others and Stigma

Issues can also arise for the person living with dementia where they see themselves as being the same but are seen as being different by others and at a societal level, leading to a dilemma between how the person sees themselves and how others see them (Alzheimer Europe, 2016). Concern about how others see them, within and outside the family can lead to people living with dementia not disclosing their diagnosis due to fear of the negative attitudes of others (Alzheimer Europe, 2016). They can feel that due to their diagnosis they are seen as less capable, or incorrect in what they are saying, even when this is not the case. This can result in their isolating themselves from others, particularly people they do not know well. This feeling of disconnection with their community and sometimes their family can lead to feelings of loneliness, impacting the person's wellbeing and their sense of self. Feelings of loneliness amongst people living with dementia have been linked not so much to the changes associated with dementia but rather negative attitudes regarding dementia leading to changes in relationships and community connections (Alzheimer Society of Ireland, 2019).

Erving Goffman, a sociologist in post-World War Two America described stigma as something that changes how a person is seen by others from a "*whole and usual person to a tainted, discounted one*" (Goffman, 1963, p. 12). In 2019, Alzheimer's Disease International (ADI) commissioned a survey to be undertaken by the London School of Economics and Political Science (Alzheimer Disease International, 2019). The global survey had almost 70,000 responses, making it the biggest of its kind at the time. The groups targeted in the survey were, people living with dementia, caregivers, healthcare practitioners and the general public. The main focus of the survey was exploring perspectives of dementia and in particular dementia related stigma. The subsequent report highlighted a lack of knowledge and an abundance of misconceptions about dementia, not only amongst the general public but also worryingly, healthcare professionals. They found that this lack of knowledge and myths surrounding dementia, are directly associated with dementia related exclusion, discrimination and stigma (Alzheimer Disease International, 2019). Stigma can also extend to family members, and this can have a detrimental impact on not only their wellbeing, but the wellbeing of those people with dementia for whom they are caring (Alzheimer Europe, 2016). A sense of excess disability associated with stigma in the context of dementia, not only impacts wellbeing and confidence but can also lead to a sense of loss of autonomy (Yates *et al.*, 2019). Additionally, the actions of others can result in diminished

sense of self, again resulting in excess disability (Sabat, 1994; Kitwood, 1997). *Holding on to Me* in relationships can be more difficult for people living with dementia due to what Swinnen and Schweda (2015, p. 9) call the “*alarmist rhetoric*” within society and the media, which impacts on how they view themselves in the context of dementia. Werner *et al.* (2021) in their study examining dementia fear among lay persons, people with mild neurocognitive disorder and their relatives in Israel and Germany identified two main themes. These were fear of developing Alzheimer’s Disease (AD) and fear of the stigma associated with AD. Furthermore, how dementia is represented in the media is associated with negative attitudes and feelings and social distance between those living with dementia and those without (Low and Purwaningrum, 2020).

There is a further consideration in discussing *Holding on to Me* regarding relationships and social context. In holding on to their sense of self, people living with dementia are also challenging the stigma and discrimination associated with the diagnosis of dementia. In 2016, Alzheimer’s Disease was the most feared conditions in the over 50’s, ahead of cancer in a survey of 376 people in Norway (Bystad *et al.*, 2016). They concluded that the fear associated with Alzheimer’s Disease, could in part be caused by coverage of the condition in the media, and this is reiterated by multiple authors (Cahill *et al.*, 2015; Bystad *et al.*, 2016; Cahill, 2021). Despite the often negative rhetoric surrounding the condition, people living with dementia speak about not letting dementia beat them. They seek opportunities to learn how to live well with their diagnosis. They adapt to continue to do things that are important to them, through *holding tighter* and *letting go*. They engage in *relational grappling* to maintain, renegotiate and let go of existing relationships and build new important relationships. In doing so they are actively trying to hold on to their sense of self.

The challenges faced by the person living with dementia in terms of *Holding on to Me* are influenced by the attitudes and behaviours of the wider society, including healthcare professionals. Alzheimer Europe, in their *Discussion Paper On Ethical Issues Linked To The Changing Definitions/Use Of Terms Related To Alzheimer’s Disease* (Alzheimer Europe, 2016) argue that the labels and terms used to describe dementia have far-reaching, often unthought-of consequences. For example, they refer to the term “disease” and how this can have both positive (increased caring) and negative (stigma) impacts on personal behaviour (Alzheimer Europe, 2016). There has been increased medicalisation in terms of the terminology used to discuss dementia in the last number of decades. This has resulted in a

tendency to pathologise, not only dementia but also growing older (Alzheimer Europe, 2016). It has also led to several stigmatising labels such as “*living death*” or “*empty shells*” (Alzheimer Europe, 2016 p. 8). This medicalisation of dementia often adds to the stigma associated with the condition (Alzheimer Europe, 2016; Cahill, 2021). Of particular concern is the acknowledgement that discourses associated with dementia are not limited to biomedical parlance, and new interpretations and public representations are increasingly coming from the media (Swinnen and Schweda, 2015).

Stephen Post (2000) argues that there is an emphasis in Western cultures on cognition and that humans should not be defined by their ability to remember things or their material successes. He further suggests that the prevalence of a hypercognitive society in Western society makes people living with dementia vulnerable to stigma, discrimination and paternalism (Post, 2000). In turn, stigma adds to the fear associated with a diagnosis of dementia (Cahill, 2021; Werner *et al.*, 2021). Supporting people with dementia to *hold on to me* enhances person-centred care and wellbeing of people living with dementia. Yet when this selfhood is not recognised or supported this can lead to illbeing, excess disability and interpersonal issues (Sabat, 1994; Kitwood, 1997; Dewing, 2008a; Kelly, 2010). How dementia is depicted in the media and negative stereotypes not only impacts how others see the person but also how they see themselves (Low and Purwaningrum, 2020). Additionally, people living with dementia and their families, who perceive negative stereotypes and discrimination relating to their dementia from the public and healthcare professionals reported, tend to isolate themselves, have more negative feelings toward themselves and even delay getting help (Nguyen and Li, 2020).

Bhatt *et al.* (2021) defines self-stigma as “*a cognitive process whereby an individual internalises negative stereotypes and prejudice related to their stigmatised self*”. They further suggest that people living with dementia are particularly vulnerable to self-stigma. This can lead to the person mistrusting their own ability and accepting restrictions on what they can do, even if they feel the restriction is not justified. It can also mean that they feel they have little of interest to contribute in terms of conversation with others, even within the family, due to their diagnosis. Consequently, people living with dementia and their caregivers can isolate themselves from relationships and supports that could enhance their wellbeing (Bhatt *et al.*, 2023; O’Shea *et al.* 2017). This has implications caregivers supporting people living with dementia who can experience loneliness in their caring role (Alzheimer

Society of Ireland, 2019). It also has implications for people living with dementia having opportunities to seek support in social environments that support their sense of self. *Holding on to Me* emphasises the importance of a supportive social context and environment to support positive sense of self, growth and learning, thus promoting wellbeing and inclusion. Similarly, Cheston, Christopher and Ismail (2015) recognise the significance of self-esteem, social connectedness and meaning in life as a means for managing dementia as an existential threat. They conclude that when people living with dementia feel good about themselves, are connected with their worlds and have meaning in their lives, they are better able to live well with their diagnosis of dementia. This has implications for how people living with dementia are supported to hold on to their sense of self in all social contexts, including healthcare settings.

9.4 Implications and Recommendations for Care Practices

The concepts of self, personhood, identity and selfhood have been used interchangeably in the literature. As already stated, the term “self” will be used in this thesis, unless specifically referring to authors using different terms. When referring to dementia, the work of Tom Kitwood (Kitwood, 1997), is most used in terms of the concept of personhood (Hennelly and O’Shea, 2022). In the last number of years there has been a focus on dementia care in terms of prevention, assessment and care delivery in Ireland and an acknowledgement of the need for multi-dimensional interprofessional approaches to dementia care (Begley *et al.*, 2023). To examine the implications of the theory *Holding on to Me* in terms of clinical practice it is necessary to look at the landscape within which dementia care is situated in Ireland and globally.

To address the complexity of dementia and following suit with other countries the Government of Ireland launched the National Dementia Strategy in 2014 (Department of Health, 2014). The strategy provides a comprehensive framework for supporting people with dementia, their families and caregivers. It encompasses a wide range of initiatives to enhance care, support and raise awareness, detailed in six priority action areas.

- Increasing understanding of dementia, both within healthcare settings and the wider society.
- Promoting timely diagnosis and intervention including prompt access to diagnostic and post diagnostic services and therapeutic interventions.

- Developing integrated pathways between services to provide seamless transitions of care across the lifespan of the person with dementia.
- Driving cultural change and ensuring a skilled and responsive workforce through training and education.
- Building dementia research capacity and information systems for monitoring prevalence and effectiveness of interventions.
- Clear leadership and governance structure to oversee its implementation.

The dual overarching principles of the strategy are personhood and citizenship (Department of Health, 2014). To fulfil this remit, the National Dementia Office (now National Dementia Services) was established to oversee and champion the implementation of the strategy and its aims of improving the quality of life for people with dementia and their caregivers thus creating a more dementia inclusive society. It can be surmised then, that there is, at some level, Irish Government recognition of the challenges faced by dementia to individuals, caregivers and society and prioritisation of personhood and person-centred dementia care. Yet as we have already seen this can be a complex concept that can be difficult to deliver.

Similarly, The World Health Organisation (World Health Organisation, 2017, pp. 8–9) in their ‘*Global action plan on the public health response to dementia 2017-2025*’ set out seven action areas to provide a framework for the plan:

- Dementia as a public health priority
- Dementia awareness and friendliness
- Dementia risk reduction
- Dementia diagnosis, treatment, care and support
- Support for dementia carers
- Information systems for dementia
- Dementia research and Innovation

Underpinning these actions is upholding and promoting the human rights and personhood of people living with dementia to reduce stigma and discrimination and promote inclusivity (World Health Organization, 2017). So, in a landscape that aspires to person-centredness, human rights, quality of life and active partnership, this theory offers a perspective from the lived experience of people with dementia. The theory *Holding on to Me* emphasises that

people living with dementia are actively involved in holding on to their sense of self, what and who has meaning and matters to them. Essentially, they too are endeavouring to attain these ideals, outlined above, and their perceived success or otherwise in doing that has a direct impact on their wellbeing. *Holding on to Me* supports the overarching principles of personhood and citizenship but also advocates the importance of people living with dementia being part of the solution in terms of how these ideals can be become a reality. This is an important consideration, given that maintaining personhood through person-centred care is, even considering policy ideals, often still absent in health and social care settings (Bracken-Scally et al 2019; Bosco et al 2019). As previously alluded to, *Holding on to Me* highlights another issue in terms of realising maintenance of self in the context of dementia, namely, the attitudes and assumptions of others. This is particularly impactful if there is a perception of loss of self in dementia. So whereas these global and national policy and ethical ideals for dementia care are to be saluted, there may be some difficulty in embracing them when people living with dementia are seen by others as having a diminished or lost self (Kitwood, 1997; Dewing, 2008a; Schweda and Jongsma, 2022). It is therefore essential to examine the social context and the care environment.

9.4.1 Social Context and Care Environment

As stated, the theory *Holding on to Me* supports the perspective of the persistence of self in the context of dementia. Additionally, there is a tentative consensus in the literature regarding the persistence of self in dementia (Caddell and Clare, 2010). Despite this, prevailing views on the loss of self in dementia, particularly in the media can add to the fear associated with dementia (Cahill, 2021) and impact attitudes towards people living with dementia (Swinnen and Schweda, 2015; Schweda and Jongsma, 2022). Kitwood (1997) suggests that there is a particular fear associated with dementia that may not be present with other conditions. This fear relates to not only ageing, frailty and cognitive decline, but worse still to “*entering the realm of unbeing, where even the sense of self is undermined*” (Kitwood, 1997 p. 14). This globally felt fear of dementia is reiterated in the literature and the media (Bystad *et al.*, 2016; Cahill, 2021).

In relation to healthcare, Dewing refers to the potential impact of such rhetoric on care practices when she comments that “*healthcare systems are acquiring large groups of ageing people with a condition traditionally portrayed as a slow living death*” (Dewing, 2008a, p. 4). So, if as Millett (2011) argues there is a widespread perception that there is a loss of self

associated with dementia, this presents a difficulty for care that is based on the premise of promotion and maintenance of selfhood and personhood (Dewing, 2008a; Millett, 2011). Sabat (2002) argues that people living with dementia are often in situations, particularly in healthcare settings that focus on new Self 2 characteristics (based on the diagnosis of dementia), which in turn makes other older Self 2 characteristics (humorous, kind) become more and more invisible. As stated, people may be less likely to even seek help if they fear the attitudes of healthcare professionals (Werner *et al.*, 2021; O'Shea 2017). So, we can take an example from this study to illustrate this point. Tom is an adventurous, lively gentleman, who likes his quiet time but also loves spending time with others. Within his own home, Tom comments that dementia has not really impacted him and he feels much the same as always. To facilitate his wife travelling to a family occasion, Tom has agreed to go into respite for a week. Within respite he notices that there are activities available for residents however, nothing that really interests him, or indeed, he says, many of the other residents. He decides to make some suggestions to the staff, which are met with what he refers to as a firm no. All suggestions were met with the same response and so, Tom says he withdraws, does what he is told and simply waits his time until he can go home. In this situation Tom feels dismissed and that he cannot be an active participant in how he spends his day, due to the attitudes and behaviours of care staff. He says he will never go back there again.

The scenario above highlights that although the promotion of personhood through person-centred care underpins current policy and care direction, the reality for people living with dementia is often different. Despite the fact that the concept of person-centred care is used frequently as a marker for excellence in care, there is very little thought or use of the concept of personhood as integral to person-centred care (Sofronas, Wright and Carnevale, 2018). This could signify a possible disconnect in terms of nurses actually linking the concept of person-centred care to the concept of personhood (Sofronas, Wright and Carnevale, 2018). Additionally, Dewing (2008a) argues that despite person-centred care in dementia being seen as essential to excellence in nursing care, there is often uncertainty as to what person-centred care, and indeed personhood actually means. The theory, *Holding on to Me* , highlights the importance of recognising and supporting self, from the perspective of people living with dementia. Given that people living with dementia are the intended focus of person-centred dementia care, *Holding on to Me* cannot be ignored in the provision of person-centred dementia care. The theory of *Holding on to Me* , whilst acknowledging the importance of others recognising and supporting the self of people living with dementia in dementia care,

adds another consideration to the discussion. People living with dementia are actively trying to *hold on to me* in the context of their dementia. One size does not fit all and people with dementia need to be actively involved in learning what holding on to their sense of self means for them. It cannot be decided by others and requires a move to a different care approach. In particular, the theory supports the calls for a shift in the focus of care to a more partnership-based approach to person-centred care (Bosco et al., 2019).

This study highlights that for nurses and healthcare providers to meet the needs of people living with dementia, there is a need for a shift in focus from traditional, task orientated models of care. Instead, what is needed is care that is based on a person-centred approach that recognises and nurtures the self of the person, their uniqueness, abilities and life narrative. Bosco *et al.* (2019) suggest that despite current care approaches claiming the term person-centred care, people with dementia are often seen as passive recipients in care. They posit that personhood can be supported and maintained through the person's active participation in care. Furthermore that this is often not the reality in the culture of care delivery, with power imbalances persisting, despite the use of the term, person-centred care (Bosco *et al.*, 2019). Werner *et al.* (2021) argue that decline occurs in dementia, not only due to the neuropathology of the condition, but due to the impact of malignant social psychology (MSP) on the personhood of the person living with dementia. MSP, stems from the work of Tom Kitwood (Kitwood, 1997) and refers to the attitudes and behaviours of others that undermine personhood, relevant to all care settings. Additionally, as approximately 63% of people living with dementia are residing at home (O'Shea et al, 2023), the shift in care approaches also applies to informal caregivers.

Nurses support people living with dementia and their caregivers from first presentation with memory concerns to end of life care in a variety of care settings. These include community, acute hospital, mental health services and intellectual disability services (Department of Health (UK), 2016). As such, nurses are uniquely positioned within the health and social care system to proactively support, person-centred compassionate care (Department of Health (UK), 2016). Nurses and other clinical leaders can become role models for other formal and informal caregivers in terms of the provision of person-centred care (Kitwood, 1997; Abbott *et al.*, 2022). A further consideration is if there are discrepancies between the values of the nurse and the care environment (Kitwood, 1997). For person-centred care to be realised, there must be an alignment of values to allow such changes to occur. This

recognises the values of individuals but equally the need for an organisational and societal culture that recognises and supports person-centred approaches.

Holding on to Me highlights the critical importance of the social care environment in affording the person living with dementia opportunities to learn to live well with the diagnosis of dementia. This enhances their ability to hold on to their sense of self. This requires a supportive environment that focuses on the person rather than the diagnosis of dementia. Nurses have a role in creating a supporting environment, promoting active involvement and balancing safety with the person's wish for independence and self-determination. Yet, this is not a new idea and is a central premise of person-centred care, aspired to in the model for dementia care in Ireland (Begley *et al.*, 2023). Despite this person-centred dementia care is still an aspiration in many healthcare settings (Brooker, 2007; Bosco *et al* 2019; Bracken-Scally *et al* 2019). *Holding on to Me* , does not suggest that people living with dementia should be in a constant state of wellbeing and this would be erroneous as well as unattainable for any person. However Kitwood (1997) recognised that ill-being in dementia is often caused by the undermining of personhood by others and the social environment (Mitchell and Agnelli, 2015).

If we think about Tom's scenario again. Although Tom's situation was for a short period of time (respite) consideration needs to be given to those people with dementia living in such environments on a permanent basis. Koszalinski and Olmos (2022) examined the impact of communication challenges and social isolation on older adults living with dementia and subjective cognitive changes in long term care during COVID 19. In their scoping review of literature related to subjective cognitive decline and mental health status, they found that the social isolation and impaired communication networks associated with lockdown directly impacted on stress related cognitive changes and psychological wellbeing (Koszalinski and Olmos, 2022). While it is acknowledged that Koszalinski and Olmos (2022) were specifically referring to COVID 19, the communication challenges and social isolation Tom identified could be felt by people with dementia living in such environments beyond lockdown, leading to ill-being and diminishing sense of self.

Given Tom's scenario, there is another consideration for the social context and care environment, that of opportunities for decision making. Bosco *et al.* (2019) argue that people living with dementia are often vulnerable to significant power imbalances in terms of

opportunities for decision making in their lives and care. However, this study has shown that people living with dementia can be active partners in their care journey and decisions impacting their lives. Indeed, this is essential to their wellbeing, sense of self and human rights as individuals and as citizens. This theory highlights that rather than being passive recipients of care people with dementia are and can be actively involved in decision making. This helps them to accept the changes associated with dementia as rather than having decisions imposed on them, they are part of the decision-making process. Moreover, this study shows that people living with dementia, want to be, and equally as important can be, actively involved in decisions impacting their lives and care. Nurses are in a prime position to support and optimise opportunities for decision making for people living with dementia, which is central to their ability to *hold on to me*. Within the literature, the involvement of people living with dementia in decisions that impact their lives has implications for their wellbeing and sense of self (Kitwood, 1997; Smye et al 2012) and is a central tenet of person-centred care (Brooker, 2007; Dewing, 2008a; Sofronas, Wright and Carnevale, 2018).

9.4.2 Decision Making and Autonomy

It is well documented that people living with dementia and their carers encounter many ethical dilemmas throughout the journey of their condition, many relating to autonomy and decision making (Alzheimer Europe, 2016). Respect for autonomy and self-determination in decision making are key guiding principles underpinning person-centred dementia care and the maintenance of personhood, aspired to as the gold standard in compassionate dementia care (Berenbaum, Tziraki and Mazuz, 2017; Fazio *et al.*, 2018). Furthermore, people living with dementia want more personal choice, influence and control over decisions that impact their lives (Alzheimer Society of Ireland, 2016). Despite autonomy being sought by people with dementia and its importance and inclusion within policy and legislation being seen as essential, this does not always translate into practice (Fitzgerald *et al.*, 2020). Additionally, it is often difficult to have a clear understanding of what autonomy actually means. Wolfe *et al.* (2021) state that one of the limitations of their study, exploring the perspectives of people with dementia, caregivers and professionals was poor understanding of the term autonomy amongst the participants.

Autonomy in the context of dementia involves complex ethical, psychological and practical considerations (Curtice and Exworthy, 2010). As dementia progresses, impaired cognition

such as memory loss, impaired reasoning and linguistic difficulties can undermine the individual's ability to make autonomous decisions. This raises significant ethical dilemmas regarding balancing the person's right to autonomy and protecting them from harm (Fitzgerald *et al.* 2020).

Dementia impacts on autonomy in a number of ways including cognitively, psychologically and relationally (Soofi, 2022). Cognitive decline and fluctuations in cognitive ability can impact decision making processes, particularly for more complex decisions. However, Karlawish, Casarett and James (2002) state that there should be a distinction between complex and simpler day to day decisions, which people with dementia often retain their ability to make, even in the more advanced stages of dementia. Loss of autonomy for people living with dementia is a fundamental problem to maintaining wellbeing, self-esteem and sense of self, often resulting in excess disability for the person (Wilkins, 2017). This can regularly lead to increased care burden for families/ carers and can play a pivotal role in decision making for people with dementia, particularly as the condition progresses (Smebye, Kirkevold and Engedal, 2015). Psychologically losing autonomy may lead to diminished quality of life, feelings of helplessness and illbeing (Wright, 2019). Preserving a sense of control, even in small aspects of daily life can enhance the wellbeing of people with dementia (Kitwood, 1997).

From the perspective of *Holding on to Me*, when deciding an action relating to holding on to their sense of self, the issue is less about the perceived complexity of the decision and more about the meaning and what matters to the person in terms of their sense of self. Additionally, it is not the complexity of the decision, but the level of involvement in decision making that can support or hinder the person holding on to their sense of self. To illustrate this, we can draw on another example from the study. Jim is a retired professional, having had what he terms a very successful career. This success has allowed him to provide for his family. They have a beautiful home with a big garden that Jim loves. Jim's house is currently being sold, he has been told not to drive, and he worries about getting lost on his walks. Jim does not want any of these changes, but he has different ways of responding to them based on the meaning they have for him in terms of his sense of self and the level of decision-making involvement he feels he has. In relation to the former two changes, Jim feels he was not involved in these changes that impact his life significantly. He decides to *let go* of the house move, but it still leaves him feeling "hoodwinked" by his family. In relation to driving

Jim *holds tighter* and resists this being taken from him. He feels it is unjustified and unfair, and it directly impacts on his sense of self, how he sees himself and how he wants others to see him. Jim is angry and upset about this, cannot accept it and looks for ways he can get back driving. For him it makes the impact of his dementia much greater. In relation to his going out walking, he can still do this but fears if he gets lost, this might also be taken from him. He therefore asks questions (*relational grappling*) about things he can do, including technologies to continue to go out walking alone. So, it is not necessarily the complexity or simplicity of the decision to be made. Not all decisions have the same weighting in terms of meaning for the individual. Jim's illustration shows it is what matters to the person and the meaning in terms of their sense of self that needs to be considered in terms of decision making. Additionally, an element of Jim's sense of self being diminished is that he does not feel included in decisions that impact significantly on his life. Most importantly, in terms of care provision it needs to be recognised that this is an issue for Jim and the weighting Jim places on these decisions in terms of the impact on his sense of self. It does not mean that Jim should continue to do things that are unsafe for himself or others but that he be involved in the decision-making process to arrive at possible solutions. It is only then that Jim can be supported to *hold on to me*.

Kitwood (1997, p. 9) argues that given the extreme individualism prevailing in Western societies, essentially what he terms a "*business culture*", personhood has been reduced to two main criteria, autonomy and rationality. Given this premise, he argues it could easily be rationalised that humans not possessing these criteria should be excluded from the "*personhood club*". Yet, Jim's scenario highlights that giving the person opportunities (at whatever level) to be involved in decisions impacting their lives and care is essential. It is also a central tenet of person-centred care for the promotion and maintenance of self (Bosco *et al.*, 2019). However, this does not always translate into practice (Mitchell and Agnelli, 2015; Higgs and Gilleard, 2016). This begs the question, do our current perspectives of autonomy meet the needs of people living with dementia in terms of supporting *Holding on to Me*? To answer this question, it is important to give a brief overview of the extant literature relating to autonomy.

Ethical discussions in dementia care often revolve around the principle for respect for autonomy versus the need for beneficence and non-maleficence. According to Beauchamp and Childress's "*Principles of biomedical ethics*", whilst respect for autonomy is

fundamental it must be balanced against other ethical principles, particularly when decision making capacity is compromised (Beauchamp and Childress, 2019). Concerns regarding legal capacity or paternalistic attitudes towards people living with dementia, particularly in relation to risk and safety can impact negatively on the rights of people with dementia to exercise autonomy and live their lives according to their will and preference (Alzheimer's Disease International, 2019). Yet, despite this Smebye, Kirkevold and Engedal (2015) argue that in certain circumstances paternalism could be justified when autonomy is conflicted with prevention of harm, wellbeing of caregivers and autonomy of family carers. Dworkin (1986) argues that autonomy in the context of dementia must be viewed in terms of the person's former competent self. He states that there should be cognisance given to the individual's previous wishes and preferences as the person is still the person despite having dementia. Therefore, abiding by previous wishes, Dworkin (1986) argues is an assertion of autonomy rather than paternalism. However, he states that this can cause conflict between people living with dementia and their caregivers (Dworkin, 1986). However, this discounts the decision-making ability, autonomy and indeed the rights of the person living with dementia to change their mind (Dresser, 1995). Whilst recognising that decisions may sometimes need to be made for the safety of the person living with dementia, this should be done, where possible in consultation with the person, so they can continue to feel involved and active in their lives (Wolfe *et al.*, 2021). Indeed, in *Holding on to Me* people engage in *relational grappling* activities to try to make this happen for themselves.

9.4.2.1 *Relational Autonomy*

Traditional theories of autonomy, rooted in the works of Immanuel Kant (1724-1804) emphasise individual independence and self-determination. In contrast, relational autonomy is grounded in feminist ethics and challenges the traditional view of autonomy as purely individualistic (Mackenzie and Stoljar, 2000). It emphasises the role of relationships and social context in the development and exercising of autonomy. Proponents of relational autonomy argue that classic models of autonomy neglect the interconnectedness of individuals and the significance of social relationships, arguing that autonomy cannot be fully understood without giving consideration to interdependence, social context and relational capacities (Davidson, 2019). Relational autonomy is based on the premise that people are inherently interdependent, and that autonomy is developed and practiced within a network of relationships, both intimate and casual (MacKensie and Stoljar, 2000).

Holding on to Me highlights that caregivers play a crucial role in supporting autonomy for individuals with dementia, particularly in creating a safe environment for independent decision making. However, caregivers attitudes and perceptions towards dementia and towards autonomy in dementia can significantly influence the level to which autonomy is supported or restricted (Davidson, 2019). Research highlights the importance of caregiver education and support in promoting autonomy (Sörensen *et al.*, 2002). Critics of relational autonomy argue that there is a risk of undermining the importance of individual rights and freedoms. The concern is how to balance relational considerations with respect for individual autonomy (Klein, 2022). A further consideration is the care relationship, and how this lived dynamic, with possible power imbalances relates to autonomy (Davy, 2019).

In a similar vein, care ethics is closely related to relational autonomy. It is a normative ethical theory that emphasises the importance of interpersonal relationships and the moral significance of care and compassion. It was primarily developed by feminists, including Carol Gilligan and Nel Noddings. Care ethics challenges traditional ethical theories such as deontology and utilitarianism. In a shift from traditional thinking, care ethics prioritises relationships and emotional connections over abstract principles, such as autonomy, which, according to Gilligan and Noddings are often grounded in the masculine perspective (Craig *et al.*, 2021). Care ethics offers a valuable perspective that enriches our understanding of moral life by emphasising the importance of care, relationships and emotional engagement. While it faces challenges and criticisms, it continues to influence a wide range of fields, including healthcare and encourages a more compassionate and relational approach to ethics. There is, however a need to reconcile perspectives of autonomy and perspectives of care within the context of the lived experience (Davy, 2019).

9.4.2.2 *Contextual Factors in Autonomy*

As already discussed, relationships and the social context play a crucial role in supporting the person living with dementia to *hold on to me*. The attitudes of others in relation to dementia impact their actions and behaviours towards people living with the condition. As such this can have an impact on their sense of self in terms of how they see themselves and how others see them. In a similar vein, there is a growing awareness of the importance of context in terms of ethics and moral thinking (Christensen and Eriksen, 2020). According to van Loon *et al.* (2021) the social environment, within which the person resides is a crucial factor in sustaining and reinforcing autonomy. They conducted a systematic literature review

of facilitators and barriers to autonomy in older adults with physical impairments living in nursing homes. The themes emerging from the review highlight that in terms of barriers and facilitators of autonomy cognisance needs to be given to the characteristics of the residents, prerequisites of professional caregivers, care processes between the caregiver and the resident and the environment of care (van Loon *et al.*, 2021). With reference to dementia care in nursing homes, Soofi (2022) argues that existing frameworks for autonomous decision making need to be revised in order to make them relevant to people with dementia living within the social context of nursing homes.

The social environment and context within which the individual with dementia lives cannot be ignored and is not limited to residing in long term care. Smebye, Kirkevold and Engedal (2015) explored ethical dilemmas associated with autonomy for people with dementia who wished to remain at home. Within the study there was an acknowledgement, including amongst the individuals with dementia involved that to uphold autonomy and remain at home, particularly as dementia progresses there is an increasing reliance on those around them. They identified three areas in which autonomy was challenged. Firstly, when it conflicted with family/caregiver trying to prevent harm (non-maleficence). Secondly, when it conflicted with the family/caregiver trying to do good (beneficence). Thirdly, when the autonomy of the person with dementia conflicted with the autonomy of the caregiver. They concluded that given the increasing reliance of people with dementia on others to maintain autonomy, paternalism could be justified in terms of beneficence and non-maleficence and within the realms of care ethics (Smebye, Kirkevold and Engedal, 2015). However, this does not mitigate the onus on families and professional caregivers to involve people with dementia in decision making, given the importance of autonomy to sense of self, personhood, dignity and integrity (Smebye, Kirkevold and Engedal, 2015). Indeed, the rights of people to be involved in decisions that impact their lives is underpinned by legislation (Government of Ireland, 2015). However, if we go back to the illustration of Jim's scenario, the theory *Holding on to Me* highlights that a blanket one size fits all approach to autonomy might not be needed or indeed be useful. What is important is determining what matters to the person and is meaningful to their sense of self.

9.4.2.3 *Legislative Frameworks for Decision Making*

Legal frameworks in various jurisdictions aim to protect individuals with dementia while promoting their autonomy. Advanced Directives and Powers of Attorney are legal tools that

allow individuals to outline their preferences for future care, which can help to maintain autonomy, even when cognitive functions decline (Fagerlin and Schneider, 2004). The United Nations Convention on the Human Rights of People with Disabilities (CRPD)(United Nations, 2006) is a comprehensive international treaty that seeks to promote, protect and ensure the full and equal enjoyment of all human rights and freedoms by all persons with disabilities, including those with dementia. The core principles of the CRPD aim to promote the principles of autonomy, non-discrimination and inclusion. Although Ireland signed up to the CRPD, changes in legislation were required to ratify it.

In Ireland the Assisted Decision Making (Capacity) Act (ADMA) (Government of Ireland, 2015) was enacted as a requirement to ratification of the UN Convention on the rights of people with disabilities (United Nations, 2006). It represents a significant and long-awaited legislative development, aiming to enhance the autonomy and protection of individuals with impaired decision-making capacity, including those with dementia. The Act provides a comprehensive legal framework to support individuals in exercising their autonomy, particularly where this ability is questioned due to a neurodegenerative condition such as dementia. It aims to balance the ethical principles of respect for autonomy with those of beneficence and non-maleficence. Underpinning the Act is a presumption of capacity unless proven otherwise and a functional approach to capacity assessment that is time and issue specific (Government of Ireland, 2015). Other key features of the Act are a framework to support the shift from substituted decision making to supported decision making and provisions for advanced planning including Enduring Power of Attorney and Advanced Healthcare Directives. Additionally, the Decision Support Service was established to oversee the implementation of the Act, ensuring the protection and empowerment of individuals with diminished capacity, or for whom decision making ability is called into question (Safeguarding Ireland, 2023). Although this provides a robust legislative framework for promoting autonomy, decision-making and protecting self-determination, the ADMA is in its infancy and has not yet been fully tested either within the courts or for practicality in clinical and societal settings.

Whereas a rights based approach and promotion and maintenance of autonomy and decision making is seen as an essential tenet of both policy and legislation, there is often little understanding of how this can be promoted in health and social care settings (Fagerlin and Schneider, 2004). Wolfe *et al.* (2021) highlight that people with dementia and their

supporters may not come at the issue of autonomy from the same perspective as legislators and healthcare workers. The perspective of people with dementia, Wolfe argues, seems to be more related to what matters to them, and the maintenance of their sense of self (Wolfe *et al.*, 2021). This line of thought supports the perspective underpinning the theory of *Holding on to Me* in relation to the importance of understanding what matters to the person and maintaining sense of self. Interestingly, both standpoints come from the perspectives of people living with dementia and therefore are essential to understanding how autonomy and sense of self can be understood for people living with dementia. Additionally, conflict can arise when individuals are seen by others as making “bad” decisions (Fitzgerald *et al.*, 2020). Amid these differences in perspectives there is a need for legislative frameworks to support and protect individuals whose capacity might be called into question or who might be vulnerable to paternalism.

Involvement in decision making is key to person-centred care and the supporting of personhood (Kitwood, 1997; Dewing, 2008; Sabat, 2018; Sofronas, Wright and Carnevale, 2018; Bosco *et al.*, 2019; Hoe *et al.*, 2024). Yet, as Wolfe *et al.* (2021) argues, maybe there is a need to look at autonomy from the viewpoints of people living with dementia, essentially in terms of what matters to them, rather than extant theoretical perspectives. Schweda and Jongsma (2022, p. 9) concur arguing that adopting a perspective that promotes, personhood, embodiment, biography and relationality can mean that the person is seen as an active participant in their world, autonomy is nurtured, wellbeing is promoted, and the person’s sense of self is maintained.

9.4.2.4 *Autonomy from the Perspectives of People with Dementia*

There is a lack of research relating to the perspectives of people with dementia in relation to autonomy. Wolfe *et al.* (2021) explored the meaning of autonomy for people with dementia, their family caregivers and healthcare professionals, with the aim of informing rights-based practice. They conducted a study using a Q-method. This involves a two-stage process, firstly a Q-set relating to the topic of autonomy was developed. People with dementia, family caregivers and healthcare professionals were involved in development of the Q Set. This consisted of as full a range as possible of statements relating to the topic that were then ranked, by people with dementia and family carers (n=20) in terms of the extent to which they agree or disagree with the statement. Healthcare professionals were not involved in the ranking stage. Subsequent interviews were held with people with dementia (n=4), family

caregivers (n=3) and healthcare professionals (n=3). The findings of the study suggest that prioritisation should be given to the preferences and relationships of people with dementia to support them to be autonomous (Wolfe *et al.*, 2021). Wolfe *et al.* (2021) states that for the participants in their study, autonomy encompasses more than pure independence or relational outlooks. So, this would seem to signify, there is a need for creativity and flexibility on the ways in which people with dementia can be supported to live their lives autonomously and have their personhood maintained. Additionally, it brings into focus the symbiotic relationship between autonomy, maintenance of self and person-centred care.

Within healthcare settings there is another point for consideration in relation to self, autonomy and person-centred care. Beauchamp and Childress (2009, p.5) identify “*particular moralities*” specific to certain groups or cultures. Healthcare professionals receive moral guidance from public policy and professional bodies. In relation to nursing, the Nursing and Midwifery Board of Ireland (NMBI) provides ethical and moral guidance through their Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives (Nursing and Midwifery Board of Ireland, 2025). Underpinning these codes are legislative, professional and societal consequences for those who act outside of the moral norms, including fitness to practice committees and criminal law. Hennelly and O’Shea (2022) in their study exploring the concept of personhood from the perspectives of people living with dementia, their families and formal carers state that whereas formal carers recognised that autonomy was important in supporting personhood, it also presented a barrier in terms of balancing risk to the person living with dementia and others. This can pose an ethical dilemma for healthcare professionals, including nurses. Balancing a perceived duty of care and the prospect of legal repercussions with patient autonomy and safety in the context of older person care, often leads to a paternalistic approach in healthcare (Hennelly and O’Shea, 2022; Hoe *et al.*, 2024). When caregivers reduce their paternalistic approaches, this strengthens personal choice, independence and autonomy (Sánchez-Izquierdo *et al.*, 2019), elements central to the provision of person-centred care (The American Geriatrics Society Expert Panel on Person-Centred Care, 2016).

Hoe *et al.* (2024), in their systematic review of risk assessment for people living with dementia identified a disparity in terms of attitudes towards risk between people living with dementia and healthcare providers. In general, people living with dementia and informal carers were more risk tolerant, whereas healthcare providers were more risk averse. They

surmise that the organisational structures could have a bearing on healthcare workers attitude to risk (Hoe *et al.*, 2024). Yet risk is a part of everyday life, regardless of underlying conditions (Gordon *et al.*, 2020). However, given the impact of dementia on cognition and functioning, risk enablement in dementia, in all settings where people with dementia reside, is complex with no one size fits all solution (Dickins *et al.*, 2018). Those supporting people living with dementia often have to balance, what is an acceptable risk and what is a hazard (Gordon *et al.*, 2020). Negotiating of the person's preferences and wishes balanced with resources can help to enable positive risk taking and this can in turn enhance person-centred care (Dickins *et al.*, 2018). Stamou *et al.* (2022) argues that a flexible, collaborative approach, promoting person-centredness and decision making is particularly relevant in supporting people with younger onset dementia. This approach would be in line with The National Dementia Strategy (Government of Ireland, 2014), Model of Dementia Care in Ireland (Begley *et al.*, 2023) and The Assisted Decision (Capacity) Act (Government of Ireland, 2015) as well as international and national best practice (Alzheimer Europe, 2016).

Being an active participant in one's world is central to *Holding on to Me*, and the promotion and maintenance of sense of self. In his exploration of what it means to be a person, Kitwood (1997) looks to the work of Martin Buber. Buber, Kitwood (1997, p.10-12) suggests identifies two ways of being in the world and relationships. Firstly, I-It, refers to a way of being that implies detachment and coolness in which relationships are trivial and shallow. Secondly, I-Thou, refers to a way of being that implies self-disclosure, a giving of oneself, warmth, engagement and inclusion. It is the latter that is essential to person-centred care and supporting the person to *Hold on to Me*. Yet all too often it is the former that prevails in healthcare, despite the term person-centred care being used (Bosco *et al.*, 2019). Rather than seeing the person as a passive recipient of care, nurses are in an ideal position to shift the focus of care from traditional biomedical, task orientated care to a more holistic and person-centred approach (Kitwood, 1997). However, there is a need to go further, to a care approach in which the person living with dementia is an active partner in their decision making, care and support. Bosco *et al.* (2019) argue for a co-production approach to care. *Holding on to Me* supports that people living with dementia want to, and can be, active partners in care. Additionally, through explaining how people living with dementia hold on to their sense of self, it provides ways in which caregivers can recognise and support the actions of the person in holding on to their sense of self.

The promotion and maintenance of personhood (self) is essential to person-centred care (Kelly, 2010; Hennelly *et al.*, 2021). As already stated Kitwood (1997) refers to personhood as the value, respect and dignity bestowed on the person by another in the context of relationships. He further states that the attitudes, behaviour and language of others can either promote or undermine the personhood of the person living with dementia. Actions promoting and nurturing personhood he calls positive person work and include negotiation, collaboration, recognition and validation (for full list see Appendix 10) (Kitwood, 1997). In contrast malignant social psychology refers to the behaviours of others that undermine the personhood of the individual living with dementia. These include seventeen behaviours that include, treachery, disempowerment, labelling, outpacing, ignoring and infantilisation (for a full list is available see Appendix 7) (Kitwood, 1997). In terms of malignant social psychology, there is a distinction to be made between malicious intent and lack of specialised education that essentially leaves the person with dementia invisible (Kitwood, 1997; Sabat, 2018). However, no matter how benign the intent, the impact is equally as grave in terms of undermining personhood. Additionally, nurses have a responsibility to act as role models for positive person work for other formal and informal caregivers (Mitchell and Agnelli, 2015). *Holding on to Me* illustrates the importance of others in terms of supporting or hindering the person's actions in holding on to their sense of self. However as seen in this study and acknowledged by Kitwood (1997) there is often no malicious intent in the behaviours of others, rather a lack of dementia awareness or an attempt to protect the person. As such *Holding on to Me* , highlights the needs of caregivers in terms of education but also in terms of their own support needs.

Werner (2023), argues that the wellbeing of people living with dementia, particularly in relation to distressing behaviours is intertwined with the wellbeing and perceptions of their caregivers. This is important to note as people living with dementia in healthcare settings, particularly those with perceived behavioural changes are more vulnerable to having their freedom restricted through physical and chemical restraints (Pu and Moyle, 2022). Additionally, people living with dementia in hospitals and institutions can be at risk of abuse or neglect (Kelly and Innes, 2013). This has implications for the person's human rights, autonomy and citizenship (Kelly and Innes, 2013), but also for maintaining their sense of self (Schweda and Jongsma, 2022). Where people living with dementia are viewed as being devoid of self, with metaphors and dehumanising views such as "living death" and "human shell", healthcare workers can show less empathy towards the person and deliver poorer care

(Schweda and Jongsma, 2022). Thinking in terms of Sabat and Harré's tripartite model of self (Sabat and Harré, 1992; Sabat, 2001). When the healthcare worker in viewing the person's Self 2 characteristics, focusses on the deficits associated with dementia this in turn can construct a Self 3, in which the person is recognised as a "human shell" devoid of self. This is essentially what Schweda and Jongsma (2022) call the zombification of dementia and could be a justification for less empathetic or compassionate care (Kitwood, 1997). This also has a knock on effect, in that it can lead to "excess disability" for the person living with dementia (Sabat, 1994). Moreover, where these views persist, the person's agency (drive for independence) and communion (drive for relationships) can be undermined (Hedman *et al.*, 2016).

There is another important consideration, in discussing the role of caregivers. That is maintaining the wellbeing and personhood of the caregiver (Kadri *et al.*, 2018; Werner, 2023). Kadri *et al.* (2018) in their secondary analysis of qualitative data from interviews with paid carers in care homes in the UK identified the symbiotic relationship between carers personhood being acknowledged and valued and the provision of person-centred care. Additionally, there could be a disconnect between the ideals of person-centred care and the expectations of management in terms of completion of tasks. Where carers felt valued and acknowledged for their work there was higher job satisfaction, better team and family carer relationships and less burnout. In contrast where carers did not feel valued, they were more likely to lack motivation, feel frustrated and feel they are unable to deliver the care they would like to aspire to (Kadri *et al.*, 2018). It cannot be denied that there is often a disconnect between best practice and reality (Mitchell and Agnelli, 2015; Sabat, 2018; Bosco *et al.*, 2019). Marulappa *et al.* (2022) in their scoping review of implementing person-centred care in outpatient and home community settings, highlighted several barriers. These included resource constraints, lack of healthcare worker education and conflicts within the family (Marulappa *et al.*, 2022). Additionally, as already highlighted, the attitudes and behaviours of caregivers and indeed the person themselves can impact whether the person is supported in *Holding on to Me*. Attitudes and behaviours can be impacted by the level of and opportunities for dementia education, to support change in how people with dementia are seen in terms of their personhood and value (Irving, 2017).

9.4.3 Recommendations for Dementia Care

Based on the discussion above there are several recommendations for formal and informal care:

1. Health and social care services must ensure that the social environment supports the identification and maintenance of personhood/self, including opportunities for shared decision making, where possible, and interventions that reflect the will and preference of the person living with dementia. To this end there should be a review of health and social care services to:
 - i. Enhance person-centred communication.
 - ii. Develop flexible care environments that support choice, as much as possible. Where choice may be limited due to safety concerns, efforts should be made to work with the person and their care partners to mitigate the impact on what matters to the person and their sense of self.
 - iii. Provide opportunities for risk enablement.
 - iv. Provide guidance and tools for people living with dementia, tailored to their needs and ability to support self-management.
 - v. Support staff to meaningfully deliver person-centred dementia care and build partnerships with the person living with dementia.
2. There is a need to identify ways in which health and social care professionals can support *Holding on to Me* to help mitigate the impact of nihilistic discourses surrounding dementia and promote active partnership tailored to the person's preferences and ability.
3. People living with dementia should be and can be active partners in their care journey and this should be meaningfully promoted in all care settings, formal and informal.
4. There should be monitoring and evaluation of service and care provision to align with *Holding on to Me* to address the perception of people living with dementia in terms of their perception of *losing me* .

9.5 Implications and Recommendations for Education

The concept of learning featured heavily in this study and in the theory *Holding on to Me* , and features in all sub core categories, *holding tighter* , *letting go* and *relational grappling* . This theory highlights the importance of education and learning in several ways. Firstly, in

managing fear and uncertainty and secondly, in creating a social environment in which people living with dementia, their caregivers and healthcare staff can be afforded opportunities to learn, thus supporting decision-making and *Holding on to Me*.

9.5.1 Coping with Fear and Uncertainty

Within the context of dementia and *Holding on to Me*, people living with dementia and their caregivers often must manage fear and uncertainty. To adapt to the changes associated with dementia, both in the present and in the future, people living with dementia need to be able to avail of opportunities to learn to adapt and live well with the condition (O’Shea, Keogh and Heneghan, 2018; Begley *et al.*, 2023). Importantly, it is essential not to discount that persons living with dementia want to learn for themselves, how to adapt and live well with a diagnosis of dementia (Mitchell, 2022). People living with dementia want to be given the opportunities to make mistakes, without it being thought of as progression of dementia (Smith, 2021). As such, another important consideration in terms of social interactions and *Holding on to Me*, is that of the promotion of opportunities for learning for the person themselves. When given that opportunity people with dementia often use learning to help them adapt to the changes associated with dementia (O’Shea and Keogh, 2019). The social context and social interactions within which the person resides plays an important part in terms of affording them opportunities to learn.

Social interactions are created by the people involved, including the person themselves, family members, close friends and others. These interactions are influenced by the behaviours and attitudes of all within the social environment and can be impacted by their awareness of dementia (Kitwood, 1997; Brooker, 2007). Accuracy of knowledge and experience of the people involved regarding dementia awareness plays a large part in how the social context is constructed, in terms of the attitudes held towards people living with dementia (Werner *et al.*, 2021; Schweda and Jongsma, 2022). For example, where there is an awareness of dementia, or a drive to learn more about dementia, there is less influence from erroneous information and stigmatising rhetoric (Irving, 2017). Furthermore, the person themselves and their immediate circle are more likely to promote acceptance, growth and learning. Mistakes are seen as being part of being human rather than a direct result of dementia and the person is supported to learn themselves what they can and cannot do, particularly as dementia progresses. Where there is little accurate dementia knowledge and poor experiences of supporting others with dementia there can be an overfocus on the deficits

associated with dementia. This can lead to a perception that the person cannot be involved in decision making, do things for themselves or maintain their independence (Brooker, 2007). These assumptions can be held by any of the people within the relationship, including the person living with dementia themselves and can be a source of fear and uncertainty (Cahill, 2021). An overfocus on dementia rather than the person themselves and preconceived ideas can mean that support approaches within the social context add to the impact of dementia in terms of excess disability (Sabat, 1994, 2018; Kitwood, 1997). It can also mean that people with dementia need to prove themselves before they can continue to do things that are meaningful to them. Caregivers can engage in behaviours such as disempowerment, infantilisation, invalidation and outpacing (malignant social psychology) without understanding the impact on the person (Sabat, 1994, 2018; Kitwood, 1997). As stated previously, this is not in any way meant to be malicious but is often meant to protect the person and indeed their sense of self, despite the often paradoxical effect.

To illustrate this point we can take an example from the study. Olive is a very social seventy-seven-year-old and avid card player. Since her diagnosis of dementia her family have recommended that she not go to play cards as they fear she will make mistakes or drop the cards. Olive finally gets to go and play cards, again and indeed wins her matches. Olive now goes to play cards regularly. Her family had wanted to protect her from embarrassment and did not want dementia to change how others see her. However, paradoxically, they had stopped her from doing something that is important to her sense of self. It is only when she wins her matches that the fear is dispelled. This illustration highlights the importance of dementia education in supporting others to recognise what is important to the person. Additionally, the importance of seeing the person living with dementia as they are and not someone who has to prove themselves to others to be supported to *hold on to me*. Furthermore, it is important that Olive be given opportunities to learn and be afforded opportunities to make mistakes (she might not have won her matches, or she might have dropped the cards, but this might not be due to her dementia).

9.5.2 Learning and the Social Environment

Dementia awareness and post diagnostic supports are pivotal in helping people with dementia and their families manage fear and uncertainty as well as promote wellbeing, improve self-efficacy and even delay institutionalisation (O'Shea and Keogh, 2019). Furthermore, Gibb *et al.* (2019) in their guidance for the provision of post diagnostic

supports identify a number of key elements for inclusion, learning about dementia, legal and financial planning, signposting to local services, brain health information, memory skills, supportive self-management and enabling environments. Additionally, they highlight the particular needs of people with young onset dementia in terms of employment rights, mortgage protection and accessing social services (Gibb *et al.*, 2019). Øksnebjerg and colleagues (2020), conducted a pilot study exploring self-management, cognitive rehabilitation and use of assistive technologies to support coping and wellbeing for people living with dementia (Øksnebjerg *et al.*, 2020). They found that people with dementia and their caregivers actively enjoyed learning and engaging with the technology and activities. This allowed them to enhance wellbeing, promote acceptance and coping, and maintain independence (Øksnebjerg *et al.*, 2020). Through increasing dementia awareness, maintaining person-centred social engagement, and attending to the practicalities of a diagnosis of dementia, people living with the condition can be supported and in turn can support themselves to *hold on to me*.

Negative attitudes relating to the capabilities of people with dementia still abound in modern society and amongst healthcare care professionals (Alzheimer's Disease International, 2019). Furthermore, in healthcare settings, paternalistic approaches that place emphasis on safety and security, decrease levels of autonomy as care promoting autonomy is deemed to be less safe (Sánchez-Izquierdo *et al.*, 2019). Moreover, previous dementia education, as well as past experience of supporting people with dementia has been shown to impact positively on the attitudes of healthcare workers towards people with dementia in acute care settings (Keogh *et al.*, 2020). The challenge then is to develop and deliver dementia education for formal and informal caregivers that will impact on care delivery, but more importantly impact on the social care environment. With cognisance of the significant complexities associated with supporting people living with dementia there is a need to ensure that both formal and informal caregivers receive appropriate levels of dementia education (Annear *et al.*, 2015). Yet there are significant deficiencies in the levels of dementia knowledge among family caregivers and healthcare workers (Robinson *et al.*, 2014) as well as more generally with the public (Cahill *et al.*, 2015). In a recent review of dementia research priorities in Ireland it was found that from the perspectives of people living with dementia, their caregivers and healthcare professionals, dementia awareness and education, ranked first in terms of need for further research (Rogan *et al.*, 2023). This highlights awareness among the cohorts surveyed of the importance of impactful dementia education.

This acknowledgement of the need for dementia education requires a refocussing in terms of how we deliver education to people living with dementia, family caregivers and formal caregivers. It requires a move from didactic, task centred approaches to ones in which the self of the person is recognised and nurtured. However, equally as important, this shift requires an acknowledgement of the need for dementia education for people living with dementia, to promote and maintain self, autonomy and active involvement in their lives and care. An ongoing challenge in terms of any healthcare education is to ensure it is impactful in terms of influencing the way healthcare workers, think, act and behave. Dementia education, using a combination of theory and practice based approaches was found to impact positively on the knowledge, attitudes and confidence of radiographers in caring for people living with dementia (Berry *et al.*, 2024). This could warrant further exploration of dementia simulation and virtual reality simulation in terms of enhancing empathy and communication skills and promoting person-centred care (Hirt and Beer, 2020; Kobiske and Deprey, 2022; Meyer *et al.*, 2022). However, although the use of such technologies have demonstrated positive outcomes, it is acknowledged that the use of such technologies in dementia education is in its infancy and requires further research (Hirt and Beer, 2020). Novel dementia education strategies for family caregivers, such as dementia simulation has also been seen to have a greater impact, than lecture based education on quality of care and quality of life for people living with dementia and family caregivers (Han, Kim and Hong, 2021). Additionally, Terayama *et al.* (2018), in their study exploring the impact of dementia caregiver education on feelings of depression and care burden, found that both feelings were reduced at three months after the education programme. However, to understand the full impact of dementia education, particularly the use of new techniques and technologies for all impacted by dementia further research is required.

9.5.3 Recommendations for Education and Learning

1. Given the importance of learning and dementia literacy in supporting the person living with dementia to self-manage their condition, education that promotes self-management should be included as part of post diagnostic interventions focussed on people living with dementia.
2. In recognition of the importance and impact of care relationships and the social environment in *Holding on to Me* there should be tailored and tiered educational

supports to enhance dementia literacy for informal and formal caregivers and the public.

3. Dementia education programmes should equip all partners in the dementia care relationship to recognise and mitigate against power imbalances and malignant social psychology.
4. Professional education programmes should incorporate the properties of *Holding on to Me* and prepare practitioners to meet the individual and often complex needs of people living with dementia and their caregivers.

9.6 Implications and Recommendations for Future Research

Glaser (1998) suggests that grounded theory provides many leads for future research in terms of possible avenues for theoretical sampling that were beyond the limits of the study. This grounded theory is no different. The theory *Holding on to Me* highlights the importance of supporting self in the provision of person-centred dementia care, which is also championed within the literature (Kitwood, 1997; Kelly, 2010; Kontos and Martin, 2013; Sabat, 2018). Yet there can be multiple perspectives as to what constitutes self, which is much debated in the literature. When considering people from culturally diverse populations this adds another layer of complexity to the debate (Vignoles *et al.* , 2016). A valuable addition to the research and knowledge base would be exploring the implications of this theory from the perspectives of diverse populations, in terms of holding on to (or not), their sense of self.

Another issue highlighted by Cadell and Clare (2010) in their systematic review, was that whilst acknowledging that some existing studies did use non-verbal means of researching self, such as observation, the majority of studies used verbal interactions involving people living with dementia. It would be interesting and useful to explore other data collection methods such as observation so that people living with dementia and those with linguistic difficulties are not excluded from the research process. This is extremely important in terms of ensuring people living with dementia are not denied their rights, their personhood and selfhood, due to their inability to communicate their perspectives verbally. Additionally, the use of assistive technologies such as talking mats and visual aids could be explored to promote the involvement of people living with dementia in research. This could be more inclusive for people with more advanced dementia, who are often excluded from research. Yet it is essential that their sense of self is recognised and supported in relationships, society and healthcare settings. Additionally, more inclusive research methods could involve

innovative approaches, such as use of music, theatre and dance. Moreover, observational studies could explore expression of self through behaviour and movement, mirroring studies exploring representations of embodied self, such as Kontos (2004, 2014).

In their survey of people living with dementia, their families and healthcare professionals working in dementia care to ascertain areas for prioritisation in dementia research in Ireland, Rogan and colleagues (Rogan *et al.*, 2023), identified the top ten research priorities. Eight of the top ten priorities related to care provision, indicating that this is a key concern for all impacted by dementia. Within the survey, education of healthcare staff, involvement of people living with dementia and their caregivers in research and care systems including design and delivery, were highlighted as top ranking research needs (Rogan *et al.*, 2023). This is reflected in the current study with learning and education being central to the theory, *Holding on to Me*. Of particular interest going forward would be how and when to deliver dementia education to make it most impactful in terms of care practices. Additionally, this study has shown the pivotal role of the social environment and relationships in *Holding on to Me*. This raises another consideration for future possible research in terms of the impact of dementia education on the social care environment and relationships and vice versa.

In all future research it is important, to be cognisant of Sabat (2002) who posits that we need, as researchers to be cognisant of the fact that people living with dementia might not want to talk about their dementia and also that they may be embarrassed and feel vulnerable to concerns about how others see them. He therefore argues that to ensure meaningful engagement researchers must be cognisant of these vulnerabilities and be open to using “*person-centred methods of investigation*” in addition to statistical methods (Sabat, 2002 p. 290). He also highlights the importance of self-awareness on the part of the researcher in recognising unconscious biases and attitudes towards dementia that may exist (Sabat, 2002). This study has shown that the use of PPI can fulfil this remit both in terms of meaningful engagement and enhancing the researcher’s self-awareness. Additionally, the use of PPI in grounded theory can enhance the method and as there is currently a dearth of research evidence on the synthesis of these two approaches, this warrants further research.

9.6.1 Dissemination Plan

In addressing the issue of dissemination, it is important to reflect upon why the research was carried out. As a nurse, an important consideration is the desire to make a difference to the

lives of people living with dementia and their caregivers (both informal and formal). To this end, devising a dissemination plan is essential. Dissemination of research is one of the first steps in translating research into practice (Edwards, 2015). There are a number of ways to disseminate research, depending on the targeted audience and desired impact (Gagnon, 2011). Elements of the current study including research methods have already been disseminated at conferences, such as navigating ethical issues and meaningful engagement of people living with dementia in research. In line with best practice, members of the DRAT PPI team were, and will continue to be involved in conference presentations and dissemination plans. To reach wider audiences, and increase the possibility of impacting care practices, publishing in peer reviewed journals is a key dissemination method (Edwards, 2015). It is hoped that there will be three publications from this study. Firstly, relating to the theory, secondly relating to the use of PPI in CGT and thirdly relating to meaningfully involving people living with dementia in doctoral research as participants and contributors. Finally, use of social media and podcasts also form an element of the dissemination plan.

9.6.2 Recommendations for Future Research

Based on the discussion above there are a number of recommendations for future research:

1. The theory of *Holding on to Me* should be further developed by:
 - i. Addition of other data collection methods such as observation to:
 - a) Observe people living with advanced dementia or dementia and verbal fluency issues.
 - b) Observe the interactions between people living with dementia and formal and informal caregivers and others to discover additional concepts relevant to the theory.
 - ii. Involving people living with dementia from different ethnic and socioeconomic backgrounds and those living alone without supports.
 - iii. Involving people living with an intellectual disability and dementia.
 - iv. Replication or modification of the study to different care settings.
 - v. Incorporating a longitudinal element to ascertain variations in *Holding on to Me* over time and as dementia progresses.
2. Further research is necessary to identify how the properties of the theory *Holding on to Me* can be strengthened and expanded.

3. Research is needed to identify interventions to meaningfully support people living with dementia to learn how to self-manage their condition and the impact of these interventions on wellbeing or illbeing over the course of their condition. One such intervention that should be investigated is promoting the use of positive self-talk.
4. Research is needed to ascertain how the social environment can be modified to support people living with dementia to identify and maintain what is important to them and their perception of their sense of self.
5. *Holding on to Me* involved the perspectives of people living with dementia. Further research is needed to conceptualise the processes engaged in by informal carers and formal carers to *Hold on to Me* .
6. The theory of *Holding on to Me* is a substantive theory. To raise it to a formal theory, its applicability to people living with other life limiting or chronic conditions should be investigated.

9.7 Summary

Understanding self in dementia has important implications for care practices, education and research. Additionally, understanding how people hold on to their sense of self is essential to supporting the person to accept and adapt to their diagnosis. Within the literature there is much debate as to the persistence or loss of self in the context of dementia. *Holding on to Me* supports the extant theories and literature supporting the multidimensional nature and persistence of self in dementia. However, it adds an understanding of self from the perspectives of people living with dementia and more particularly, their active involvement in holding on to their sense of self through *holding tighter, letting go* and *relational grappling* .

The importance of people living with dementia *Holding on to Me* is inextricably linked to their wellbeing, autonomy, social relations and the social context. *Holding on to Me* challenges the literature suggesting that people living with dementia are passive recipients of care, increasing our understanding of their actions in holding on to their sense of self. Additionally, the role of others in recognising and supporting self, particularly as dementia progresses cannot be denied and has implications for care practices. This would essentially mean, understanding what matters to the person, has meaning for them and supporting them to *Hold on to Me* . It would also mean understanding the essence of personhood as ascribed by Kitwood (1997) in terms of respect, dignity and inclusion. In explaining from the

perspectives of people living with dementia how they endeavour to hold on to their sense of self, the theory *Holding on to Me* identifies ways in which the person can be supported to hold on to their sense of self. This can include adopting interventions not often used in dementia care such as promoting positive self-talk. Given the evidence, from other fields, identifying that positive self-talk helps to reduce anxiety, regulate emotions and enhance coping, this could be an avenue for further exploration and research. Although there is a lack of evidence relating to self-talk in dementia, this study shows that people living with dementia are already engaging in self-talk to guide actions. Additionally, self-management techniques, assistive technologies and opportunities for peer-to-peer support need to be explored further and promoted to help the person to live well with their diagnosis and ultimately *hold on to me* . This requires a refocusing of how supports and education are developed and delivered for people living with dementia and their families.

A focus on recognising and supporting the self in dementia, requires a strength based, human rights approach, essentially ‘seeing’ the person, rather than a focus solely on the impact of dementia. However, the use of the correct words (such as person-centred care) is not enough and there needs to be a practical, sustainable change in care practices and culture. This requires, as Bosco *et al.* (2019) advises, a co-production approach to care and *Holding on to Me* , as stated, provides ways in which families and healthcare workers can support this. Where the self is recognised, at all stages of dementia, people living with dementia can become active partners and decision makers in their lives and care, enhancing wellbeing and reducing excess disability. Additionally, the importance of recognising and valuing the self of caregivers has implications for their ability to fulfil this role and may require a cultural change at organisational level.

The final chapter explores considerations and criteria for judging the theory. Additionally, theoretical and methodological contributions of the theory are discussed. Limitations of the study are identified. Finally, concluding comments are made.

Chapter 10

Judging the Theory and Conclusion

10.1 Introduction

As a brief reminder to the reader, the purpose of this study was to generate a theory to explain how people living with dementia resolve or process their main concern. In Chapter One, the main concern was identified as *losing me*. This related to the participant's concern about losing their sense of self, who and what matters to them and how they see themselves and others see them in the context of dementia. Chapters Two, Three and Four detailed the approaches undertaken in this study in doing CGT and particularly how PPI was incorporated into the study to ensure meaningful involvement of people living with dementia and generate a theory that was relevant and had meaning for people with lived experience of dementia. The theory *Holding on to Me* was introduced and explained in detail in Chapters Five, Six, Seven and Eight. Additionally, central properties of *Holding on to Me*, namely *holding tighter*, *letting go* and *relational grappling* were also explained in these chapters. In Chapter Nine, the theory was discussed with reference to the extant theory and literature, with specific reference to implications and recommendations for practice, education and learning and future research. What remains for this chapter is to explore the criteria for judging the theory with reference to how they are addressed in the study. The theoretical and methodological contributions of the theory are discussed. Thereafter, limitations of the study are discussed. Finally, concluding remarks are made.

10.2 Judging the Theory

During the time of inception of classic grounded theory in the 1960's, there was distrust in and criticism of qualitative research by proponents of quantitative research (Charmaz and Thornberg, 2021). Glaser and Holton (2004) suggest that this is in part due to the interpretive nature and subjectivity of the qualitative analysis process. This argument was widespread within the fields of research and led to the development of criteria with which to judge the quality and trustworthiness of qualitative research (Guba and Lincoln 1994). In *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Glaser and Strauss (1967) set out to develop a new research method, but also through proposing a systematic method for conducting data analysis they wanted to defend the quality of qualitative research (Charmaz and Thornberg, 2021). In fact, according to Elliott and Lazenbatt (2005) the grounded theory method itself has a number of inbuilt checks and balances to promote

quality and raise awareness of the scientific merit required through the theory generation process including constant comparative analysis, theoretical sampling and memo writing.

According to Glaser and Strauss (1967) for theory to stand up to scrutiny it must “fit” the situation being researched and it must “work” in terms of being meaningfully relevant and able to explain the behaviour/topic of study (Glaser and Strauss 1967). Additionally, others including people not directly involved in the area of study (laypeople), should be able to understand the theory. The “fit” and “work” of the theory should be robust enough so as not to be completely refuted by more data or replaced by another theory. Glaser and Strauss (1967, p. 261) argue that in grounded theory the “*theory should fit the data*” rather than the “*data fitting the theory*”. Inclusive of the above, Glaser (1978, 1998) identifies four criteria for assessing the quality of classic grounded theory, namely, fit, relevance, workability and modifiability.

Glaser’s first criteria, fit refers to the theory “fitting” within the area of study through its close connection with the data. Ensuring that the theory has fit, is a guard against preconceived ideas, assumptions and deductions that could be forced onto the data and the emerging codes, categories and theory (Glaser, 1998). Adherence to the classic grounded theory method, as detailed above extensive memo writing and discussions with supervisors and the Dementia Research Advisory Team (DRAT) PPI team helped me to ensure that the emergent theory “fit’ within the substantive area. Additionally, using in vivo codes and mind maps of possible emerging codes and categories, helped to ensure the codes and categories remained firmly in the realms of the data.

The second criteria, relevance, refers to the theory making sense and having “grab” within the substantive area. This ensures that the research has meaning and importance to the people in the area of study. As discussed in Chapter One, and is further discussed in Chapter Four, the concept of self and particularly the persistence, or not of self in the context of a diagnosis of dementia is widely discussed within the literature. This would seem to indicate that it has relevance within the field of dementia care. Importantly, by remaining open to the emergence to codes and categories from the data and ensuring diligent adherence to CGT procedures for data collection and an inductive approach to data analysis, relevancy in terms of the importance to participants in this study can be assured.

The third criteria, workability, refers to the explanatory power of the theory in terms of explaining the main concern of participants within the substantive area and how they resolve or process that concern (Gibson and Hartman, 2014). The theory *Holding on to Me*, fulfils this remit in terms of identifying the main concern of participants and explaining how they resolve or process it, namely *holding tighter, letting go* and *relational grappling*. Glaser (1998) in acknowledging that a grounded theory is but one theory, argues that it works in the area of study if the codes and categories integrate into the theory and account for most of the variation of what people do to resolve or process their main concern. This is evident in the detailed accounts given in Chapters Five, Six, Seven and Eight as to how people living with dementia resolve or process *losing me* through *Holding on to Me* and its properties, *holding tighter, letting go* and *relational grappling*.

The fourth criteria, modifiability, argues that the theory should be open to and able to accommodate further development, ensuring as Glaser (1978) advocated a process of continued modification that ensures continued relevance within the area of study. Additionally, it must be noted that claims of generalisability are not being made in this study. However, the theory could be modified to another area of study by constant comparison with new data for a new substantive area (Glaser, 1998). The theory *Holding on to Me* and its properties could be further developed and modified in several ways by using other data collection methods such as observation, particularly for those with advanced dementia or linguistic difficulties. Additionally, the study could be modified to different care settings and include different populations, such as formal and informal caregivers. Further development of the theory could also include people living with dementia from different ethnic groups, those living with intellectual disability and from the LGBTQI community.

In addition to Glaser's criteria Vander Linden and Palmieri (2021) argue that when assessing the quality of grounded theory studies there are certain reporting criteria that need to be considered. In particular, in terms of classic grounded theory, there should not be a preliminary literature review. Within this study, the literature was briefly reviewed in order to develop the project proposal. The impact of this review in terms of influencing the research project with preconceived ideas and extant theory was limited through staying open, memo writing and discussions with supervisors. Additionally, there should be adherence to the methods of classic grounded theory such as theoretical sampling, theoretical saturation, data collection, constant comparative analysis, coding methods and memo writing (Vander

Linden and Palmieri, 2021). Chapter Two and Three give an in-depth discussion relating to the rationale for using classic grounded theory and adherence to the classic grounded theory method. As such this aims to assure the reader that the researcher has endeavoured to ensure rigour in ‘doing grounded theory’ according to classic grounded theory methodology. Perhaps equally as important, as a doctoral student and novice grounded theorist, I have detailed the challenges encountered both in learning the method and the practicality of using it in a healthcare setting (Glaser, 1998).

In judging the theory, it is also important to address the use of PPI in the study. In Chapter Four I outlined how the use of PPI added rigour, relevance and richness in terms of ensuring the meaningful engagement of people living with dementia in the study (Gove *et al.*, 2018). The GRIPP 2 (short form) (Appendix 2) was used to report the use of PPI in the study to ensure transparency and improve quality (Staniszewska *et al.*, 2017). By meeting these criteria, diligently adhering to the CGT method and using approaches to enhance meaningful data collection the quality of the CGT can be assured.

10.3 Theoretical Contribution

This thesis presents a multivariate classic grounded theory, *Holding on to Me*, generated to explain how people living with dementia hold on to their sense of self in the context of dementia and their main concern, *losing me*. In doing so it has presented an explanation of how participants engaged in patterns of action to *hold on to me*, essentially, their sense of self and what matters to them. They do this through *holding tighter, letting go* and *relational grappling*. As such it adds to the knowledge relating to how people living with dementia, from their perspective, address their concerns in relation to losing their sense of self. However, understanding what constitutes self within the literature is not without its challenges. Self, personhood, selfhood are terms that are often used interchangeably in the literature (Norberg, 2019). Moreover, there is a level of ambiguity and debate within the literature as to what actually constitutes self (Fazio and Mitchell, 2009; Caddell and Clare, 2013; Bomilcar *et al.*, 2021; Hennelly and O’Shea, 2022). Within the literature, several authors propose multidimensional perspectives of self, to argue for the preservation of self beyond the deterioration of cognitive abilities. A multidimensional perspective of self is supported by this theory informed by the work of Mead (1934), Blumer (Blumer, 1969), Tom Kitwood (Kitwood, 1997), Kontos (Kontos, 2005), Sabat and Harré (1992) and Sabat (2001, 2018). These perspectives are widely cited in in the literature relating to self,

personhood and person-centred approaches (Dewing, 2008a; Kelly, 2010; Norberg, 2019). In doing so *Holding on to Me* weaves together multiple multidimensional perspectives of self to explain how people living with dementia hold on to their sense of self in the context of their dementia, grounded in their own lived experience.

Theoretical perspectives of self are essential to understand, particularly in terms of the persistence or loss of self in dementia (Caddell and Clare, 2013). However, the emphasis of *Holding on to Me* is how people living with dementia are actively engaging in holding on to their sense of self to enhance their wellbeing in their everyday lives. In doing so this theory adds to the knowledge on the persistence of self in dementia but furthers the knowledge by offering an explanation of how people living with dementia are actively involved in holding on to their sense of self. This is essential as understanding the persistence of self in dementia has important implications for care, in terms of how the person is seen by others (Hampson and Morris, 2016). As the provision of Irish healthcare services endeavours to move to a more patient oriented and inclusive model (Health Service Executive, 2025), this theory increases our understanding of what matters to people living with dementia from their perspective. It highlights the importance of recognising and supporting self as essential in dementia care from two key standpoints. Firstly, the actions of caregivers in recognising and supporting self for the person living with dementia. Secondly and equally important is providing opportunities and for the person themselves to learn and adapt in the context of dementia to hold on to their sense of self. To this end, the theory *Holding on to Me* provides families and healthcare workers with practical ways in which people living with dementia can be supported to hold on to their sense of self. These include novel approaches such as supporting people living with dementia to get along with themselves through promoting positive self-talk. Additionally, promoting adaptive actions to support self-management and coping skills. Furthermore, supporting risk enablement and active partnership in decision making to promote learning and adaptation. This is crucial as understanding sense of self for people living with dementia has implications for how they react in their relationships with others and their ability to adapt and live well with their diagnosis (Caddell and Clare, 2010).

Holding on to Me adds to our understanding of the importance of the social context in several ways. Firstly, in terms of how the attitudes, and actions of others can either hinder or support the person to *Hold on to Me* . Secondly, in presenting opportunities for growth and learning, for both people living with dementia and their supporters. This is important for enhancing

wellbeing and actively supporting the person's sense of self. It can also reduce the risks of stigma, discrimination and paternalistic approaches impacting on the person's right to active decision making in accordance with their will and preference. In a similar vein, dementia literacy, particularly in addressing how dementia is portrayed in the media (Cahill *et al.*, 2015; Cahill, 2021) could go some way to addressing the fear associated with dementia and again, reduce the risks of paternalism and stigma (Swinnen and Schweda, 2015). The theory highlights the importance of the person being given opportunities to learn to redefine their boundaries of what they can and cannot do. This is important in allowing them to accept the changes associated with the diagnosis of dementia. They learn to adapt and live well with dementia in the present. They are also learning to manage fears of an uncertain future in which they feel their sense of self and decision-making capacity could be diminished.

Holding on to Me challenges the notion of people living with dementia as passive recipients of care. Rather it highlights that when the self is supported, wellbeing, adaptation, coping and active engagement in decision making is supported. In a similar vein in relation to care provision it champions recognising and supporting the self of people living with dementia to ensure their active partnership in person-centred care at all stages of the condition. Maintenance of self is a central concept in person-centred care, vagueness relating to what it means could contribute to a disconnect between personhood and care approaches (Higgs and Gilleard, 2016). To add to the complexity the concept of person-centred care is also often prone to ambiguity, particularly in relation to how it can be practically realised in dementia care (Mitchell and Agnelli, 2015). It is therefore important to understand from the perspectives of people living with dementia how they are actively involved in holding on to their sense of self, to offer clarity and practical solutions to healthcare practitioners in how to best meet the person's unique needs in supporting self. However, importantly within the social context, *Holding on to Me* , highlights that supporting and valuing self must also include the sense of self of caregivers. This has implication for the wellbeing of all persons in the care relationship and requires a shift in cultural thinking.

Holding on to Me also provides an insight into when the self is not supported, or indeed is undermined, the person can experience feelings of discontent and isolation and the impact of dementia can be more pronounced and overwhelming, often leading to what Sabat (1994) refers to as excess disability. Undermining of the self of people living with dementia can at best be from paternalistic approaches and at worst result from stigma, discrimination and

exclusion. Therefore, opportunities for learning should not be limited to the person living with dementia but are essential for caregivers and society. This would assist in increasing the levels of dementia literacy and it is hoped, reduce the level of fear and stigma associated with dementia. However, this education must go beyond a biomedical approach to how sense of self can continue to be recognised and nurtured throughout the lifespan of the condition.

In summary, *Holding on to Me* presents a multivariate grounded theory to explain how people living with dementia hold on to their sense of self in the context of a diagnosis of dementia. It supports the persistence of self in dementia from a multidimensional perspective and challenges assumptions of people living with dementia as passive recipients of care. It highlights the vital importance of the recognition and maintenance of self in everyday life and care delivery and offers practical ways this can be attained. Finally, *Holding on to Me* emphasises the importance of relationships and social context in the formation and maintenance of self. Moreover, it makes emphatic the detrimental impact of paternalism, stigma, self-stigma and exclusion on the sense of self of people living with dementia. This has implications for the person's ability to cope and adapt to their diagnosis, which can result in excess disability for the person, increasing the need for healthcare interventions. People living with dementia have longer lengths of acute hospital stay and increased levels of adverse incidents (Bracken-Scally *et al.* , 2020). Therefore, excess disability has cost and practical implications for the person living with dementia, their families, organisations and society. Given the current healthcare challenges in terms of costs and staffing (Curley, 2023), the theory *Holding on to Me* , is timely in offering ways in which self can be supported and excess disability reduced. Therefore, recognising and supporting the person's actions to *hold on to me* is essential.

10.4 Methodological Contribution

The aim of this study was to generate a multivariate grounded theory to explain people living with dementia resolve or process their main concern, *losing me* . The theory *Holding on to Me* was generated using Classic Grounded Theory (CGT) methodology. It has been argued that classic grounded theory is one of the most systematic and rigorous qualitative research methods (Smith-MacDonald *et al.* , 2019). Since its inception in the 1960's classic grounded theory, and its variants have become some of the most widely used research methodologies, in all disciplines including healthcare (Gibson and Hartman, 2014). In Chapter Three a detailed account of using classic grounded theory to generate the theory *Holding on to Me*

is given. However, newer research approaches were also used, namely, Person and Public Involvement (PPI) and flexible approaches for the purpose of meaningfully engaging people living with dementia as participants in the study. This study marries a traditional rigorous research method, classic grounded theory, with a modern research approach, PPI. In doing so it is important to explore synergies between the two as well as address any potential tensions. These are discussed in depth in Chapter Four but warrant a further mention in terms of the methodological contribution of the study.

In more recent times, there has been a move from traditional approaches to healthcare where service users are seen as passive recipients of care to one in which service users and the public are seen as active partners in co designing healthcare delivery (HSE, 2024; Bombard *et al.*, 2018). In a similar vein, there has been a corresponding shift in approaches to research (Nelson *et al.*, 2023). In recognition of this shift to more inclusive research, and the importance of actively involving people with lived experience of the area of study, it is now often a funding requirement and policy direction (Gilfoyle *et al.*, 2022). The value of engaging people with lived experience of conditions in research as participants but also as contributors in the research process is well documented (Holliman, 2017; Gove *et al.*, 2020). Engaged research, including PPI enhances relevancy, quality and translatability to practice (Hoddinott *et al.*, 2018; Smith-MacDonald *et al.*, 2019; Han *et al.*, 2021; Nelson *et al.*, 2023). Given that relevancy, fit and workability are criteria set out by (Glaser, 1998) for judging the quality of classic grounded theory (CGT), this would seem to be a strong argument for the use of PPI in CGT, within this study. Another key point in favour of the use of PPI in CGT is its person orientated approach. The starting point for CGT is to remain open to and understand the main concerns of participants in the area of study, rather than extant theories, a-priori assumptions and existing literature (Glaser and Strauss, 1967; Smith-MacDonald *et al.*, 2019). In a similar vein, PPI involves research that is with and by people with lived experience with a focus on asking research questions that are important to those people (Health Service Executive 2021; Health Service Executive 2024). To this end, it is important that I remained open to and address any unconscious bias that might impact on the research process and understanding what is important to people participating in the study (Glaser, 1978, 1998). As detailed in Chapter Four, the DRAT PPI contributors in this study were invaluable in this regard in terms of highlighting preconceived ideas and assumptions I held that were previously unknown to me.

Both CGT and PPI require meaningful engagement with participants for diverse, robust data collection (Smith-MacDonald *et al.*, 2019). Indeed PPI can enhance recruitment for participants deemed hard to reach, including those living with dementia (Smith, Baillie and Gill, 2024). So, it can be argued that using PPI enhances the relevancy, fit and workability of CGT, through accessing and meaningfully engaging with people with lived experience as both participants and contributors. It can also be argued that the use of CGT can add rigour to studies using PPI, given that there is often a lack of clear, methodological guidance for judging the quality of PPI studies (Staniszewska *et al.*, 2017; Smith-MacDonald *et al.*, 2019). However Glaser (2002b) was very vocal in his assertion that the CGT method should be adhered to diligently and not weakened by the interchangeable use of other methods. Therefore, it is important to address possible points of divergence between the two approaches.

PPI does not require that contributors are involved at every step of the research process, but that, where appropriate, they are involved as much as possible (Hoddinott *et al.*, 2018). This is an important distinction when examining the compatibility of PPI use in CGT in terms of possible tensions between the two approaches. Smith-MacDonald *et al.* (2019) identify several points for possible conflict between patient orientated research (POR) and CGT. These are issues relating to patient engagement, researcher autonomy in data collection and analysis and the inductive method (Smith-MacDonald *et al.*, 2019). However as stated there are numerous ways in which PPI can be incorporated into a study throughout the research cycle from informal involvement in research design discussions, to advisory groups to user led research (Health Service Executive: Research and Development, 2021). Through choosing the right PPI approach these methodological concerns can be addressed. The DRAT PPI team acted as an advisory group for this study, reviewing participant documentation, giving advice on flexible approaches to interviewing and acting as “critical friends” throughout the research process. Therefore, PPI engagement was limited to elements of the CGT research process, where input would be valuable without compromising my researcher autonomy or interfering with the inductive nature of the method. As such the use of PPI can be seen to have enhanced the study, whilst maintaining the integrity of the CGT method.

The use of PPI in this study has an additional relevance, namely, there is a paucity of research detailing the use and reporting of PPI in doctoral research (Dawson *et al.*, 2020; Smith, Baillie and Gill, 2024). PPI can be particularly useful in engaging with groups of people who

might be considered vulnerable, and as such are often excluded from research (Gove *et al.*, 2018). In doctoral research vulnerable groups can be excluded due to a perception of additional difficulties, particularly in relation to ethical issues and data collection (Smith, Baillie and Gill, 2024). Similar issues have been highlighted within this study. Involving people living with dementia in research has not been without its challenges, from a practical perspective, but also from an ethical perspective. Practical issues related to recruitment, communication and flexible, meaningful engagement. Ethical issues related to consent, self-determination and safeguarding. A detailed account has been given in Chapters Three and Four of these issues and steps taken to resolve ethical and practical issues as they arose. These included rolling consent, PPI involvement in reviewing participant documentation, developing gatekeeper relationships and flexible approaches to data collection. Additionally, GRIPP 2 reporting guidelines were used to accurately report the use of PPI in the study ((Staniszewska *et al.*, 2017). As such it provides a roadmap for other doctoral researchers on the use of PPI in research and more particularly CGT. Importantly, this study shows how PPI and CGT can generate theory that has relevance, fit and workability to the lives of people living with dementia and their caregivers. This is essential as this is a group of people whose perspectives are often overlooked, particularly by doctoral researchers. Given the lack of extant literature relating to the use of PPI in CGT and in doctoral research involving people living with dementia, this has the potential to add to our understanding of how such approaches could be used to enhance the quality and relevance of research involving people living with dementia.

In summary, the generation of this theory has made an argument for the appropriateness of using PPI in CGT, showing that there is compatibility and scope for combining the two approaches, enhancing rather than adulterating the CGT method. Through working with the DRAT PPI collaborators, it has been shown their valuable contribution to ensuring meaningful engagement with the study participants. Moreover, their input as “critical friends” again, has given confidence in the relevance and translatability of the theory to healthcare practice. Additionally, in meaningfully engaging with people living with dementia as participants and contributors in the study, adhering to the methodology of classic grounded theory, the theory has fit, relevance, workability within the area of study, and the possibility of modifiability inside and outside the substantive area.

10.5 Limitations of the Study

Although this theory does not set out to be all encompassing, there are several limitations to the study that should be acknowledged. These are largely reflected in the opportunities for further research discussed above. Firstly, the participants recruited for the study were primarily verbally articulate. Although communication aids such as pictures were used (for example with a participant with Primary Progressive Aphasia) this participant was also articulate once the correct communication method was used. Therefore, the results may not be extendable to people living with more advanced dementia or more significant linguistic difficulties. Secondly, all participants lived at home, with the support of family (although some lived alone). Whereas it is acknowledged that most people with dementia in Ireland live at home, to gain a fuller understanding of *Holding on to Me* in the context of dementia, other care settings should be considered for future research. Thirdly, all participants were from similar socioeconomic and cultural backgrounds, which may not be reflective of a growing number of older people with dementia in modern Irish society. Fourthly, the role of the researcher as a nurse, who worked in the outpatient clinics (from where participants were recruited) needs to be considered. Issues relating to potential power imbalances, the wellbeing and self-determination of the participants were addressed as part of the ethical approval process, and cognisance given to it throughout the data collection process. However, the possibility that participants were influenced by my role as a nurse cannot be ruled out.

10.6 Reflection

Many times during the completion of this PhD study I have reflected upon why I started and what kept me going when, inevitably, there were times I wanted to give up. The decision to pursue this PhD was not only an academic one but stemmed from a desire to make a meaningful impact on the lives of people living with dementia and their families. When I commenced this journey I was working as an advanced nurse practitioner in dementia care in a memory assessment and support clinic supporting people living with dementia and their families. I became acutely aware of the relative absence of the voices of people living with dementia and the fact that the focus of many available supports was centred on caregivers. This imbalance reinforced my commitment to exploring person-centred rights based approaches for people living with dementia. I was motivated by the potential for my research to act as a catalyst for change in policy and practice. But even more so I wanted to challenge

the narratives of dependency and decline because this was not what I was seeing when I spoke to people living with dementia. People wanted to continue to live their lives in accordance with what mattered to them. I also felt this study would be timely given the enactment of the Assisted Decision Making Capacity Act (Government of Ireland, 2015), given the remit for rights based approaches, including the right to autonomy. Yet, I wondered how could this be achieved if we did not know what autonomy meant to people living with dementia from their perspectives. I wanted to ensure this question was answered through a commitment that this research should have the potential to impact directly on care practices.

10.6.1 Key Insights and Surprises

A central focus for me throughout the PhD was a commitment to meaningfully engaging with people living with dementia. To this end I engaged with the DRAT PPI team to discuss flexible approaches and review participant documents to ensure relevancy and meaningfulness. However, what was most insightful for me was how this process challenged my own assumptions and preconceived ideas about dementia, which I had not even realised existed. It was a humbling reminder of the importance of approaching research with openness, reflexivity and a willingness to be challenged and in turn question my own preconceived ideas and assumptions. It strengthened my commitment to ensuring this research was inclusive, meaningful and impactful, particularly for groups of people often excluded from research, namely those living with dementia.

In a somewhat similar vein, and perhaps due to preconceived ideas about dementia, the theory of *Holding On To Me* surprised me. I had anticipated narratives of loss, decline and grief. Whereas these were often present for participants what I did not expect is how active, creative and adaptable the participants were in holding on to their sense of self and what mattered to them. It has reshaped my understanding of dementia and as such has been as much a personal journey as an intellectual one.

Learning classic grounded theory added another layer of complexity and excitement. It demanded patience, openness, and a willingness to let patterns and meaning emerge rather than forcing them to fit pre-existing frameworks. Each breakthrough carried with it a sense of accomplishment, reminding me why I had chosen this path in the first place. Using classic grounded theory allowed me to ensure that the study remained firmly within the realms of the data and consequently with the participants. This wasn't always comfortable. Sometimes,

it felt like standing on shifting ground, but it taught me to be comfortable with ambiguity and the unknown and that I would have the resilience to get through the foggy. I have included a list of activities undertaken to learn classic grounded theory, engaged research and enhance my academic and research proficiency (Appendix 6).

Reaching the end brought an overwhelming sense of pride, not just in the thesis itself, but in having navigated the challenges, adapted my thinking, and grown in resilience and skill. The journey has changed me, leaving me both humbled by what I have learned and proud of the persistence that carried me through.

10.7 Concluding Remarks

The theory *Holding on to Me* highlights that rather than being passive recipients of care, people living with dementia are active players in terms of *Holding on to Me* , their sense of self. However, whereas this theory highlights that people living with dementia can be active participants in their care, it also highlights that this can be impacted both positively and negatively by the actions of others and society. The shift, mentioned above, must not be limited to individuals but also occur at organisational and indeed societal level. This is essential to empower people living with dementia to adapt to their diagnosis of dementia and learn to live well and enjoy a good quality of life in accordance with their wishes and preferences. Furthermore, the study has highlighted that through dementia education, creativity and practical intent, the self of the person can be recognised, supported and nurtured throughout the condition, enhancing wellbeing and active partnership. Whilst dementia care policy in Ireland is underpinned by the concept of personhood, in practical terms this does not always translate into person-centred, compassionate and human rights-based dementia care practices. This requires a shift from a task orientated approach to care that sees people living with dementia as passive recipients of care to a more person-centred, human rights-based approach that recognises and nurtures the uniqueness of self and encourages active partnership in care. Given that people living with dementia continue to have much to contribute to their families and friends, their community and society, a social environment that supports the person's activities to *hold on to me* is essential.

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Appendix 1
Ethical Approval

16th December 2021

Susan O'Reilly
xxxxxxx

Re: Study xxxxx- Exploring Autonomy from the Perspective of People Living with Dementia.

Dear Susan,

Thank you for your submission to xxxx Hospital Research Ethics Committee and providing your revisions as we requested to this study. These revisions have been reviewed and I would to confirm that your study has been approved.

If you require any further information, please do not hesitate to contact me or xxxxxxxx

Yours sincerely,

Xxxxxxx Clinical Director
Chairperson, Research Ethics Committee

Susan O'Reilly
School of Nursing, Psychotherapy and Community Health

Dr. Kate Irving
School of Nursing, Psychotherapy and Community Health

2nd February 2022

Proposal Title: Exploring Autonomy from the Perspectives of People Living with Dementia.

Dear Colleagues,

With regard to the above proposal, DCU Research Ethics Committee (REC) acknowledge receipt of your application to [redacted] Hospital Research Ethics Committee and subsequent letter of ethical approval. These documents will be kept on file in the Research Support Office. As the appropriate ethical approval is already in place, you are not required to submit an application for ethical approval to DCU.

Yours sincerely,

[redacted]



[redacted]
Chairperson
DCU Research Ethics Committee

Appendix 2
Gripp 2 Short Form for Reporting PPI

GRIPP 2 Short Form for reporting PPI (Staniszewska <i>et al.</i> , 2017)
1. Aim: Report the aim of the study
The aim of this study is to generate a theory explaining how people with dementia resolve or process issues relating to their main concern of losing self. An important element of the study was to collaboratively involve people living with dementia and their supporters in the research process, as appropriate.
2. Methods: Provide a clear description of the methods used for PPI in the study
<p>One person living with dementia and one dementia caregiver were recruited to assist with the research process. The PPI contributors, Dementia Research Advisory Team (PPI DRAT team) were recruited through an application process from the Alzheimer Society of Ireland (ASI), Team up for Dementia Research.</p> <p>An initial meeting was held between the ASI, DRAT PPI team and I, early in the research project, to discuss expectations and to help to build a relationship. ASI staff were available to both me and the DRAT PPI team should any difficulties arise. Furthermore, they acted as a support for the DRAT PPI team, thus providing a safeguard for them should they need it. Initial meetings took place monthly, this helped to build the relationship.</p> <p>In planning my work with the PPI DRAT team I was aware that PPI must be tailored to the individual, ensuring they are supported for meaningful engagement through exploring communication methods and providing relevant training (Gove <i>et al.</i>, 2018; Roberts <i>et al.</i>, 2020; Smith, Baillie and Gill, 2024). Given that dementia is a progressive condition, contributor's cognitive and functional abilities may change over time, requiring additional supports or the option to withdraw. If appropriate I would discuss this with the individual or ensure they received the support, they needed through the ASI.</p> <p>There are several different ways in which people with dementia can be contributors in the research process, but it is crucial to plan meticulously to ensure that the expectations of all stakeholders, including contributors and researchers, are clearly defined and that the engagement process is mutually beneficial (Bethell <i>et al.</i>, 2018, Di Lorito, 2018). To enhance role clarity for stakeholders for this study, the DRAT PPI group jointly discussed a role descriptor and this was agreed at our initial meetings.</p>

Gove *et al* (2020) recommends safeguarding the wellbeing of people living with dementia in PPI by ensuring they understand the study, receive regular updates, feel no pressure to contribute and given tasks suitable to their ability or supported as needed. As part of the ASI application process, potential contributors received a lay summary of the study, a brief outline of what could be their role (this was then decided by the group), and the project timeline. PPI DRAT team members were also given the option to have a trusted friend or carer with them. Although the team members did not take up this option, I had given consideration to ensuring that the input of the person living with dementia would not be overridden by their carer as advocated by (Gove *et al.*, 2018). Bird *et al* (2020) also warn about the possibilities of power imbalance in the researcher-contributor relationship but state that developing clear roles and responsibilities can help to mitigate against this. As previously indicated, this was discussed with the PPI DRAT team in our initial meetings.

It was in the earlier stages of the study that the DRAT PPI team had the most input into the study in terms of reviewing and giving feedback on participant documents, advising on recruitment and reviewing the interview schedule/techniques. This was essential in creating opportunities for meaningful encounters with participants and their supporters.

As the study progressed the DRAT PPI meetings were as necessary to give updates about the study and also during this period the DRAT PPI team acted as ‘critical friends’ in giving their opinions as to the initial codes and categories emerging from the study. Although this did not influence the data analysis process, it helped me to enhance my theoretical sensitivity. Additionally, their opinions and perspectives helped in the consideration of the fit and workability of emerging codes and categories.

To ensure meaningful involvement, all materials for review by the PPI DRAT team were provided in accessible formats and sent two weeks in advance to allow time for review and feedback. One contributor required information in 14-point bold font, which was accommodated. The group also had time to review materials on the day. Contact details for the researcher were shared for any clarification or concerns. At the request of the PPI DRAT team reminders were sent two days prior to meetings. All meetings were held on zoom. Initially, this was to adhere to COVID 19 restrictions, but subsequently the DRAT

PPI team found them easier given their geographical spread. ‘Check in’ meetings were also held with the ASI to keep them informed of the progress of the study and the work of the PPI DRAT team. Memoing and discussions with supervisors ensured the emerging codes, categories and subsequently the theory remained firmly grounded in the data.

3. Results/Outcomes: Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects.

PPI contributed to the study in several ways:

- Reviewing participant documents, including the format, wording and language used in the participant documentation and amendments were made in accordance with their guidance.
- Reviewing the interview schedule and interview technique
- Reviewing and advising on recruitment processes
- Challenging preconceived ideas and assumptions
- Contributing to the preparation of presentations for and ethics symposium in Copenhagen and a research conference in Ireland. PPI contributors to dementia research have indicated that acknowledging their work as essential in articles and conferences is not only good practice but also recognises their valuable work as contributors (Roberts *et al.*, 2020).
- Acting as ‘critical friends’ throughout the research study

While facilitating the PPI DRAT meetings it was important to recognise and acknowledge where people are at, personally, in the group as this can influence their thinking, and whereas this is valid and important, it may not necessarily have relevance for the study. For example, if a member of the DRAT PPI team had or was having a bad care experience, or simply having a bad day, they may be reacting to that situation rather than what is happening in the study. I wanted to ensure their participation was meaningful and purposeful and would not in any way be vulnerable to tokenism. It was important for me to listen to what they had to say and acknowledge it, even though it was not always have relevance for the study.

This could equally be said of the researcher, and it was through building a trusting and open relationship between all members of the PPI DRAT team that such instances could be acknowledged, discussed and reflected upon. Writing reflective memos was essential in this process of reflection for me.

Similarly, it is important to remember that their opinion, is exactly that, their opinion. Wendy Michell's book (Mitchell, 2022) "*What I wish people knew about dementia; from someone who knows*" refers to the well-known adage, in highlighting the uniqueness of each individual living with dementia: "when you know one person with dementia, you know one person with dementia". Although not necessarily a challenge, this is something that required careful consideration in terms of the role of the DRAT PPI team as critical friends, and in particular to ensure that I was staying true to the codes and categories that were grounded in the data and had 'earned' their way into the theory.

4. Discussion: Comment on the extent of which PPI influenced the study overall.

PPI was an important and effective element of this study, influencing many central aspects of the study, particularly in the planning stages. A principal factor in the success of PPI in this study, was the recruitment of the contributors from the ASI DRAT teams. As such, they were experienced and had been PPI contributors in previous studies.

Additionally, the correct processes were in place as the PPI DRAT team were involved from the early stages, a trusting, open relationship had been built and as they were linked to the ASI, there were safeguards in place should they have any difficulties.

However, there were limitations to the use of PPI in this study. The perspectives of the PPI DRAT team was not sought in terms of their roles and collaboration in the research study. This could impact on the evidence of the impact of PPI, which although often omitted from PPI reporting, makes the process more transparent (Miah *et al.*, 2020).

Additionally, although the PPI DRAT team were recruited through the ASI, thus there was little control over who was recruited, the study might have benefitted from representation from more diverse populations and possibly a larger group. However, a larger group may have been more difficult to facilitate on Zoom. Nonetheless, this could be borne in mind in future studies.

5. Reflection: Critical perspective- Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience

Miah *et al* (2020) argue that an essential element of reporting PPI is reporting the reflections of the researcher. PPI can be difficult sometimes, particularly as the PPI DRAT team challenged preconceived ideas and assumptions, I was not even aware I had. For example, PPI DRAT input was sought in reviewing participant documents, particularly the accessible documents. The contributors reviewed and changed the documents to make them more accessible for people living with dementia. I had originally decided to have the documents in two formats, one to be in an accessible format. However, upon review by the PPI DRAT team it was decided to have one document that could be used by all participants. The DRAT team challenged by assumptions and preconceived ideas by simply questioning why two documents had been needed? Why had I made a distinction between who I felt would need an accessible format and who would not? As there was no arguable reason for two documents, it was decided to use one easy read, accessible document for all participants. In research involving groups that may be vulnerable to stigma or discrimination, PPI is deemed essential as it can challenge preconceived ideas and assumptions held by the researcher (Smith-MacDonald *et al.*, 2019).

Acknowledging preconceived ideas requires a level of self-awareness, and I found that my experience in supporting people living with dementia and my background in mental health nursing made me more open to acknowledging preconceived ideas and assumptions. However, I can say that without the PPI DRAT team my engagement with the participants in the study would not have been as meaningful. This, I feel would have impacted on the richness of the data collected and subsequently on the robustness of the theory generated.

Additionally, grounded theory method is also important in acknowledging preconceived ideas, putting them aside and staying open to what emerges from the data. Memoing is a central element of grounded theory and through this process I was able to acknowledge and confront my preconceived ideas and ensure they did not impact on or influence the study. For example, when some participants were saying that they were happy and content and even that they were the same as they always were, I assumed this could not be really what they meant. I was putting my assumptions onto the data and almost trying to

conceptualise the data to fit these assumptions. Through the grounded theory method, particularly memoing, listening to the thoughts of the PPI DRAT team (critical friends) and my supervisors, I was able to acknowledge and confront my assumptions and stay open to what was emerging from the data, ensuring preconceived ideas did not impact on the study. My assumptions and preconceived ideas regarding dementia truly surprised and shocked me, given I have worked in the field for many years. It shows how combining grounded theory and PPI can help ensure that the grounded theory is exactly that, grounded.

Furthermore, it must be noted that although, detailed planning had taken place, to ensure meaningful engagement, particularly of people who might be considered vulnerable, such as people living with dementia, it was often the DRAT team, who guided the me, rather than the other way round. This, yet again challenged my own assumptions.

Appendix 3
Helping Us To Know You Form

Helping us to know you

This information will help us to support you during the interview by telling us what you like, dislike and what upsets you. We invite you, your family, friends and carers to complete this form with as much detail as you want to share with us.

Preferred name: What do you like to be called?

Who knows you best:

Would you like them to support you during the interview?
(You can change your decision during the interview if you like)

What things are important to you? (family, friends, pets, hobbies)



What upsets you?

How do you show you are upset? (restless, walking away, facial expression)



Hearing, Vision, Communication difficulties?

Is there anything else you would like us to know?



Completed by _____ Date _____

Appendix 4
Informed Consent Form for Participation in Research



Dublin City University
School of Nursing, Psychotherapy and Community Health

Informed Consent Form For Participation in Research

Research Title:
"Exploring Autonomy from the Perspectives of People Living with Dementia"

Researcher: Susan O'Reilly



Supervisors: Professor Kate Irving
Dr. Mark Philbin
Dr. Therese Leufer

All participant documents have been reviewed by the Alzheimer Society of Ireland Dementia Research Advisory Team

Purpose of the research:

The purpose of this research is to explore autonomy from the perspectives of people with dementia. This should help to inform healthcare professionals in promoting and maintaining autonomy for people living with dementia.

Involvement in the research:

I have read and understand the accompanying plain language statement



I have been given the opportunity to ask questions about the study

I have received satisfactory answers to all my questions

I understand that I will be asked to take part in an interview

I understand that I may be asked to take part in more than one interview

I understand that I can ask a family member or trusted friend to be with me during the interview

I understand that the interview will be audio taped

Voluntary Involvement:

I understand that I can stop answering questions at any time and that this will not affect the services I receive in any way



Confidentiality:

I understand that the information I give will be confidential and that my name will not be used

I understand that the information I give will be stored in a secure, locked cabinet and that computer files will be password protected in line with data protection legislation



I understand that only the researcher and her supervisors will have direct access to the audio taped information provided

I understand that the results of this study may be published in a book, article or report and consent to quotes of my interview being used as no names or details relating to me will be used



I understand that confidentiality cannot be promised regarding information disclosed that indicates a persons' safety or welfare is at risk from peers, staff, family or another source

**I have read and understood the information in this form.
My questions and concerns have been answered by the researcher and I have a copy of this form.
I agree to take part in this study**

Name of Participant (please print): _____

Signature of Participant/Family member: _____

Signature of Researcher: _____

Date: _____

Appendix 5
Interview Guide

Interview Guide

Study Title: Exploring Autonomy from the Perspective of People Living with Dementia.

The beginning of the interview will consist of introductions and demographic information such as age. I will explain the study and there will also be time to ask questions about the study and discuss consent/assent.

Autonomy can be a very hard concept to grasp, and participants may have difficulty answering questions directly asking about autonomy. Additionally, in Grounded Theory the topic of study is determined by the participants through constant comparative analysis. Therefore, the initial open question for exploration is broad such as: “How do you like to spend your day” or “how has your day been”

If the person finds it difficult to answer the initial question, I will use information from the “knowing me” document such as “I see you like gardening, what do you like about gardening?”

- I will then ask more focussed questions based on what the person tells me that will be more focussed on the concept of Autonomy such as “who decides what you do during the day” or “how do you decide what you want to do, when to get up?”- this question was changed when discussed with the PPI group as they made the comment that it was leading- this was extremely useful as I had let preconceived ideas and assumptions guide my questions, without my knowing.
- When interviewing it will be more like a conversation and the researcher will be guided by the participant in terms of pace, ability and preferred communication method.
- Attention will be paid to the other people in the person’s life and the role they play in the person with dementia’s life. “Is this different now the person has dementia?” “Do others help the person with dementia make decisions?”
- I will use wrap-up question e.g. “Is there anything further you would like to add?”
- If applicable I will also use probing questions such as “can you tell me more about that?”
- The interview will be guided by the person and their ability to communicate verbally or non-verbally. I will also be memo writing and keep field notes to detail non-verbal communication and my sense of what is going on for the person.

Appendix 6
Learning Opportunities

Overview of a selection of learning opportunities availed of during my PhD journey.

Learning Opportunity	Benefits
Supervision	Monthly meeting with supervisors
Grounded Theory Online: Troubleshooting Workshops for Grounded Theory ran by Dr Helen Scott and Dr Tom Andrews	I attended three troubleshooting workshops at different stages of the project (Beginning, middle and towards the end). It equipped me with the methodological tools, critical mind set, and confidence to let data lead the way.
Grounded Theory Online: Individual Mentoring	This allowed me to connect with expert Grounded Theorists and discuss issues specific to my study and helped me apply and enhance my grounded theory knowledge in my study.
Grounded Theory Online: Monthly Coffee and Chat	Monthly online discussions, troubleshooting and networking. This proved very useful in sorting out my thinking if I became stuck at any stage of the GT process.
PPI Ignite: Monthly shared learning workshops for PhD Students	Shared learning and troubleshooting for PhD students engaged in PPI.
Grounded Theory Conference- Kara Van Der Linden	Leading experts in GT and also hearing presentations on other GT studies- what worked and challenges.
Grounded Theory Online conference	Leading experts in GT and also hearing presentations on other GT studies- what worked and challenges.
Dementia and ethics summer school, Copenhagen	Worked with the DRAT PPI team to develop a presentation detailing the ethical challenges of meaningfully involving people living with dementia in research. Discussions regarding ethical issues in dementia care early in my PhD journey helped me to navigate ethical issues in my study.
Dementia and Ethics Spring School, Barcelona	Purpose: Upskill early-stage researchers in theoretical and applied aspects of ethical issues as they pertain to dementia care. Attended later in my PhD journey
Engaged Research Module	This 10 credit module in DCU was invaluable in helping me to learn about engaged research and understand how PPI could be used in my study. Additionally, I learned about PPI Ignite and IPPOSI groups that I could link with to learn how to successfully implement PPI in this study.
Research Integrity Module	Mandatory and valuable module that helped me ensure the highest professional and ethical standards in all aspects of the research process.
Seven secrets of successful PhD: Hugh Kearns	Extremely useful in helping me to navigate the PhD process including tips and tools for supervision and organisation of work.

Academic Writing	A series of six webinars to support academic writing.
Writing in the First Year: Dr Dan Soule	Excellent tips and tools to get started and create a habit for writing.
Writing in the Final Year: Dr Dan Soule	Excellent tips and tools to create habits that would ensure the completion of the thesis. Tips for accessing resources such as the Manchester Word Bank were valuable.
Writing for Publication: HSELand	Tips and information regarding dissemination of the study in peer reviewed journals.
TCD Poster: 2024	Ethical conundrums of involving people living with dementia in research.
RCSI presentation: 2024	Enhanced presentation skills
Engaging Dementia Conference, Presenting with a member of the PPI group: 2025	Presenting with my PPI partner enhanced my presentation and PPI skills

Appendix 7
Malignant Social Psychology

Malignant Social Psychology

- 1 Treachery
- 2 Disempowerment
- 3 Infantilization
- 4 Intimidation
- 5 Labelling
- 6 Stigmatization
- 7 Outpacing
- 8 Invalidation
- 9 Banishment
- 10 Objectification
- 11 Ignoring
- 12 Imposition
- 13 Withholding
- 14 Accusation
- 15 Disruption
- 16 Mockery
- 17 Disparagement

(Kitwood 1997, p. 46/47)

Appendix 8
Participant Information Leaflet

Plain Language Statement: Recruitment Information for a Research Project

Research Title:
“Exploring Autonomy from the Perspectives of People Living with Dementia”

Researcher: Susan O’Reilly

Contact details:



All participant documents have been reviewed by the Alzheimer Society of Ireland Dementia Research Advisory Team.

Introduction

This leaflet is designed to give you some information about a research project that I am undertaking so you can decide if you would like to be involved. My name is Susan and I work in the Memory Assessment and Support Service in [redacted]. The research is part of my PhD studies, and three senior researchers are acting as my supervisors.

Participation is voluntary:

That means that it is entirely up to you whether you would like to take part. You can also change your mind or withdraw from the study at any time. If you decide not to take part, it will not affect any services you receive in the Memory Assessment and Support Service or any other service in [redacted].



What the study is about:

This study asks people living with dementia to talk about what matters to them or concerns they may have and how this relates to autonomy. Autonomy means the respect given to a person’s rights and choices not only in decisions relating to healthcare but also everyday concerns from what to wear to finances and where, how and with whom the person wishes to live. Loss of autonomy can affect a person’s wellbeing and self-esteem, often resulting in loss of independence for a person with dementia.

People with dementia sometimes require extra supports to make decisions and their capacity to make decisions can change over time or even from day to day. This can mean their rights to make decisions about their lives can be overlooked due to communication difficulties, perceived lack of capacity or in favour of what others might feel is safe or best for them. This can impact directly on their ability to live their lives according to their wishes.

I am interested in exploring people with dementia’s perspectives of autonomy to gain greater understanding of what is important to them and determine how autonomy can be protected and maintained, both in everyday life and in healthcare settings.

Who can participate in the research:

I am looking to recruit people living with a diagnosis of dementia. Family members or a trusted friend may also be involved to support the person with dementia if needed.

What you will be asked to do:

The study will involve a face-to-face conversation. The conversation will take about 60 minutes. This might be split over two or three conversations, depending on your wishes. You will be asked to talk about what is important or concerning to you in your life. You can have a family member/carer/supporter with you if you wish. The conversation can take place at a time and place most convenient for you. You can take a break or withdraw from the study at any time.

Communication aids such as pictures or talking mats will be used if you have difficulty with communication. The conversation will be audio taped.

Why you might like to get involved:

You might find it interesting to talk and think about what matters to you or concerns you in your life. It is important that people with dementia are given the opportunity to take part in research that involves looking at their opinions, experiences and perspectives.



The information learned from this study could help inform the development of supports and guidance, based on the perspectives of people living with dementia to help carers and healthcare workers promote and maintain autonomy.

Possible risks from taking part:

Some people may find answering the questions difficult or distressing. To help avoid this: The researcher has specific skills and experience in communicating with people living with dementia. The interview will be at your pace and at a place and time of your choosing. You can take a break whenever you want. You can stop the conversation whenever you want. You will be given the contact number of the researcher and dementia specific community support services, should you need them.

Confidentiality: How the information you give will be used

The information you give will only be used for the purpose of the study. The information will be treated in confidence and no identifying information about you will ever be shared or published. The audio recording of the conversation will be destroyed as soon as it is transcribed. The information you give will be stored securely according to Data Protection legislation with access to your information only by the researcher and her supervisors.



We are committed to protecting people involved in our research. Confidentiality cannot be promised regarding information disclosed that indicates a persons' safety or welfare is at risk from peers, staff, family or another source.

If you would like to take part:

Please contact the researcher: **Susan O'Reilly** on [redacted]

If you are given this leaflet by a healthcare professional, you can let them know that you are interested. I can then contact you and we can talk more, and you can decide if you want to be involved. There is no pressure to be involved and you can change your mind at any time.

**Thank you for reading this information and for considering this project.**

If participants have concerns about this study and wish to contact an independent person, please contact: The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. [redacted]

Appendix 9
Participant Profile

Participant	Gender	Age	Living Arrangements	Approximate Time Since Diagnosis
1	Female	75	With spouse	3 Years
2	Female	78	With spouse	2 ½ years
3	Male	72	With spouse and family members	1 Year
4	Male	81	Alone	1 ½ years
5	Male	80	With spouse	6 months
6	Female	62	Alone with caregivers	10 months
7	Male	77	With spouse	2 Years
8	Male	69	With spouse	6 Months
9	Male	73	With spouse	8 Months
10	Female	69	With adult child	6 Months
11	Male	71	With spouse	3 Years
12	Male	73	With spouse	4 Years
13	Male	76	With spouse	6 Months
14	Female	73	Alone	6 Months
15	Male	68	With spouse	1 Year
16	Female	72	With spouse	2 ½ Years
17	Female	71	With spouse	1 ½ Years
18	Female	75	Alone	9 Months
19	Male	65	With spouse	1 Year
20	Male	70	With spouse	7 Months
21	Male	70	With spouse	6 Months
22	Female	72	With spouse	2 Years
23	Female	68	Alone	10 Months
24	Female	77	Alone	1 Year
25	Female	74	With spouse	4 Years
26	Female	78	Alone	7 Months

All participants had support from family members, whether living alone or with their spouse.

Appendix 10
Positive Person Work

Positive Person Work

- 1 Recognition
- 2 Negotiation
- 3 Collaboration
- 4 Play
- 5 Timalation
- 6 Celebration
- 7 Relaxation
- 8 Validation
- 9 Holding
- 10 Facilitation
- 11 Creation
- 12 Giving

(Kitwood, 1997 p. 119/20).

Appendix 11
Sample Memos

Early Memo: (2022)

Memo: Grief and Loss:

Dementia has taken away the ability of the person to do tasks that they would have done- but this is not merely tasks its related to the identity of the person, and her role as mother.

“...so I don't do the medicines now in case I make a mistake so I give that to (husband), you have to be very very ...you have to check ,and then you kind of feel, “oh God is this the stage I'm at?” and you just sit down you have a good cry and then you get on with it 'cause I love doing everything and I found that very difficult to kind of have to give that to somebody else yeah but then it just just wait is it's about safety like having somebody like (Son)and that like he has special needs..”

This is something that is very upsetting for the participant, yet there are times when it seems she feels that others don't understand her loss:

“...but he's a man, but he doesn't understand, he's no sisters so he doesn't understand if a woman cries “what are you crying for?” (laugh) I'm a woman I will cry (laugh)”

There is also an acceptance of the loss, and the participant tries to adapt so she can remain as independent as possible, whilst also accepting what she may not be able to do.

“...it's how you deal with it, but I mean they're very good , they would know if I was kinda sitting there, I'm not one for house hatching , sure I'm not (asks daughter), now I love going out I love to be out but now I can't go into town on my own and I miss that then I thought you just have to deal with it love you can't change it ,yeah I could hop on off the buses with absolutely no bother on my own, now I'd be more cautious, and it's wise to be cautious, because it's not fair to whoever is here worrying about me, if I got on the wrong bus and that so I don't go out my own anymore..”

Not being able to go out on your own anymore must be a very difficult adjustment to make. But does having an optimistic personality and supportive family help with this transition?

“...yes yeah well and that, I don't have many bad days I must say 'cause I would be very optimistic and then I have my daughters and they're great and I'm not just saying that just because you're there, but they are actually great well we give one another space and I think that is so important as well, you don't want someone kind of smothering you “can you do this, can you do that”

Is the person's ability to cope with this grief and loss based on their existing coping skills? The participant has a son with special needs and Janicki et al (2011) refers to the carers of people with ID and Dementia as “adaptive copers”, which he feels helps them to cope with changes and make adaptations more readily as they have been doing this all their lives. Have this family been making adaptations all their lives and does this help with the grief/loss, adaptations/adjustments and changes associated with the diagnosis of dementia? The participant has developed strategies to cope with “bad days”

“...it might be simple things like turn the Telly on and look at something funny and that or get out and go for a walk or pick up the phone and have a chat with a friend...”

There are also Mantras: - not sure about this yet

“...we'll be grand...”

“...I don't give into things.”
“...it's how you deal with it...”

Loss of ability and the subsequent fear for the future is very real for the participant- there is also an element of anger associated with it, which she has accepted and dealt with

P1: “I hated the idea of dementia I don't want, I don't want to be in that bloody club, they're all daft, that sounds awful but that's how I felt, I thought, Oh God will they be feeding me with a spoon next” (Laughs)

Me: “that must have been really difficult”

P1: “all because I'm so independent, I found that very difficult, but you know what I did, I believed in the power of prayer, now I wouldn't be over religious, but I go into the little Chapel and that and I'd say help me get through today, help me to accept the things I cannot change, what do you think ?”

I'm struck by the fact that the grief and loss associated by a diagnosis of dementia has similar elements to Kubler- Ross stages of grief. - need to think more about this.

Later Memo: Truth: RS Autobiography: (2023)

Truth plays a big role for RS in terms of how he resolves the issue of dementia and indeed “holding onto himself”. In terms of his father’s dementia he denied the truth of what he was seeing himself- the changes in his father- this was not only because he didn’t want to believe that his father was struggling (his father was a character who was larger than life), but he admits to himself that accepting the truth that his father could no longer do the things he used to do, meant that he had to postpone things he wanted to do, it impacted his life, his ability to live his life as he wanted.

In order to preserve his father’s image amongst his father’s work colleagues (who had also noticed changes and had been compensating for his father- RS had not known this) he tried to fill in the gaps and take over more of his father’s work. Also with his mother, she had decided that there was no issue with RS’s father and that he was just being difficult, even when there were serious incidents where his judgement was not as it had once been.

Accepting the truth, particularly that he was no longer able to continue to compensate for this father brought its own guilt, anxiety and sadness as a decision needed to be made regarding long term care. Again, RS hid the fact that his father was going into long term care and said that he would only be staying there for some investigations. Yet he felt that his father knew the truth and this saddened and distressed him. The subterfuge continued whilst his father was in long term care and with his mother, who continued to deny her husband had dementia.

In relation to his own diagnosis of dementia, again he talks about denying that changes were happening. He checked and rechecked things and became frustrated when he could do tasks (even when they had been simple tasks before). It was frightening to him, when he saw the similarities between his behaviour and what he had seen in his father, but again this was put down to a number of different factors. He adjusted his work life so that he could continue to work as he had.

It was only when his wife suggested that he get tested that he decided to get assessed. Even then the truth of the diagnosis and the implications of it were difficult to accept and this was something he and his family did not discuss for some time. His children had exams etc and it was decided to not tell them about the diagnosis until later to allow them to complete their exams first.

Telling people was both distressing but freeing for RS in that it was difficult to say it out loud, but once he had done this and realised the support of his family and friends, he felt somehow lighter. He chose the people he would tell carefully. He continued to work (which was really important to him).

Thoughts:

Truth or lack of truth leads to actions. Whether you accept the truth or don’t accept the truth, it leads to actions- what you do next.

There also seems to be a difference between the person’s truth and that of others and this can impact on the wellbeing of the person.

Appendix 12
Support Organisations

National Support 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 13
Whiteboards and Memo Sorting

