**Capturing the experiences of younger people with dementia and those close to them: co-constructing the ‘Sharing Model’**

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**Contents Page**

**Abstract 7**

**Chapter 1: Introduction to the Thesis 8**

**Chapter 2: Setting the scene 10**

2.1 Background to the study 10

2.2 Initial Research Aims 10

2.3 Foreshadowed Questions 11

2.4 What is dementia? 12

2.5 The challenge of dementia at a younger age. 13

**Chapter 3: So what do we already know? 16**

3.1 The background literature informing the study 16

3.2 Concepts of dementia in society and the importance of personhood 17

3.3 Emerging autobiographical accounts by people with dementia 19

3.4 Investigating the social context of dementia 21

3.5 A temporal model of dementia 22

3.6 Literature focused on partner relationships experienced 25

by people with dementia

3.7 Review of the literature related to younger people with dementia 27

3.8 Literature search strategy 27

3.9 Literature related to the experience of younger people with dementia 35

3.10 Critique of the YPWD literature 38

3.11 Conclusions from the initial literature review 40

3.12 Sensitizing concepts, overall study aims and foreshadowed questions 42

3.13 Chapter conclusions 44

**Chapter 4: Why Constructivist Grounded Theory**? 45

4.1 Methodology 45

4.2 Selecting a research approach, qualitative or quantitative? 45

4.3 Constructivist Grounded theory 48

4.3.1 Grounded Theory 49

4.3.2 Why Constructivist Grounded Theory? 51

4.3.3 Theoretical sampling 54

4.3.4 Constant comparison 55

4.3.5 Sensitizing concepts 55

4.4 Methods 57

4.4.1 Purposive sampling 57

4.4.2 Theoretical sampling strategy 57

4.4.3 Recruitment of participants 58

4.4.4 Data collection 60

4.4.5 Management of the data 66

4.4.6 Procedures 66

4.4.7 The challenge of recruitment 68

4.4.8 The role of clinician/researcher 71

4.4.9 Data analysis process 72

4.5 Memo Writing 80

4.5.1 Diagramming 81

4.5.2 Strategies for co-construction 82

4.5.3 Judging the quality of a grounded theory study 83

4.5.4 Ethical considerations 85

4.5.5 Chapter conclusion 89

**Chapter 5: Introducing the Key Characters and the ‘Temporal Stages’ 90**

5.1 Chapter conclusion 114

**Chapter 6: To Share or Not To Share 116**

6.1 Sharing diagram 117

6.2 Noticing something unusual 118

6.3 What’s happening? Seeking a diagnosis 121

6.4 Receiving and sharing a diagnosis 123

6.5 Where do we go from here? Getting on with it 124

6.6 Maintaining, modifying and abandoning 126

6.7 Sharing 127

6.8 How ‘sharing’ was experienced 129

6.9 Chapter conclusion 163

**Chapter 7: How Useful is the Sharing Theory? 164**

7.1 Revisiting the foreshadowed questions 164

7.2 Reflecting on the research process 167

7.3 Reflecting on the role of clinician/ researcher 168

7.4 Theory development 169

7.5 Judging the quality of the research 170

7.6 The relationship between the temporal model for YPWD 179

and existing theory that informed the study

7.7 Recent literature and the present study 188

7.8 Implications of the ‘sharing’ theory for Policy and Practice in light of current socio-political developments 192

7.9 Final Thoughts203

**References 205**

**Conference Proceedings 219**

**Tables & Figures**

**Table 1.** Search terms 29

**Table 2.** Literature search results 31

**Table 3.** Number of interviews conducted 90

**Table 4.** Number of interviews by type 91

**Table 5** Number of interviews by format91

**Table 6** Age/ gender range of participants at the point of recruitment. 91

**Sharing Continuum Figure 1**  127

**Sharing Continuum Figure 2**  184 & 199

**List of Appendices**

**1**. Ethical approval letter for the study (National Research Ethics Service).

**2**. Additional letter of ethical approval regarding the Mental Capacity Act 2005.

**3**. Letter of ethical approval relating to a substantial amendment, from the

National Research Ethics Service.

**4**. Scientific review from The University of Sheffield.

**5**. Letter of research governance sponsorship from The University of Sheffield.

**6**. Letter of research governance sponsorship from the recruitment site NHS Trust.

**7**. Participant Information Sheet (YPWD)

**8**. Participant information sheet (Partner)

**9**. Participant information sheet (Staff)

**10**. Research participant consent forms

**Abstract**

This thesis presents a constructivist grounded theory study of the experiences of younger people with dementia (YPWD) and those close to them. Semi-structured interviews were conducted over a two and a half year period. Younger people with dementia of age < 65 (*n* = 16), partners of YPWD (*n* = 11), adult children of YPWD (*n* = 3), a professional carer (*n* = 1) and a specialist nurse (*n* = 1), were recruited through their contact with a specialist NHS service in the north of England.

Draft study proposals were initially reviewed by a group of YPWD and their partners and also a health and social care YPWD team. The literature relating to the experience of YPWD that existed at the outset of the study was considered and informed the initial foreshadowed questions that provided direction for the study. Following a purposive sampling strategy, theoretical sampling was later employed throughout the process of data collection. Transcribed interview data were qualitatively analysed for codes and themes to produce a grounded theory. The methodological underpinnings of this constructivist study, including the processes employed for ‘co-construction’ of the findings are presented.

A four stage temporal model was identified: 1) *Noticing something unusual, 2) What’s happening? Seeking a diagnosis, 3) Receiving & sharing a diagnosis,* & 4) *Where do we go from here? Getting on with it*. *Sharing* is presented as a core social process that was present across all four of these temporal stages and was central to how participants engaged in either; *Maintaining*, *Modifying* or *Abandoning* aspects of their lives across the temporal journey of being (or being close to) a YPWD.

The usefulness and applicability of the *Sharing* theory and of how this may contribute to the broader literature related to the experience of dementia is discussed. The study findings and the *Sharing* theory are then considered in light of recent UK literature on the prevalence and experience of dementia at a younger age and current related health and social care policy in England.

**Chapter 1**

**Introduction to the Thesis**

Recent evidence estimates that there are over 40,000 younger people with dementia (YPWD) in the UK (Alzheimer’s society 2014a). Whilst a great deal of work has been undertaken addressing the experience of older people with dementia, relatively little has looked at those who are diagnosed under the age of 65. This thesis charts the unfolding of a repeated interview study conducted with YPWD and those close to them in the North of England. It begins with ‘Setting the Scene’, which describes the background to the study and provides an overview of what is meant or implied by terms such as ‘dementia’ and why this particular area of study was considered of importance and relevance. This chapter is followed by, ‘So What Do We Already Know?’, which provides an overview of the broader literature on dementia and that relating to YPWD that was extant the outset to the study which informed the study at its outset. The subsequent section introduces the ‘sensitizing concepts’ adopted at the outset of the study and the ways in which my own personal biography and professional background informed consideration of how this constructivist grounded study would be ‘co-constructed’ in partnership with the participants. The initial aims for the study are presented followed by the more specific ‘Foreshadowed Questions’ that were posed before data collection began.

The methodology chapter (‘Why GT?’) looks in more detail at why a constructivist grounded theory approach was selected as the most appropriate and what assumptions and expectations lay behind this decision. The specific methods employed for conducting the study are then presented to show how the concurrent processes of data collection and analysis led to the theoretical model of ‘sharing’ that emerged from the process of gradual refinement and testing of the themes and categories that were present in the data.

The chapter, ‘Introducing the Key Characters and the ‘Temporal stages’, provides detailed descriptions of the biographies of the participants and the extent to which these shared biographies constituted elements of the data that informed the theoretical constructs for the study. The specifics of how many people were recruited and of the number of interviews conducted are also presented in tabular form in this chapter.

‘To Share or Not To Share’ presents the findings from the study with a detailed description of the different elements of the ‘sharing’ theory including the key temporal stages of dementia at a younger age and the ways in which ‘sharing’ mediated between the varying activities of ‘maintaining’, ‘modifying’ and ‘abandoning’ that YPWD and those close to them experienced.

The following chapter, ‘How useful is the Sharing Theory?’, considers the implications of the proposed theory, and considers these in light of the original foreshadowed questions and looks in detail at how well the identified quality criteria for the study were met. My overall reflections on the research process are discussed in this chapter and the implications of the ‘sharing’ theory for health and social care policy and practice, and education and training are considered.

‘Final thoughts’ draws together my concluding thoughts and feelings regarding the study and the ‘sharing model’ and marks the conclusion to this constructivist grounded theory study that has explored the experiences over time of YPWD and those close to them.

**Chapter 2**

**Setting the Scene**

**2.1 Background to the study.**

The broad aim of this study at the outset was to explore how the experience of dementia at a younger age impacts on the lives and relationships of those living with this diagnosis and those who they are in close contact with. The term ‘younger’ is chosen rather than alternatives such as ‘early onset dementia’, since this is the terminology used both by the Alzheimer’s Society and support groups established by younger people with dementia themselves and those who closely support them (Alzheimer’s Society 2005). The term YPWD in this study relates to people experiencing the onset of dementia before the age of 65, in line with definitions from the Alzheimer’s Society (2005, 2014, 2014a) and World Health Organization (2012). My intention was to investigate social processes, such as how the presence of dementia impacts on relationships, communication and activities (such as work and leisure), for YPWD and those around them. Due to the relatively limited existing published literature relating to the experience YPWD at the outset of the study (see later literature review), a research approach was sought that would enable an open and in depth exploration of these processes. As well as intending to add to understanding or knowledge of what younger people with dementia and those who support them experience, it was also hoped that any descriptions of, or insights into these experiences would help to inform the development and provision of health and social care for this group of people. This was considered particularly important as existing provision from statutory services in the UK was patchy and diverse at the outset of the study (Cordery et al 2002 & Daker-White et al 2002). As will be apparent later, this led to the adoption of a Constructivist Grounded Theory approach that was heavily influenced by the writings of Charmaz (2006). The initial aims and foreshadowed questions for the study are summarised below

**2.2 Initial Research Aims**

The overall aims of the research were to develop:

1. A fuller understanding of how YPWD and those close to them experience their social world.

And

1. To explore how this social world may alter over time.

.

**2.3 Foreshadowed questions**

1. What impact does dementia at a younger age have on the person’s life in terms of their social roles and participation?
2. Of these, which are most significant to them?
3. How does the presence of dementia at a younger age impact on the person’s work and recreation?
4. Does the impact of dementia on the person’s life alter over time as symptoms progress?
5. How does dementia at a younger age affect the nature of the person’s relationship with their partner (or those close to them) and how does this change over time as symptoms progress?
6. How are these relationship issues experienced from the perspective of the younger person with dementia’s partner and/or carer?

This chapter begins with a brief overview of our understanding of what dementia is and how this is experienced. A broad approach has been taken to include those aspects of the experience not limited to medical concerns, but also psychological, social and relational. In the next chapter the key literature existing at the time the study commenced and relating to dementia that guided the study during its early phases is then presented. This is followed by an overview of the extant literature that related more specifically to YPWD, which informed the ‘sensitising concepts’ and shaped the initial ‘foreshadowed’ questions for the study.

**2.4 What is dementia?**

The word dementia is derived from the Latin *de,* meaning ‘from’ and *mentis* meaning mind (West 2003).The person with dementia will typically experience impaired memory functioning, especially for short term memory recall and may also experience difficulty in maintaining independence and in their perceptions of the world around them. For some older people an element of deterioration in memory can occur as part of normal ageing, without having a significant impact on a person’s independent functioning (Dennis et al 2007). Dementia is separate and distinct from this normal ageing, with more persistent and progressive memory loss impacting on the person’s ability to perform their usual life and daily activities (Alzheimer’s Society 2008). Other changes are likely at some stage in the progression of dementia, affecting the person’s communication abilities, personality, or patterns of behaviour (National Audit Office 2007). Dementia is identified as a condition, which directly affects a person’s sense of self and identity, and also impacts on family and social relationships, the person’s sense of worth and purpose, and even personal connection to past memories and experiences (Clare 2003). The range and severity of the symptoms of dementia vary from person to person, as does the progression of the disease process. Dementia therefore affects everybody individually in terms of; onset and course of their illness, symptoms experienced and the effect of these symptoms on their day-to-day lives.

Descriptions of dementia have been evident in society for centuries, yet it has remained in many ways accepted or hidden in the experience of ageing as a form of expected ‘senility’ until relatively recently (West 2003). The association between dementia and chronological age remains significant and this is perhaps unsurprising given that the risk of developing dementia does statistically increase in line with greater chronological age (Alzheimer’s Society 2014b, World Health Organization 2012). At age sixty-five one in twenty people may experience dementia and by age eighty, typically one in five people have a diagnosable dementia (Alzheimer’s Society 2008). Still today dementia is often depicted in the media in its most negative manifestation, of people institutionalised and completely dependent on others for their daily physical care needs (Van Gorp & Vercruysse 2012). These negative depictions of dementia remain and persist in many peoples’ minds, associated with distress and images of dementia in its most severe and advanced form. Families can be fearful of the stigma created by any disease affecting ‘the mind’ and there can be significant distress for carers in disclosing that a family member has a diagnosis of dementia (Alzheimer’s Society 2008). Associations with institutional care of the 1960’s and 1970’s and family histories of previously institutionalised older relatives in living memory and family lore, have created powerful images for many people, despite recent significant modernisation of health and social care provision for people experiencing dementia (Alzheimer’s Disease International 2012).

The Alzheimer’s Society (2014b), have reported that the number of people experiencing dementia is growing. The World Health Organization (WHO 2012) have estimated that 35.6 million people worldwide are experiencing dementia and that this number will double by 2030 and triple by 2050. In 2013 there were 815,827 people in the UK with dementia and 773,502 of these people were aged over 65 (Alzheimer’s Society 2014). It is expected that the total number of people with dementia in the UK will have risen to 856,700 people by 2015. Based on current trends it is predicted that the number of people experiencing dementia in the UK could increase by 40% over the next 12 years.

The WHO (2012) report indicates that few population based samples, have been completed worldwide to obtain the prevalence of dementia in those under the age of 65, but UK based consensus reviews indicate that prevalence of dementia at a younger age increases exponentially with chronological age;

“roughly doubling every five years from 9/100000 at age 30 to 156/100000 at age 60-64” (WHO 2012, p 15).

Younger people with dementia and those closest to them can face potentially different experiences to older people when living with this chronic progressive condition (Alzheimer’s Society 2005). Dementia is a group of symptoms caused by the impact of disease on the brain and as previously discussed, the person experiencing dementia will typically have symptoms which may include impaired

short term memory functioning, word finding difficulties and difficulty in perceiving the world around them. In 2013 there were 42,325 people with dementia below the age of 65 (Alzheimer’s Society 2014a). Over the last decade there has been an increasing awareness that dementia in younger people presents particular challenges, in the provision of appropriate health and social care.

**2.5 The challenge of dementia at a younger age**

The specific causes of dementia in younger people are more variable than in people aged over 65 years, where Alzheimer’s disease is the most common diagnosis or dementia sub-type, accounting for over 60% of dementia in this age group. In younger people Alzheimer’s disease accounts for only one third of dementias, with other conditions such as, Lewy Body disease, fronto-temporal dementias, variant Creutzfelt-Jacob disease, Human Immunodeficiency Virus and alcohol related dementias more prevalent than in older people (Beattie et al 2004, Dearden 2004). Harvey et al (2003) identify that by far the majority of younger people with dementia will become engaged with diagnostic services at some stage, but it is much less certain what follow up and support services these individuals will then receive. NICE (2006), identified that younger people with dementia have special requirements and that specialist multi-disciplinary services should be developed, allied to existing dementia services, to meet their needs for assessment, diagnosis and care. Dementia in younger people is often misdiagnosed, due to the variety of potential symptoms other than specific memory loss and the potential for specific disease processes other than Alzheimer’s to be experienced (Mendez 2006).

Prior to the commencement of this study, the Department of Health (DoH 2005) identified that there were at least 18,000 younger people with dementia in the UK and that the availability of specialist services for this group was not widespread. A need for personally defined needs and goals for each younger person with dementia was recommended in the DoH report and the following issues were seen as particularly relevant or problematic for many younger people with dementia; employment, supporting dependent children, being physically fit and active, financial commitments and experience of rarer forms of dementia. In 1997 only 12 out of 354 surveyed NHS Trusts had established a specialist service for younger people with dementia (Barber 1997) and this situation was little changed prior to the commencement of the current study (DoH 2005). The Department of Health (2005), report indicated that in large urban conurbations a dedicated service for younger people with dementia may be justified, while in other areas this provision was more likely to be provided by individuals ( usually senior healthcare clinicians), already employed in other existing services such as NHS mental health or dementia services, for older people.

In 2007 a report commissioned by the Alzheimer’s Society (2007), identified that two thirds of all cases of younger people with dementia were aged over 55 years, as later re-affirmed by the World Health Organization (2012) and second Dementia UK report (Alzheimer’s society 2014b). These reports suggest that methods of data collection for population statistics may underestimate the true number of younger people with dementia in the UK by up to three times. Access to dementia diagnosis has been described as particularly problematic for some younger people, where General Practitioners do not initially believe they are experiencing dementia (due to their young age), extending the time taken for diagnosis and resulting in inaccurate diagnosis of depression, or other illness, rather than dementia (NAO 2007).

The Alzheimer’s Society UK (2005), has identified that younger people with dementia often face particularly complex difficulties and have forms of dementia which may change or deteriorate quickly. This potential for more rapid progression in symptoms may result in changes for the YPWD and those around them that are difficult to adapt to. Sudden cessation of employment, loss of income, or reduced ability to care for younger children, are all examples of the ways in which a rapidly deteriorating dementia at a younger age may have significant, or potentially catastrophic, consequences for a YPWD and their family. This is especially so if access to a diagnosis, support services and benefits is lengthy or protracted. An important issue for many YPWD and their carers is that dementia services are aimed at meeting the needs of older people and may not be suitable for those from a younger generation (Beattie et al 2005). A review of published literature relating to YPWD in 2002, identified the need for specialist, flexible, age appropriate and dedicated services, as a recurring theme (Beattie et al 2002). Recommendations for service provision within the literature at that time were largely based on the reported practical experiences of *professional* carers, rather than from systematic research with younger people with dementia themselves and their *family* carers (This is explored in more detail in the following chapter). People with dementia have been identified as one of the most excluded groups in western society, and until recently their ‘voice’ had not been present in research accounts of the experience of dementia, where the ‘proxy’ voice of carers had more traditionally been relied on to provide descriptive accounts (Hellstrom et al 2007a).

It was the desire to capture the voices and experiences of YPWD and those close to them that was the impetus for this study.

**Chapter 3**

**So what do we already know?**

**3.1 The broader literature informing the study**

The following section outlines key literature related to dementia in general (rather than specific to people with dementia at a younger age), which I had a general awareness of at the outset of the study and which when subsequently combined with a more focussed review of existing literature relating to YPWD, provided the backdrop to the foreshadowed questions which informed the initial study. As will be explained later the study adopted a Constructivist Grounded Theory approach and the role of the literature in Grounded Theory has been, and remains, contested. The originators of the approach, Glaser and Strauss (1967) argued that the literature should not be considered until after data analysis, so that what emerged might be seen to be truly ‘grounded’ in the data. More recently others have argued that the extant literature should be considered at the outset and acknowledged as one source of knowledge, amongst others, including personal experience that helps to shape the initial direction for the study (Rodwell 1998, Charmaz 2006). These positions and that adopted in this study are elaborated upon below.

The ‘classic’ Glaserian Grounded Theory approach to the literature warns that engaging with the literature in the area of enquiry prior to, or during initial data collection and analysis may erode the researcher’s theoretical sensitivity and that if a literature review is to be completed then this should be incorporated through comparative analysis once the core category has emerged and the theory is well developed (Glaser 1978, 1992). Later, and in contrast to his initial position, Strauss proposed that an early overview of the literature can be beneficial but may hinder the creative process of data analysis and theory development if this is exhaustive (Strauss & Corbin 1990, 1998). For Strauss familiarity with the literature may however improve theoretical sensitivity and assist in the development of a research question.

In the later development of a constructivist approach to Grounded Theory (see next chapter) Charmaz (2006) extends Strauss’s arguments contending that an overview of the literature existing at the time the study commenced should be acknowledged as one of many sources of knowledge (including personal experience) that helps to shape the initial direction for the study. A later review of the literature that may have emerged after the study concluded can then enable links to be made between the emergent theory and existing knowledge to identify the significance of the findings and their relative contribution.

In adopting this latter rationale this chapter will therefore outline the broader literature on dementia which was influential in the initial direction of the study, before presenting an overview of the more specific defined literature relating specifically to YPWD that was then conducted prior to development of the ‘foreshadowed questions’ for the study (Charmaz 2006). A later review of subsequent literature was undertaken after the study was completed and used to discuss the study findings in chapter 7.

However in Constructivist Grounded theory the literature is not the only source of knowledge that can influence the study. Given my extensive personal experience in the field it was impossible for me to have no prior conceptions and I therefore decided to reflect on the literature I was already aware of and combine this with my more personal professional experiences, in order to clarify the focus and bounds of the subsequent literature search relating specifically to the topic of interest, the experiences of YPWD and those close to them. This next section is therefore not a ‘systematic’ review, or even a narrative synthesis of this initial literature and personal clinical experience. Rather it highlights particular studies that were recognised as having been influential in guiding the initial direction of the study and which, as analysis progressed, were also built upon. It traces in particular the emergence of more person-centred approaches to dementia care and their implications for understanding and supporting people with dementia in the context of the relationship they have with others, over time. These temporal aspects of how the experience of dementia can alter over time were a significant feature of the later findings from this study, as discussed in subsequent chapters.

Our understanding of living with dementia and developing appropriate service responses has been limited by a number of factors. Prominent amongst these is the focus of much early research on the bio-medical manifestations of the condition and the relative emphasis on the views of carers, rather than people with dementia themselves. The literature highlights these influences.

**3.2 Concepts of dementia in society and the importance of personhood.**

Adams & Bartlett (2003) identify two dominant discourses which developed in relation to the conceptualisation of dementia in the 20th century. The bio-medical discourse lay in the identification and classification of neurophysiological and neurochemical changes in the brains of people with dementia, highlighting the physiological nature of the condition. Neuropathological and neurochemical explanations of dementia have been reinforced by the availability of anti-dementia drug treatments over recent decades and the desire to prevent, halt or reverse neurodegenerative changes (O’Conner et al 2007). The discourse of cognitivism also became prevalent, understanding dementia in terms of how the disorders affect cognitive functioning and specifically memory performance (Adams & Bartlett 2003).

A significant shift in emphasis towards the notion of personhood in dementia can be viewed as a recent powerful discourse lead by the late Tom Kitwood which recognized the depersonalization of the person with dementia that results from the bio-medical model is a critical factor (Kitwood 1997).

In arguing for a new approach to understanding dementia Kitwood presented dementia as a;

*“dialectical interplay between neurological impairment and malignant social psychology”* (Adams & Bartlett 2003, p98).

At the core of Kitwood’s approach is the belief that the personhood of people with dementia remains present throughout, despite the impact of the disease. Kitwood (1993) understood the reality of the person’s dementia at any one time, to be comprised of complex interactions between; their physical health, their biography or life history, their social psychology (the network of their social relationships) and their neurological impairment. A key element of delivering effective and relevant care and support to people with dementia, was for Kitwood (1993) assisting the person with the identification of meaning in the illness experience and provision of care practices which might contribute to the preservation of personhood. The individual response to dementia can be seen in this way to be influenced by both the coping responses of that person and of those around them (Kitwood 1997, Clare 2003).

Person centred approaches to the care of people with dementia recognise the potential impact of malignant social psychology, where the social and psychological environment inhabited by the person with dementia does not recognise, foster and promote their personhood (Kitwood 1997). Kitwood outlined the benefits of understanding the unique psycho-social context of dementia for each affected individual, to enable appropriate individually tailored support and interventions to assist positive coping. The concept of malignant social psychology has been used to describe the negative and harmful experience of a person with dementia being objectified and communicated with in ways which reinforce their cognitive losses, rather than promoting and engaging with retained strengths.

In considering the notion of personhood in respect of people experiencing dementia, Kitwood (1997), identified the historically prevalent western philosophical traditions and concepts of personhood, based on notions of autonomy and rational capacity. These previous approaches to personhood are contrasted with Kitwood’s notion of relationship ‘between’ persons, as primary to the concept of personhood. Kitwood asserts that personhood must be seen in relational terms if dementia is to be understood. He utilises Buber’s concepts of human relating to discuss this relational perspective, where the relationship can be I-it, implying; *“coolness, detachment, instrumentality*” (Kitwood 1997, p10), or the relationship can be I-thou, where to be addressed as thou with everything this implies is by its nature to be a person. Kitwood’s work has had a significant impact on the discourse relating to dementia, placing the *person* with dementia at the centre of their world, reaffirming their worth and intrinsic value and identity as a person. This re-framing of dementia as a social and psychological construction has become a cornerstone of educational curricula and training for health and social care staff in this area of work (NICE 2006). Kitwood’s work in this way marked a significant shift away from a dominant biological, neurological and neurochemical discourse focused on the deficits and negative impact of dementia, towards a more hopeful and optimistic concept, of the opportunity to positively create social and psychological environments that promote personhood in dementia at any stage of this condition. Over recent decades there have been some examples of people experiencing dementia providing personal accounts of their experiences and these will now be considered in the following section.

**3.3 Emerging autobiographical accounts by people with dementia**

Keady et al (2007) have described how people experiencing dementia began to ‘find a voice’ in published research and subjective accounts from the 1980’s into the 1990’s, but that much of the research was conducted ***on*** rather than ***with*** people with dementia. Keady et al cite the work of Harris & Sterin (1999) as an exception to this where a person with dementia (Sterin) was fully integral to the design, conduct and reporting of the research. For Keady this approach carried an explicit message of partnership and collaborative working with the person experiencing dementia in the research process. This Keady et al argue, brought a “greater level of authenticity and representativeness” (Keady et al 2007, p2), to the reporting of the research, with an apparent level of awareness in the findings that was possibly absent from other more objective or distanced research with people experiencing dementia. Gloria Sterin (2002), who was experiencing dementia at an older age, provided a powerful personal description of how a diagnosis of dementia had a major impact on her social interaction and self-concept. She identified that when, “names become labels, these have powerful psychological consequences – more powerful than we usually realise” (Sterin 2002, p2). She perceived that the term dementia implies, “a very derogatory and negative circumstance” (Sterin 2002, p1), since ‘demented’ means literally ‘deprived of mind’ and to be without mind is to not be fully human. Sterin argued that the experience of deficits in short-term memory, while critical (in everyday life), do not necessarily deny the person with dementia the capacity for, “useful mental and social activities” (Sterin 2002, p2). She described the label of dementia as transforming a person from the role of spouse, parent, or lover, into the ‘caregiven’, with people reacting differently to the person in the presence of this. She perceived that people were ‘acutely uncomfortable’ with her and therefore many old friends withdrew from social contact. For Sterin this avoidance of, or treatment of her as if she is ‘no longer there’, is compatible with the treatment of someone perceived as not ‘fully human’, Sterin described the ‘sick pity’ of carers, wanting to escape and be free of their burden and their ‘sad distaste’ for the transformed once familiar person with dementia. The ‘smothering’ of well-intentioned professionals is also described, as “suffocatingly over-protective” (Sterin 2002, p2), in ways that can be both welcomed and simultaneously unwanted. Sterin felt she was able to re-frame the disease, seeing this as a challenging personal project. For her, we are all people with certain strengths and certain limitations, including those experiencing dementia.

Sterin (2002) was not chronologically a YPWD and there have been a small number of similar autobiographical accounts that were written by younger people with dementia while in their’ 40’s and 50’s (McGowan 1993, Rose 2003 and Bryden 2005). These accounts equally demonstrate the importance of listening to ‘the voice’ of the person with dementia. These autobiographical accounts allow an insight into the personal individual experience of living in society with this label, both emotionally and psychologically. Within the current study it was hoped that a research approach could be utilised that would enable YPWD and also those close to them, to describe with similar richness and depth, how they experienced dementia over time in the context of their own social networks and relationships, so that this interactive element could be more fully explored.

**3.4 Investigating the social context of dementia**

Kitwood describes having an identity as;

*“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.”* (Kitwood 1997, p 83).

Traditional ways of understanding identity since the enlightenment have been based on the principle that a person’s identity results from some essential feature associated with that person (Adams & Bartlett 2003). More recently the concept of identity as occurring within a surrounding social setting, proposes that social practices within which discourses are contained, enable people to occupy certain social positions within a society. Social construction theory has previously been applied to surviving manifestations of selfhood in dementia, through case study research (Sabat 2002). The importance of considering dementia from the perspective of its impact on the nature of relationships and communication between the person with dementia and those in close contact with them has been highlighted (Adams & Gardiner 2005). Insights have also been provided into how couples actively construct awareness of dementia in ways which can maintain both a sense of ‘self’ for the person with dementia, and the relationship between the couple (Hellstrom et al 2005a). The relationship between the person experiencing dementia and others has been viewed as a key factor in maintaining a sense of self and personhood, but at the outset of the current study little research was apparent that had explored the nature of such relationships.

From the 1990’s a move to re-focus dementia care literature away from an emphasis on the carer towards the involvement of people with dementia, to enable an understanding of their own subjective experience has occurred (Keady et al 2007). Keady et al identified that people experiencing dementia increasingly described their experiences as being lived within the context of a relationship, with the complex dependency and inter-dependency, which that brings. Such relationships have been considered within a temporal context that has been applied to help understand the experiences of YPWD, as well as those experiencing dementia in older age (Keady 1999). From work primarily with carers, this framework identified six stages from the initial awareness of possible cognitive changes, through to bereavement and beyond. From further interviews with both the carer and the person experiencing dementia, Keady described the ‘dynamics of dementia’, where both parties experienced parallel but separate processes in working through the realisation and diagnosis of dementia, and adaptation to living with this condition (Keady 1999). Later work has applied such an approach to the idea of ‘couplehood’ (Hellstrom et al 2005a). I will now consider this temporal approach in greater detail as it had a significant bearing on the development of my own study.

**3.5 A temporal model of dementia**

Keady & Nolan (1999a) described the following framework from the experience of family carers of YPWD as a temporal model with, “six stages, or transition points” (p204):

1. Building on the past
2. Recognising the need
3. Taking it on
4. Working through it
5. Reaching the end
6. A new beginning.

Keady (1999) interviewed the family carers of people with dementia (inclusive of primarily carers for older people), utilizing a grounded theory approach to explore the dynamic nature of caregiving in dementia as a temporal model developing over time. In four of the earlier research interviews in this longitudinal study the person with dementia themselves had also asked to be involved and the study was then adapted to also capture the experience and perspective of the person with dementia (PWD), as well as their family carer. Eleven of the later interviews in this study then purposively involved the person with dementia themselves and this enabled an integration of the temporal model derived from the caregivers, with that obtained from the people with dementia. The result was a grounded theory;

“which suggested that the primary aim of both caregiver and PWD was to try and maintain the involvement of the PWD as an active agent in the world” (Keady & Nolan 1999, p201).

Keady and Nolan (2003), identified four forms or types of relationship dynamic, and the associated ‘work’ that was involved and could be experienced by these couples:

Working alone

Working together

Working separately

Working apart

Keady and Nolan explained what was meant by the term, ’work’ in this context:

*….we have adopted the term ‘working’ to capture the largely proactive, but frequently covert, strategies adopted by both PWD and their family carers.* (Keady & Nolan 2003, p *29).*

‘*Working alone’*, described the situation where one partner was actively engaged in the process of recognising, or adapting to the presence of dementia, while their partner was either not yet engaged in this process, or had ceased to be engaged with this. Typically this would be either at the beginning of the process, (where only the carer or PWD had recognised the problem and the other was not yet engaged with this), or much later, when the dementia had progressed significantly and the person with dementia could no longer effectively engage with their family carer.

‘*Working separately’*, occurs where both the carer and PWD were engaged with the process in separate ways, with the person with dementia disengaging from discussing their problems and attempting to hide or cover up any difficulties, while the carer becomes increasingly alert and vigilant in trying to identify changes.

‘*Working together’*, describes where both the PWD and carer were being open with each other, seeking help and support and working together to deal with any challenges or difficulties.

‘*Working apart’*, is used to describe the point at which communication has become increasingly difficult, either in the context of a difficult relationship prior to the onset of dementia, or due to unresolved difficulties during the earlier ‘working separately’ stage.

I think it apt at this point to reflect upon the importance of this study to my own work and how it relates to both the development of the work and the subsequent theory. As will become apparent later in this thesis, (in the findings and discussion chapters), there were similarities between aspects of the temporal model of dementia previously outlined by Keady (1999) and the temporal model derived from the experiences of the YPWD in this study. As both younger and older people with dementia are typically experiencing a significantly progressive neurological condition, it was unlikely that there would be major dissimilarities between findings from my study and that of earlier research with older people experiencing dementia. The centrality within Keady et al’s (2003) study of the notion of ‘working’, alone separately or otherwise, highlights a key social process, which has implications for the person with dementia and family carer. As will become apparent my study identifies additional and different significant social processes, especially that of ‘sharing’ which may be considered as a major form of what Keady et al might call ‘working’ (see later). This is consistent with grounded theory (GT) principles as described by Glaser (1992), which highlighted the importance of building on and complementing existing theory by combining the awareness of the researcher with existing literature, allowing them to recognise leads within the literature but not be dominated by them (Morse & Field 1995). Moreover it highlights the key characteristic of GT in that they should be ‘modifiable’ in the light of subsequent data (Glaser 1992).

Whilst most early work on dementia relied primarily on proxy accounts provided by family carers and professionals (Keady & Nolan 2003, Phinney 1998, Clare 2002 & 2003), more recent studies have highlighted the importance of the person with dementia in their own right as a focus for research. For example, Keady utilised a grounded theory approach employing in-depth interviews with people experiencing early stage Alzheimer’s disease, identifying the impact of cognitive assessment on the participants’ personal identity and concepts of self. Phinney (1998) has presented thematically analysed interview data from research with people experiencing dementia and their spouses, to present perceptions of ‘being unsure’ (living in an unfamiliar world due to the symptoms of dementia) and ‘trying to be normal’ (attempts to maintain continuity despite the experienced symptoms of dementia). Clare (2002 & 2003) utilised phenomenological interpretive analysis with interview transcripts to present a preliminary model of the construction of ‘awareness’ in early stage Alzheimer’s disease.

**3.6 Literature focusing on partner relationships experienced by people with dementia**

Within the existing literature, few studies have to date systematically explored the nature of the ‘dyadic’ relationship between people with dementia and their main carer or partner (Keady & Nolan 2003 & Hellstrom et al 2005a,b & 2007b). Limited existing published research has indicated that dynamic multi-dimensional relationships occur between the person with dementia and their family carer(s) (Hellstrom et al 2007b & Whitlach 2001). Much of the existing literature described a focus on the experiences and perceptions of the family carer. Hellstrom et al (2007b) utilised a constructivist grounded theory methodology, to explore the ways in which people with dementia and their spouses experienced dementia over time, conducting 152 interviews over 5 years with 20 couples. The age range for the study was 65 – 84 years. Hellstrom et al report that analysis of the data identified three broad phases, which were ‘temporal’ but not linear. This involved, “a delicate interactive and iterative relationship” (Hellstrom et al 2007b, p3). These phases were identified as; ‘sustaining couplehood’, ‘maintaining involvement’ and ‘moving on’. ‘Sustaining couplehood’ describes the efforts made by both spouses to maintain and enhance the quality of their lives together, as the main goal of their shared ‘work’. Hellstrom et al (2007b) identify that the majority of couples interviewed had ‘positive relationships’ prior to the onset of dementia, which they were working hard to maintain. The authors therefore suggest that the results and constructs described may potentially be very different where couples have a historically poor relationship prior to the onset of dementia.

Hellstrom (2007b) has described how longitudinal interviews conducted with older couples, where one partner had dementia, enabled identification of particular sets of activities that comprised, ‘Making the Best of Things’, to make the quality of their lives and relationship’s as good as possible. These were:

* Life’s little pleasures
* Searching for the positives
* Living for today

Other studies have also explored how couples live with dementia. For example, Davies & Gregory (2007) explored marriage biographies in couples in the presence of dementia, describing ‘symbolic realities’ based on shared meaning in their dyadic relationships. ‘Commitment’ was described as a significant factor for couples in the presence of dementia in ensuring the continued stability of marital relationships, but research on the impact of early dementia on marital relationships is limited (Davies & Gregory 2007). Previous research has identified changes in marital intimacy, satisfaction, joint negotiation and “adjustment in acknowledging losses, as well as recognizing resilience and coping strategies” (Davies & Gregory 2007, p2). Davies & Gregory identified a need for greater understanding of how couples make sense of and adjust to dementia diagnosis in the context of their relationship and exploration of how these relationships can foster coping and social engagement in the presence of dementia. Kaplan (2001) described a couplehood typology for the spouses of institutionalised people with Alzheimer’s disease. Data from interviews with 68 carers enabled description of four identified groups of couplehood: ‘Till death us do part’, ‘Husbandless wives/ Wifeless husbands’, ‘Becoming an I’ & ‘Unmarried marrieds’. This form of detailed analysis and description of typological clusters, encourages a greater and more detailed understanding of the complex experience of relationships in Alzheimer’s disease and the potential for a shift in the perception of relationships by couples over time, in the presence of this. These descriptions were identified as informing practitioners, so as to recognise forms of couplehood where one person has dementia, prior to consideration of care placement and to adapt their interventions accordingly to meet the needs, particularly as described by Kaplan (2001), of the spouse carer. The current study did not intend to specifically focus on couples, but a broader inclusion of ‘others’ who were identified by the YPWD as significant in their lives (and therefore their relationships and social functioning). It was however likely that ‘significant others’ may often be a partner and this previous literature indicated aspects of these relationships that could now be further explored where dementia was occurring in a younger age group.

This broader literature related to dementia that has been considered above, was familiar to me through my own prior experience of delivering dementia education and training. This combined with my own experience from practice, had provided a level of awareness of the experience of dementia for individuals and couples and of previous proposed theoretical frameworks to understand these experiences. Having considered this literature at the outset of the study while formulating ideas and questions, I now needed to build on this by exploring more formally what was known or described in relation more specifically to the experiences of YPWD and the key relationships and social processes that formed significant aspects of those experiences. The following section will now turn to the literature specific to YPWD that informed the initial design of the study.

**3.7 Review of the Literature related to YPWD**

The initial exploratory search strategy employed to identify relevant literature related specifically to the experience of dementia at a younger age, is now detailed in the next section. This more specific literature was integrated with that previously discussed relating primarily to older people with dementia, to identify what was already described in relation to the impact of dementia at a younger age on relationships and experiences in society both for YPWD and those close to them. It should be noted that this next section outlines searches and literature, which pre-date my own study. Literature published subsequently will be addressed within Chapter 7.

**3.8** **Literature search strategy**

Search terms employed

Three types of search strategy were considered for identifying previous qualitative research and service descriptions, involving younger people with dementia; thesaurus terms, free text terms and broad based terms (Shaw et al 2004). Thesaurus terms or subject headings are often utilised by electronic databases to categorise records. In ASSIA for example the word ‘dementia’ is one such term. Some databases utilise ‘Qualitative Research’ as a category, while others have more specific forms of qualitative research as a specific category such as ‘grounded theory’ (Shaw et al 2004).

Free text terms are commonly used terms in the literature. Based on my own prior knowledge for example, I was aware that the population of people I was interested in may be referred to in the literature as either ‘younger people with dementia’, or ‘early onset dementia’, depending on the context of the research. My own previous experience, knowledge and reading of professional literature related to this population of people, had indicated that medical and nursing literature routinely utilised the term ‘early onset’, to differentiate between people with dementia under the age of 65 years and the much larger population of people over the age of 65 years with dementia. In contrast some social science based publications and reports or studies commissioned by non-statutory organisations (such as the Alzheimer’s society), often utilised the term ‘younger people with dementia’, to identify this population.

Following consideration of these different types of search terms, the following combined terms were employed using the Boolean operator AND to search the selected databases:

1. Dementia AND Early onset
2. Alzheimer’s AND Early onset
3. Dementia AND Younger people
4. Alzheimer’s AND Younger People

Databases searched

An electronic search was conducted of the following databases in 2007:

ASSIA 1985 to 2007

CINAHL 1985 to 2007

PsycINFO 1985 to 2007

These databases were identified as likely to yield literature that would relate to the investigation of YPWD’s experiences in society and the impact of their dementia on their relationships with others. The following inclusion and exclusion criteria were applied to the identified abstracts to identify those to be obtained for review:

Inclusion Criteria

That the paper was related to one or more of the following:

1. Health & Social Care practice and provision of services in relation to YPWD
2. The lived experience of dementia at a younger age from the perspective of the YPWD
3. The experience of caring for a younger person with dementia from the perspective of a family carer.

Exclusion Criteria

That the paper was solely concerned with one or more of the following:

1. Hypotheses testing in relation to specific neurodegenerative diseases (such as related to cellular change, radiological imaging, genetic or biological markers).
2. Hypothesis testing in relation to randomised drug trials

The results are set out in the table below.

|  |  |  |  |
| --- | --- | --- | --- |
| **Table 1, Search Terms** | | | |
| **Database** | **Search Terms** | **Results** | **Selected For review** |
| CINAHL | Dementia AND Early onset | 56 | 5 |
| CINAHL | Alzheimer’s AND Early onset | 66 | 2 |
| CINAHL | Dementia AND Younger people | 46 | 17 |
| CINAHL | Alzheimer’s AND Younger People | 159 | 20 |
| PSYCHINFO | Dementia AND Early onset | 24 | 3 |
| PSYCHINFO | Alzheimer’s AND Early onset | 12 | 0 |
| PSYCHINFO | Dementia AND Younger people | 13 | 2 |
| PSYCHINFO | Alzheimer’s AND Younger people | 2 | 0 |
| ASSIA | Dementia AND Early onset | 33 | 8 |
| ASSIA | Alzheimer’s AND Early onset | 23 | 3 |
| ASSIA | Dementia AND Younger people | 52 | 6 |
| ASSIA | Alzheimer’s AND Younger people | 16 | 2 |

There was considerable replication of results across the databases. In total 27 items of literature were selected and obtained for more detailed review. The CASP (2006) tool for evaluating qualitative research (which identifies 10 questions to be asked to evaluate study quality), was applied to review the selected qualitative papers that met the identified criteria at that stage. The results are presented below in table 2.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Table 2, Literature search results** | | | | |
| **Author** | **Publication Type** | **Participants** | **Methods** | **Outcome** |
| Pollen (2004) | Journal article | 2 (YPWD & Partner) | Personal narrative | Difficulty gaining understanding from others in society. |
| Daniel (2004) | Journal article | Not specified | Service evaluation and commentary | Positively received service |
| Cordery et al (2002) | Journal article | Survey of specialist referral for YPWD between services | Survey findings and demographic data | Questions adequacy of single service assessment and diagnosis of YPWD |
| Mendez (2006) | Journal article | Not applicable | Analysis of clinical diagnostic data | Misdiagnosis of early onset dementia is common |
| Harris (2004) | Journal article | 23 Interviews with YPWD | Qualitative | Identified 8 themes of significance for YPWD. Practice guidelines suggested. |
| LaFontaine (2004) | Journal article | Single case study with YPWD | Case study | Example of psychosocial care |
| Beattie (2002) | Journal article | 74 papers relating to YPWD reviewed | Systematic literature review | Existing papers reliant on views of carers and professionals rather than YPWD themselves. |
| Beattie (2004) | Journal article | 14 YPWD | Qualitative interviews | Key issues of importance to YPWD identified. Concluded YPWD can identify their needs for themselves. |
| Killick (1999) | Journal article | 3 YPWD & their carers/ partners | Case study presentation | Participants had a strong self-awareness of what they were experiencing. |
| Kaiser (2006) | Journal article | Carers of YPWD n100 responses. | Questionnaire | Carer stress, fears for future dependency. |
| Freyne (1999) | Journal article | Carers of YPWD | Comparative study of clinical characteristics | Increased burden for carers of YPWD (compared to older PWD) |
| Chaston (2003) | Journal article | Service description | Report on service provision. | Tailored support group beneficial for YPWD. |
| Shlosberg (2004) | Journal article | Service evaluation  YPWD & Carers | Opportunistic Qualitative interviews | Service satisfaction |
| Williams (2001) | Journal article | Locality heath needs assessment for YPWD and their carers | Data analysis & demographic reports. | Recommendations for tailored service provision for YPWD |
| Parahoo (2002) | Journal article | Service evaluation of day care provision  8 YPWD and their carers | Qualitative interviews | High satisfaction with service provision described. |
| Husband (1999) | Journal article | Post diagnostic information provision to YPWD and carers | Review of care records and documentation | Differences highlighted between Neurology & psychiatry provision. |
| Thompson (2006) | Journal article | Interdisciplinary clinic for YPWD | Service evaluation and report | Positive evaluation by service users. |
| Reed (2002) | Journal article | YPWD n13  Carers of YPWD 18 | Qualitative interviews. Service evaluation for specialist YPWD team. | Ability of YPWD to participate in interviews. Service valued as responsive to individual need. |
| Katsuno (2005) | Journal article | 23 YPWD accessing services in one state in USA | Structured and semi-structured interviews. | Identified need to reduce stigma and negative psychosocial impact of this on YPWD |
| Tindall (1997) | Journal article | Literature review related to YPWD | Report on literature review | Minimal literature related to social impact on YPWD and their families. New research agenda proposed. |
| Luscombe (1998) | Journal article | Carers of YPWD n102. | Carer questionnaire. | Difficulty obtaining diagnosis. Carer stress & service dissatisfaction. |
| Daker-white (2002) | Research Report | 14 YPWD and their carers | Qualitative interviews | YPWD described a ‘loss of self’ and carers a difficult journey to diagnosis & carer burden. |
| Robinson (2000) | Book chapter | 1 YPWD | Longitudinal phenomenological case study. | Difficulties of trying to keep symptoms hidden and to maintain normality over time. |
| Keady (1994) | Journal article | Review of literature and previous findings | Epidemiological literature review. | Longitudinal model of dementia proposed as a research agenda for YPWD |
| Keady (1999) | Book chapter | 18 carers of YPWD (as part of a larger cohort) | Semi-structured in depth interviews | Six-stage model of care proposed as a framework to aid understanding |
| Nygard (1995) | Journal article | 1 YPWD | Participant observation. 3 Year longitudinal design | Impact on everyday life and activities. |
| Barber (1997) | Journal article | Review of service provision | Survey | Small number of specialist services identified in the UK. |

In addition to the database search detailed in Table 2 above, I also explored what information, reports and documents were available on the department of health (dh) website, Alzheimer’s society UK website and Royal College of Psychiatry website. This is sometimes referred to as the ‘grey literature’ (Beecroft et al, 2010). I also completed manual searching of the contents pages of The Journal of Dementia Care, for the period 2000 to 2007, (which were not available electronically), by reviewing a library journal stock. As well as potentially producing interesting or relevant articles that might inform my ideas, this process also yielded references to other published sources that could then be followed up and obtained. Bibliographic searching was also undertaken, to identify any books, or chapters within books related to younger people with dementia or early onset dementia. This was conducted electronically through the British Library national repository.

As previously stated, there was no intention at the outset of the study to complete any form of systematic review and there was at this stage no defined specific question or hypothesis. I was aware that I wanted to explore the experiences of younger people with dementia and had already identified that a qualitative research approach was likely to be most useful to achieve this and had an interest in grounded theory approaches from previous reading. I did have a developing interest in the topic combined with some awareness of existing reports and publications related to younger people with dementia. At this stage therefore I was seeking to clarify and formulate ideas and questions that would guide the methodology chosen to explore this area further.

The selected literature from this initial search was analysed to identify key themes and research findings that related to the experience of living with dementia at a younger age (Beecroft et al 2010, Rees et al 2010). In essence I was interested at this stage in identifying how the social world and key relationships related to the experience of YPWD had been previously investigated, particularly utilising qualitative methods and how this did (or did not) relate to the broader literature previously described in relation to older people with dementia and their partners or carers. As well as these specific areas of focus in analysing the identified literature, I was also interested at this stage in any literature that would inform the extent to which health and social care practice was supporting YPWD and those around them, in living with this progressive condition. Each piece of literature selected was considered in terms of its; validity in terms of presented outcomes and conclusions, reliability (do the conclusions fit with the presented data and methodology?) and applicability to my own proposed area of investigation (Rees et al 2010). This reviewed literature will now be discussed below.

**3.9 Literature related to the experience of YPWD**

The need to better understand and support people living with younger onset dementia and their families has been recognised for many years (Keady and Nolan 1994). Writing 20 years ago, Keady and Nolan (1994) noted the ‘invisibility’ of younger people with dementia (YPWD), lamenting the lack of any accurate information concerning the number of such individuals, the dearth of research exploring their experiences and the absence of any meaningful support services for either themselves or their family carers.

Tindall & Manthorpe (1997) reviewed existing literature related to YPWD and identified that the experience of younger people with dementia and their families was rarely considered at that time and that previous published work was mostly medical in nature, rather than considering the important social impact of this condition. Tindall & Manthorpe highlighted a need for both, specialist service provision to this group to be developed and a research focus on this group of peoples’ experiences. Beattie et al (2002) utilised a systematic review approach to identify literature that related to the care of YPWD, identifying a total of 74 papers, 69 of which originated in the UK. They concluded that the recommendations that had been made for service provision to YPWD were at that point largely based on the views and experience of professionals and carers, rather than YPWD themselves.

Freyne et al (1999) found higher reported levels of carer burden in the carers of YPWD by comparison with carers of older people with dementia, despite similar levels of clinical symptoms between cohorts. Luscombe et al (1998) employed carer questionnaires and reported difficulties from their perspective in obtaining a diagnosis for YPWD and carer stress and service dissatisfaction. Husband and Shah (1999) retrospectively reviewed what advice had been given post diagnostically to the carers of YPWD, identifying that those accessing old age psychiatry services received a greater level of advice and appropriate onward referral for any social care needs, by comparison with those diagnosed in an adult psychiatry or neurology setting. Kaiser & Panegyres (2006), identified burden, depression and fears for future dependency of the person with dementia amongst spouses of YPWD, utilising a questionnaire with 120 spouses of YPWD.

There were examples of service evaluations and anecdotal accounts in the literature highlighting the benefit of specific locally implemented support services for YPWD and their carers. Chaston et al (2003) described one example of a local self-help support group which enabled YPWD and their carers to meet on an informal basis to support each other and access services such as information, counselling, benefits and legal advice. This was seen as one way to address the apparent underdeveloped range of existing services for YPWD. Shlosberg et al (2004) evaluated a service provision for YPWD in Manchester for people attending a day care centre and some of their carers, utilising qualitative interviews and Daniel (2004) reported on the benefit of a day club for younger people in Wales. Williams et al (2001) reported on a health needs assessment undertaken in Leeds which demonstrated that a specialist service for YPWD and their carers was justified and should be provided in that locality. Parahoo et al (2002) described the lack of respite services specifically designed for YPWD and used qualitative interviews with 8 carers and their families to evaluate a service provided locally in Northern Ireland by the Alzheimer’s society. Carers expressed high satisfaction. Thompson et al (2006) described the trial provision of a specialist clinic for YPWD and reported that this had evaluated very positively by those accessing the service.

In the existing studies there were a relatively small number of examples of YPWD themselves being direct participants in the research. Killick (1999) talked with 18 YPWD and focused on three presented case studies where YPWD talked about their experiences. These accounts are left to speak for themselves, with no presented analysis of the content of each conversation. In conclusion, Killick identifies that there was a strong sense of the YPWD interviewed having a high level of awareness of what they were experiencing and how this was impacting on their life. Robinson (2000) conducted longitudinal interviews with one YPWD (as part of a study involving primarily older people with dementia) and described the difficulty and psychological strain for this individual in seeking to maintain normality and to ‘hide’ her symptoms over the course of the longitudinal interviews over a three year period.

Reed et al (2002) described how the social dimensions of dementia at a younger age can be quite different from people of an older age, in terms of issues such as work, potentially linked in the early stages with depression and complicated by the increased likelihood that the person will have insight into and frustration from their condition as it is so unexpected at a young age. In addition to this impact on the YPWD, Reed et al also noted previous literature indicating that carers of YPWD may have higher stress levels than carers of older people with dementia. In this study Reed et al conducted 21 interviews in total with YPWD or their carers. Of these there were; three interviews with only the YPWD, eight with carers alone, three where the client and carer were both interviewed separately and seven where the client and carer were interviewed together. The authors report how at that time little was known about how people with dementia feel about being interviewed. These interviews formed part of a service evaluation, which concluded that it was the team’s ability to respond to individual needs (regardless of age), that was valued, rather than specifically the provision of a service based on age for people with dementia and their carers.

Daker-White et al (2002) had interviewed 14 YPWD and their carers, who reported a difficult journey to receiving a diagnosis, with the YPWD perceiving a sense of loss of self and their carers often significant reported levels of burden. The authors described a lack of awareness of the needs of this group of people, combined with inadequate service provision.

Harris (2004) described the situation at that time in Cleveland Ohio USA, utilising in depth interviews with YPWD and a focus group. Harris identified 8 common themes across the interviews and focus group: 1) Difficulty obtaining a diagnosis. 2) Marginalization. 3) Changing relationships in the family. 4) Work/retirement issues. 5) Dependency. 6) Meaningful occupation. 7) Self-esteem. 8) Self-awareness of change. Twenty-three interviews were conducted in total including face-to-face, on-line and a focus group.

Beattie et al (2004) identified a growing interest in obtaining the views of YPWD in health and social care research believing that previous assumptions that YPWD were not capable of describing their experiences in a meaningful way were changing. Beattie et al conducted 14 qualitative in depth interviews with YPWD and reported four significant themes that emerged from their analysis, these were: 1)The experience of having dementia. 2) Dementia diagnosis. 3) The importance of age. and 4) Risk and danger issues. The authors concluded that YPWD were clearly capable of effectively indicating their needs with regard to health and social care provision. Whilst such conclusions may now seem self-evident they were nonetheless important due to the paucity of prior studies of this type and highlighted the need for more such work.

LaFontaine (2004) presented a case study to reveal some of the challenges in providing truly ‘person centred’ care to one younger man with dementia, but also the opportunities that can be available to achieve this, as an example of effective psychosocial care provision. Katsuno (2005) explored how YPWD self-rated their quality of life in response to adverse social stigma surrounding this condition in the USA. Semi-structured and structured interviews were employed utilising specific quality of life measures, which indicated that 21 out of the 23 participants were as satisfied with their life as the general population, although many described experiencing social stigma that affected (negatively) their psychosocial wellbeing. This contradiction in the results may have indicated that the quality of life measures did not fully capture issues of psychosocial importance for these participants and the author concluded that services and the public needed to reduce stigmatising labels and approaches to this group of people.

**3.10** Critique of YPWD Literature

Notable within this Chapter has been the dilemma faced by CGT researchers in the use of extant theory and literature. The argument goes that by engaging with such material there is a risk that one may hinder the inductive process with a danger that the researcher begins to ‘fit’ emerging theories or models in line with established work or ‘*pet codes’* (Glaser 2005). The approach taken here has been to view the literature and theory that existed at the time the study commenced as helpful in both shaping sensitizing concepts and bringing into focus the concerns of younger people with dementia as they are articulated through research. This does not mean to say that extant theory should be accepted without critique. On the contrary the CGT researcher should approach such knowledge with a critical eye, viewing it as *‘provisional, disputable and modifiable’* (Thornberg 2012, p.251). With this in mind, this section makes clear my own reflections upon existing work, particularly that of Keady 1999 and Hellestrom et al 2007a, which sought to address similar questions about living with dementia. This section is not a ‘technical’ critique of the literature, as may appear within the context of a critical appraisal or systematic review, rather it seeks to identify those aspects of the existing literature which I viewed as notable at the time the literature review was undertaken.

The literature relating to YPWD is based upon a range of methodological approaches and methods of data collection and analysis, including: surveys (n=5); reviews of clinical data (n=3); mixed method service evaluation (n=5); case study research (n=4); and qualitative approaches (largely thematic)(n=6). The surveys and clinical data reviews I have identified are useful in helping to establish the broad prevalence of particular experiences (e.g. carer burden) and clinical manifestations, but provide little in the way of the social and psychological processes experienced by YPWD and their families. Of the qualitative papers noted above several utilise approaches to help provide some insight into the daily life of YPWD and their carers, two examples being Harris (2004) and Parahoo et al (2002). Whilst helpful in establishing descriptions of daily life, particularly in service settings, the methods used rely almost exclusively upon thematic analysis. As a result works such as these, are largely descriptive and lacking in theoretical endeavour. This is in stark contrast to that literature I have noted in earlier parts of this Chapter, notably the work of Keady 1999 and Hellstrom et al (2007a, 2007b) which explore experiences of older people with dementia and their families. Both of these pieces of work provide us with accounts of the lives of families rich in theoretical insight, and as such they help to shed light upon the social and psychological processes experienced by YPWD and their carers and reveal the importance of the temporal nature of living with the condition.

Notwithstanding some significant challenges, the idea that people with dementia have a valuable role to play in the research process is now widely accepted. Indeed this Chapter has already noted the broader developments in the involvement of people with dementia in research. The YPWD literature I have identified is, however, on the whole particularly weak in relation to including the voice of the person with dementia. There is a tendency, for example, not to seek to capture the experiences of people with dementia even where the primary focus is on evaluation of services or interventions (Beattie et al 2002). Several papers; (Freyne et al 1999; Luscombe et al 1998; Husband and Shah 1999; Kaiser & Panegyres 2007) appraised services and while these studies present an increased level of knowledge in relation to the carers of YPWD, this literature makes the assumption that only carers of YPWD could provide accounts of interest or value, or that YPWD were in some way not able to provide insights into their own direct experiences. This critique might further extend into the forms of service provision which appear within the literature and which assume particular forms or models of service provision as the solutions to the challenges faced by YPWD (Chaston et al 2003; Shlosberg et al 2004; Daniel 2004; Williams et al 2001; Parahoo et al 2002; Thompson et al 2006). As such they do not start from an exploration of what YPWD themselves may describe as of most significance or importance in their lives, but appear to have been conducted to achieve often more pragmatic goals in relation to the delivery of health and social care. It is also typical of much of this literature to focus on specific periods of the disease trajectory and its relevance to service provision, such as the diagnostic phase for instance (see for example Daker-White 2002). Such an approach serves to limit our understanding of the experience of dementia to those points in time which have professional or practice salience. This absence of a ‘social context’ contrasts that work which has been undertaken in the wider field of dementia, in particular that of Kitwood (1997) which focus on the social processes to which people with dementia are exposed as a consequence of societal values, attitudes and prejudice. Placing emphasis upon broader concerns, such as agency, enables a richer understanding of the position of people with dementia within the service and non-service environments.

This is not to say that the voice of the person with dementia is absent from the existing literature. It has been noted that a small number of studies did seek to explore service experiences from this perspective, often involving carer and cared for person (Killick 1999; Robinson 2000; Reed et al 2002; Harris 2004). This approach demonstrated the potential for YPWD to be fully active in the research process and indicated the increased knowledge that could be derived from a dual exploration of both the YPWD’s experiences and that of their carers and also the relationship between these elements.

One further point to note here relates specifically to those papers addressing the measurement of carer experience (see for example: Luscombe et al 1998; Kaiser & Panegyres 2007). These papers rely exclusively upon a stress and burden framework in establishing the boundaries of the caregiving experience. In doing so this work disregards other aspects of caregiving which may assist in identifying strategies used to manage their role or indeed exploring the extent of satisfaction and reward within the population.

**3.11 Conclusions from the initial literature review**

The broader literature considered earlier relating to dementia described how a person centred approach informs us of the importance of understanding how the individual social and psychological world is experienced by people with dementia at an older age (over 65) and the role of stigma in this experience (Kitwood 1997, Clare 2003). Living with dementia is now accepted as a temporal journey, both for the person with dementia and their partner (Keady 1999). People with dementia have over recent years also begun to describe in their own words how they have experienced living with this condition (Sterin 2002, McGowan 1993, Rose 2003 and Bryden 2005). The importance and impact of the relationship between the person with dementia and their partner over these temporal stages has been highlighted as a key aspect of how this journey is experienced, in terms of the different forms of ‘working’ that can take place in such relationships and how these shift over time (Keady & Nolan 2003 & Hellstrom 2007a).

For YPWD specifically, the literature indicates that there are likely to be significant differences in how the journey of dementia is experienced at a younger age (Reed et al 2002, Daker-White 2002). A limited number of studies have focused directly on the experience of YPWD, describing various temporal models with ‘stages’ or significant points that YPWD experience over time. These temporal or staged models are often quite similar to each other in key aspects, such as in identifying the significance of the diagnostic period for example. A significant proportion of the literature related to YPWD has focused on the evaluation of local specific services such as social or day centre provision, rather than the YPWD’s perspective on their experienced social world (Chaston 2003, Shlosberg 2004 & Daniel 2004). Much of the literature related to the social experience of dementia at a younger age has drawn on the experience of carers, with little focus on the characteristics of the relationship between the YPWD and their partner. While the partner of a YPWD may be their carer and consider themselves as such, equally (particularly in the earlier stages of dementia), they may not be considered by either the YPWD or themselves as a ‘carer’, but rather as a boyfriend, wife or partner, as they had been prior to the onset of dementia. Existing literature has predominantly focused on relationships with carers or partners, rather than relationships with significant others such as their children or close friends (Luscombe 1998, Freyne 1999). There has been little focus for example on the experience of living as a YPWD who is separated, divorced, or does not have a close partner. Other relationships may be of significant importance in their life, such as with work colleagues or siblings whether they have a partner or not and this has not been reflected to date in the literature.

At the outset of the study therefore a relatively small number of UK studies were apparent that had interviewed YPWD in order to develop a deeper understanding of their social world (Killick 1999, Robinson, 2000, Reed et al 2002, Daker-White et al 2004 & Beattie 2004). The outcomes of these studies did highlight the potential different experience of dementia at a younger rather than older age, in keeping with my own anecdotal clinical experience (of working with both younger and older people with dementia in the period around diagnosis). This stimulated my interest in this topic further. It certainly appeared clear at this stage that there was value in exploring in greater depth how dementia at a younger age impacts on the person’s social situation, functioning and relationships, and to explore to what extent this was a shared experience with those close to the YPWD during their journey with dementia over time.

**3.12 Sensitizing concepts, overall study aims and foreshadowed questions**

Based on my own clinical experience and the literature relating both specifically to YPWD and more broadly to people of older age with dementia, (as described in the previous sections), a number of sensitising concepts (Rodwell 1998, Charmaz 2006) influenced both the direction that the present study took and the methodology that was adopted. The study has therefore been informed by an explicitly temporal understanding of the dementia experience which is framed within a relational and dynamic model that evolves over time (Keady & Nolan 2003). A major goal was to involve both the YPWD, and significant others as identified by them, as fully as possible. Hence the adoption of a constructivist approach. Consequently the current study aimed to increase understanding of the nature of these dyadic relationships in the particular context of the experience of younger people with dementia (YPWD) and their partners, with an additional broader focus on significant other people in relationship to the YPWD. This was intended to assist in theory analysis and development, and also inform current practice in the provision of diagnostic and post-diagnostic services for younger people with dementia.

Having worked as a clinician in a memory service over a number of years prior to the commencement of this study, I had personally become aware of the extent to which the nature of the personal relationships experienced by the PWD appeared to be a very significant influence on how they lived with this condition. Approximately 1 in 10 of all PWD that I would see in the memory service (in order to establish whether there was a diagnosis of dementia or not) were under the age of 65 years and this had led to personal observations of factors that could be different in this younger age group. I had often experienced the need to discuss with couples or with families, how they were all living with the onset of dementia at a younger age and it was very evident that the nature of these relationships between the YPWD and others was hugely significant in terms of how dementia affected their lives over time. It was far less clear to me why some couples and families appeared to adapt to the presence of dementia relatively positively, while for others this experience was catastrophic, damaging relationships and perceived as offering little hope. These observations certainly led me to consider what mitigating factors might be present within some families, yet absent within others. It did not appear from my own limited anecdotal experience that the severity of the literal neurological symptoms of dementia at a younger age equated proportionately to the impact on relationships in any one affected family or couple. This then left me with many questions and the review of the literature during the planning phase of this study gave some insights, but as described earlier, had certainly not exhaustively explored the social and relationship impact of dementia at a younger age, or provided many guiding principles or theoretical constructs that I could incorporate into to my own or others practice in working directly with and supporting YPWD, their partners and their families.

From my experiences as a clinician and my contact with younger people with dementia and their families over a number of years (in addition to an awareness of national health and social care strategy in relation to this group of people), and insights gained from the literature, the following overall study aims and initial foreshadowed questions were identified:

Initial Research Aims

The overall aims of the research were to develop:

1. A fuller understanding of how YPWD and those close to them experience their social world.

And

1. To explore how this social world alters over time.

From a consideration of the literature and my own experiences the following initial foreshadowed questions guided the study:

* What impact does dementia at a younger age have on the person’s life in terms of their social roles and participation?
* Of these, which are most significant to them?
* How does the presence of dementia at a younger age specifically impact on the person’s work and recreation?
* Does the impact of dementia on the person’s life alter over time as symptoms progress?
* How does dementia at a younger age affect the nature of the person’s relationship with their partner (or those close to them) and how does this change over time as symptoms progress?
* How are these relationship issues experienced from the perspective of the younger person with dementia’s partner and/or carer?

These were the key foreshadowed questions identified at the outset, based on my prior experiential knowledge of working with YPWD. Charmaz (2006) has identified how grounded theorists’ ‘background assumptions and disciplinary perspectives’ make them open and receptive to potential processes in the data. As Charmaz puts it:

*“Guiding interests, sensitizing concepts and disciplinary perspectives often provide us with such points of departure for developing, rather than limiting, our ideas. Then we develop specific concepts by studying the data and examining our ideas through successive levels of analysis.”* (Charmaz 2006, p 17).

This is therefore the starting point for the research and as will be discussed in more detail in the methodology chapter later, it was accepted that if pre-conceptions or foreshadowed questions were not relevant in the context of the data from participants, I was prepared to lay these aside and be open to the outcome of the data analysis to come. The application of these foreshadowed questions for the research study is returned to in the Methodology chapter, in terms of the constructivist grounded method of this study and these questions are then addressed in the findings chapter.

**3.13 Chapter Conclusion**

This introduction has set the scene and background to the study. It can be seen that the experiences of younger people with dementia and those close to them has certainly not been exhaustively researched, with limited systematic exploration of the lives of those with this condition to inform how health and social care services in the United Kingdom are planned, commissioned and provided to meet their needs. The following chapters will now outline the constructivist grounded theory research process that was undertaken, and then present the findings and outcomes from this repeat interview study with younger people with dementia and those close to them. The initial foreshadowed questions will be returned to in the discussion chapter, in light of the findings and the theoretical model derived from the data analysis, before consideration of implications for policy, practice and further research.

**Chapter 4**

**Why Constructivist Grounded Theory?**

**4.1 Methodology**

Introduction

This chapter will describe the methodological approach that underpinned this study including a consideration of why a constructivist grounded theory approach was taken to explore the foreshadowed questions as previously identified in the introductory chapter of the thesis. The second part of the chapter will then present the research methods that were employed to explore the social processes experienced by the younger people and those close to them who participated in the study.

**4.2 Selecting a research approach; qualitative or quantitative?**

In very broad terms research is often categorised as either quantitative or qualitative. Each of these two categories or forms of research has different characteristics and each is derived from different scientific traditions and generates differing forms of knowledge (Topping 2010). The choice of whether to adopt a quantitative or qualitative approach will partially depend upon the nature of what is to be studied. The nature of the research question influences whether one or the other, or a combination of both approaches is the best method of investigating the research topic. Quantitative research is philosophically underpinned by a ‘positivist’ tradition of observing and measuring what exists, while qualitative research fits within a more ‘interpretivist’ tradition, that human behaviour can be interpreted or made sense of by taking account of interactions and social processes that occur between people (Topping 2010).

A distinction has also been drawn between qualitative and quantitative research in respect of the philosophical assumptions or paradigms underpinning each of the two traditions. A paradigm can be seen as a set of beliefs that represent for the holder the nature of the world and their place in it (Guba and Lincoln 1994). Lincoln & Guba (1990) identified that paradigmatic assumptions determine research strategy and proposed that there is “no middle ground”(p107), between the positivist position and the constructivist position as summarised in the following statements:

*“there is a real world out there that one can know more or less well and where one could explain relationships among phenomena and attempt to generalise from one situation to the other (positivist) or it is pointless to worry about whether there is a real world so one should concentrate on reporting and clarifying people’s interpretations about what is happening in specific settings (constructivist)”* (Guba & Lincoln 1990, p107)

The choice of approach undertaken to conduct a research study is therefore influenced not only by the nature of the research question or study aims, but also by the paradigm or set of beliefs about the nature of the world and reality, held by the researcher in approaching the topic to be studied. The methodology defines how the researcher will undertake studying any phenomenon (Silverman 2005). Qualitative research is often undertaken where there is a lack of existing theory or adequate explanation relating to the phenomenon in question. Qualitative research is also characterised by utilising an *inductive* process where the researcher gathers data in order to build concepts, hypotheses or theories, in contrast to the deductive process of positivist research in deriving hypothesis to then be tested (Merriam 2002). For this study a qualitative research approach was identified as the most appropriate to explore the social, emotional and psychological processes experienced by younger people with dementia and those in close contact with them. It was anticipated this approach would be that most likely to yield a breadth and depth of data grounded in the experiences of YPWD and those close to them, in order to gain a fuller understanding of how they experienced their social world and how this might alter over time. As the initial literature review had indicated that this topic had not been fully or exhaustively explored previously, this approach was likely to enable an open approach to the data, rather than an evaluation based on previous published theory or data analysis.

Qualitative research has been identified as having an orientation to an ‘in-depth comprehensive understanding’ of the topic being researched, with the analyst as an active participant (Schutt 2012). Schutt identified a number of key characteristics that distinguish qualitative research from quantitative research:

* A focus on meanings rather than on quantifiable phenomena
* Collection of many data on a few cases rather than few data on many cases
* Study in depth and detail, without predetermined categories or directions, rather than emphasis on analyses and categories determined in advance
* Conception of the researcher as an ‘instrument’ rather than as the designer of objective instruments to measure particular variables
* Sensitivity to context rather than seeking universal generalizations
* Attention to the impact of the researcher’s and other values on the course of the analyses rather than presuming the possibility of value free enquiry
* A goal of rich descriptions of the world rather than measurement of specific variables (Schutt 2012, page 324)

There are a number of forms of qualitative research enquiry such as; phenomenology, case study research, ethnography and narrative analysis (Merriam 2002). At the outset of this research study each of these forms of qualitative enquiry were considered before grounded theory was selected as a suitable methodology to explore the experiences of younger people and those close to them.

Phenomenology describes research that takes the form of a reflective study of lived experience (Adams & van Manen 2008). Phenomenology as a qualitative research method has been described as having two significant strands. Descriptive phenomenology is derived from the work of the philosopher Husserl and has been applied as a research method by Giorgi (2000). This seeks to uncover the ‘essence’ of particular aspects of human lived experience. Hermeneutic phenomenology follows the philosophical tradition of Heidegger in seeking to recognise preconceptions that the researcher may apply to their enquiry. Both share the approach of beginning with the lived experience of the participants and working towards identifying an ‘essence’ that will represent the phenomena investigated (Todres & Holloway 2010).

Case study research can be an effective way of exploring a phenomenon in situ, recognising the importance of the context in which it occurs. This can be attractive to clinical health researchers, as there appears to be a natural fit with the organisation and delivery of care and treatment in health settings (Clarke & Reed 2010). The context in which the phenomena occurs is seen as a significant factor, with clear identification of the ‘case’ ensuring that it is representative and meaningful in relation to the phenomena to be investigated and understood. Clarke & Reed have described how case study research can be well planned and executed, to ensure findings have a relevance beyond the literal setting and experience of the specific ‘cases’ investigated. This in part relies on an analytic process that considers the data produced in light of existing research findings and knowledge from health practice and policy.

Ethnography as a research method involves immersion in a particular culture or social setting to achieve an insider’s perspective on the lived experience. In this way ethnography can be utilised to explore the experience of an identified group or sub-culture in order to obtain a deeper understanding of how this is experienced by the participants (Fetterman 2008 & Holloway & Todres 2010).

Narrative analysis has been described as varying in its form, depending on which discipline is utilising this research approach, but in social or anthropological enquiry often refers to a ‘life story’ taken from interviews observations and/ or documents (Reissman 2007 & 2008). Narrative research is therefore often based in the process of storytelling as a way of communicating human experiences in order to obtain a rich, personal and meaningful description. A narrative is a “journey or pathway through time” (Freshwater & Holloway p 190 2010), utilising the participants’ accounts as the vehicle to communicate an understanding of particular lived experiences or social processes. Reissman (2007), describes the importance of attention to the sequence of action in any narrative, exploring how and why events are placed in a story and what language is used to communicate that story. There may be little direction in terms of questioning or exploration of particular aspects of the participants’ experiences, with the researcher often seeking specifically not to direct or apply overt interpretation of the individual narrative.

**4.3 Constructivist Grounded Theory**

Having outlined the most important alternatives available to me in the methodological decisions I made at the outset I will now turn attention to my use of CGT. After considering each of the methods described above in planning the current research study, grounded theory was the selected approach for a number of reasons. I will set out these reasons below in summary, but it should be noted that the subsequent sections both draw attention to the specific features of the method and also underline my rationale for its selection.

In summary CGT was selected on for the following main reasons. Firstly, Grounded Theory adopts an explicitly temporal approach to the study of experience and places a major emphasis upon the role of the social and psychological processes that shape and help explain peoples’ experiences (Glaser & Strauss, 1967). This clearly emerged as important from the extant literature. Furthermore, this approach accepts that it is not possible to understand the experiences of families affected by early onset dementia via a thematic or static lens, but requires a more dynamic approach. My own work with younger people with dementia had revealed that the early recognition and subsequent diagnosis is dynamic. CGT allows for the exploration of these characteristics as an explicit goal of the method (Charmaz 2012).

Secondly, whilst it acknowledges the influence of prior work in the form of sensitising concepts (Rodwell 1998), grounded theory also provides a ‘clean sheet’ in recognising the paucity of previous research with YPWD and an opportunity to be open to participant’s accounts, in driving what should be explored over the course of the study.

Thirdly, and importantly, as the researcher, I was attracted to the opportunity of constructivist grounded theory in particular, as providing a transparent process for me to apply and consider how my own professional experience of diagnosing and working with YPWD and those close to them would interact with the data from participants and for the active role it allowed participants to play in the research process.

Finally, GT and CGT provide the researcher with the tools to undertake comprehensive and systematic analysis in order to develop substantive theory. I found these approaches to both fieldwork and analysis to be intuitive and reflective of my own epistemology. Furthermore, as a novice researcher I found the processes made explicit by CGT researchers such as Charmaz (2006), to be useful in guiding my own practice. Notable here are: theoretical sampling; constant comparison; memo-writing. I will deal with these in turn in the following sections. In the meantime below I outline the development of the CGT approach and its emergence as an alternative to a traditional GT methodology. In doing so I hope that this will further establish my own rationale for its usage.

**4.3.1 Grounded theory**

Qualitative research involves an ‘interpretive, naturalistic approach’ to the subject under study (Denzin and Lincoln 2005). Grounded theory (GT) is a qualitative method which enables exploration of social processes and the development of theoretical insights which have a practical application (Glaser & Strauss, 1967, Charmaz, 2000 & Hellstrom et al 2005a). GT is the systematic generation of theory from data, typically through concurrent processes of data collection, organisation and analysis (Higgins et al 2006). The research ‘problem’ or topic is seen to develop through these processes from the participants’ perspective, rather than an exploration of pre-defined problems being identified to ‘fit’ into a pre-existing theoretical framework. Glazer and Strauss (1967) are credited with leading the development of qualitative research by offering the first ‘systematic set of guidelines’, for managing and analysing qualitative data (Charmaz & Henwood 2008). In this way they challenged previous conventional positivist ideas that qualitative research was unsystematic and biased, through describing a rigorous and legitimate qualitative research method.

The origins of GT have been traced to the symbolic interactionist movement and the work of George Mead in the 1930’s (Holloway & Todres 2010). Mead identified the use of symbols in people’s interaction with each other as a significant aspect of human existence. This theoretical stance proposed that people develop their own actions and behaviours in response to and through taking account of, other people’s behaviour. This approach positions notions of the ‘self’ as a social rather than purely psychological phenomenon. GT incorporates this interactionist idea that people are active agents in what they experience, as they interpret what is happening to them and those around them and act according to these interpretations. GT highlights the importance of the context in which people live their lives and the social world in which they share their life with others. As Ormston et al (2014), drawing on Corbin and Strauss (1990), have described it;

*“Grounded theory aims to generate theories that explain social processes or actions through analysis of data from participants who have experienced them. Grounded theorists argue that the usual ‘canons of good science’ should be retained but that they should be redefined to fit a qualitative approach “* (Ormston et al 2014, p 15)

GT utilises data from participants to determine; what is explored in the research, the literature searched, the research questions developed and the number of participants in the study (Chiovitti & Piran 2003). The identification of participants and the number of total participants included in the research is therefore determined by analysis of the information from previous participants in the study (Strauss & Corbin 1990), so called ‘theoretical sampling’. The GT method provides identified strategies for collecting and analysing data in order to produce a theory to explain social or psychological processes that are ‘grounded’ in the data from which they are identified (Tweed & Charmaz 2011). While Symbolic interactionism explores behaviour and social roles to understand how people interpret and react to their environment, grounded theory moves on from this to develop emerging ‘theories of social action’, identifying analytical categories from the data and the relationship between them (Ormston et al 2014). Morse has described GT as the qualitative method that, “best reflects the changes that occur in illness transitions” (Morse 2012, p 23). As will become apparent there are a number of approaches to GT but they share some core principles including theoretical sampling and constant comparison.

**4.3.2 Why constructivist grounded theory?**

Charmaz (2000) has argued that the traditional GT approach using constant comparison and theoretical sampling took an objectivist position, limiting the participant to either confirming or disproving the theoretical theories or codes derived by the researcher (Keady 2007a). Charmaz’s position challenged the philosophical foundation of traditional grounded theory research in arguing that the role of the grounded theory researcher is to shape meanings in their encounters with participants enabling a mutual process of co-creating knowledge, rather than demonstrating objectivity in the theoretical process of GT.

Glaser (2002) as one of the ‘founding fathers’ of GT research, critiqued and challenged Charmaz’s position, and categorised constructivist grounded theory as a method of qualitative data capture that can sometimes be credible, but maintained that ‘constructivism’, is kept to the minimum in traditional grounded theory work;

“So we can see that constructivism—joint build of an interactive, interpreted, produced data—is an epistemological bias to achieve a credible, accurate description of data collection—sometimes. But it depends on the data. If the data is garnered through an interview guide that forces and feeds interviewee responses then it is constructed to a degree by interviewer imposed interactive bias. But, as I said above, with the passive, non structured interviewing or listening of the GT interview-observation method, constructivism is held to a minimum”. (Glaser 2002, p 1)

Mills et al (2006) propose that all variations of grounded theory do in fact exist on a methodological spiral and reflect their epistemological underpinnings. This can be understood to mean that the different specific proposed forms of GT are in fact closely linked and connected to each other, forming a spiral in so far as they are different (in application and proposed theoretical justification), but never poles apart or entirely separate, as they will always have aspects of shared characteristics and elements of common origin. While any GT approach may have its origins in the work of Glaser & Strauss (1967), the way in which the researcher is conceived as either an active party in data construction, or conversely a conduit for capturing the participant’s data, will reflect the underlying core assumptions of those conducting the study regarding how GT generates new knowledge and theory. The form of GT followed depends therefore on a clarification of the nature of the relationship between researcher and participant, and on an “explication of the field of what can be known” (Mills et al 2006). Constructivist grounded theory for Mills et al (2006), is positioned at the latter end of this methodological spiral, actively repositioning the researcher as the co-author of a reconstruction of experience and meaning. Mills et al identify the origins of constructivist grounded theory in the work of Strauss and Corbin (1990), through to the work of sociologist Kathy Charmaz (Mills et al 2006). Charmaz has also identified that the epistemological positioning of GT is increasingly recognised as operating ‘on a continuum’ from positivist forms as described by Glaser, through to post positivist forms (Strauss & Corbin 1990) and then constructivist grounded theory (Charmaz 2006, Tweed & Charmaz 2011).

In adopting a qualitative and constructivist approach, this study recognises the importance of how social constructs, processes and interactions relate to each other in GT data. Lincoln & Guba (1990) identified that ontologically the constructivist paradigm is; ‘relativist’ (in that aspects of human experience and culture are dependent in some way on their relationship with other aspects or elements), epistemologically ‘interactive and subjective’ (in terms of the nature of knowledge), and methodologically ‘hermeneutic and dialectic’ (focusing on social interactive processes).

The GT method when applied from a constructivist approach has been identified as facilitating the understanding of complex social processes as they occur over time (Charmaz 2000 & Hellstrom et al 2005a). Due to the limited published research literature specifically related to the impact of dementia on social processes experienced by younger people with this condition, and the desire to actively involve participants in the research process, constructivist grounded theory was identified as a methodology that would potentially enable these processes to be uncovered and explored, grounded in the experience of these particular participants. For Charmaz Constructivist Grounded Theory provides the researcher with:

“..tools to answer ‘why’ questions from an interpretive stance. By interrogating our data – and emerging ideas – with analytic questions throughout the research, we can raise the level of conceptualization of these data and increase the theoretical reach of our analyses”. (Charmaz 2012, P 4)

This constructivist grounded theory approach takes account of the ways in which we form and view knowledge of what is studied and the ways in which we represent this (Charmaz 2005). Data are not assumed to exist as a reality waiting to be exposed or rendered more visible through applying methodological procedures. Instead the data produced by the participants and the researcher, are identified as necessarily dependent on the researcher’s (and participants) “prior interpretive frames, biographies and interests” (Charmaz 2005 p 509). This is viewed in combination with;

1. the relationship with participants,
2. the actual unique process and experience of collection of the data and
3. the ways in which data are generated and recorded.

In this way a constructive grounded theory approach seeks to accept and openly show how all of the particular processes and influences within a particular study have come to bear on the nature of the data produced and the analysis and representation of that data. For Charmaz, theoretical sampling within GT means; “sampling for development of a theoretical category, not sampling for population representation” (Charmaz P 3, 2012). Within the necessarily limited number of potential participants for the current study, this approach was identified as enabling a thorough and considered approach to a potentially large amount of qualitative data from a relatively small number of individuals, from which to develop categories and theoretical constructs.

Charmaz and Henwood (2008), have described how constructivism has moved GT ‘out of its positivist roots’ and towards ‘interpretive social science’. The methodological strategies for coding, memo-writing and theoretical sampling lead to a ‘constructed’ rather than ‘discovered’ theory and they propose that constructivists assume the following through this approach;

1) The researcher is a part of what he or she sees, not apart from it.

2) Facts and values are connected not separate.

3) Views are multiple and interpretive, not singular and self-evident.

A constructivist grounded theory approach was therefore selected for the current study as this was anticipated to enable an investigation of the social and psychological processes experienced by younger people with dementia and those close to them, grounded in their own experiences and also cognisant of the researcher’s own role in data analysis and theory development. The constructivist GT methodology in particular offered an explicit toolkit with which to approach data analysis and was anticipated to enable an open and inclusive approach to theory development (Charmaz 2006 & 2012). Over and above other valuable potential models of qualitative enquiry, constructivist GT was selected as providing a clear structure for data analyses with systematic checks and strategies to refine theoretical categories from initial tentative interpretation of data through to more detailed coding, category development and eventual proposed theoretical constructs (Charmaz 2012).

**4.3.3 Theoretical sampling**

Theoretical sampling is a pivotal strategy in GT (Draucker et al 2007) and is often distinguished from a selective sampling process. Where theoretical sampling is guided by emerging theory, selective sampling identifies populations and settings prior to data collection (Draucker et al 2007). This selective sampling can provide initial theoretical starting points for enquiry. Within GT a sequential process occurs with the move from selective sampling to theoretical sampling as concepts begin to emerge. At the beginning of a study initial sampling decisions are made regarding specific characteristics of individuals or groups anticipated to have the knowledge or experience relevant to the particular study. Glaser (1978) promotes the approach during data collection of staying open to changing styles of interview, sites of recruitment and participants, to provide more information on categories that are central to the emerging theory. Theoretical sampling in GT is used to seek specific data to develop aspects of previously identified categories or theories and not as a mechanism to achieve some form of representative population sample (Charmaz & Henwood 2008). Strauss and Corbin have indicated that different sampling strategies can be adopted at different stages of research, with increasingly purposive sampling as a theory develops (Strauss & Corbin 1998, Ritchie et al 2014).

Strauss & Corbin (1998) linked specific theoretical sampling strategies to three forms of coding in grounded theory, (open, axial and selective). Open coding requires open sampling conducted to uncover as many relevant categories as possible and can be conducted; purposefully (as demonstrated through specific choice of sites, participants or documents), systematically (moving from one person to another on a list) and fortuitously, identifying unexpected data relevant to category development. Axial coding requires relational or variational sampling, where data are gathered to uncover and validate the relationships among discovered categories. This can also be purposeful or systematic. Selective coding requires sampling which discriminates by gathering data to verify the emerging theory and further develop categories which have not reached saturation. Strauss & Corbin describe how theoretical sampling is therefore cumulative, with each sampled event building from and adding to previous data collection and analysis. In the early stages the researcher is interested in generating as many categories as possible, but once categories are identified, sampling is concerned with, “developing, densifying, and saturating those categories” (Strauss & Corbin 1990 p203). Whether or not one employs the above approach to analysis theoretical sampling is central to all forms of GT (Charmaz 2006).

**4.3.4 Constant Comparison**

Unlike quantitative research where data collection and analysis occur consecutively, with one preceding the other, in qualitative research data collection and analysis take place concurrently with one informing the other. Theoretical sampling above provides a prime example of this relationship. Also in grounded theory constant comparison plays a leading role. Here data from the same participant over time or from differing participants at the same time are compared with one another both within and across data sources, so that item is compared with item and incident with incident, with each informing the other. This process is described by Charmaz as follows. Constant comparison is;

*‘a method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, data with category, category with category and category with concept. Comparisons then constitute each stage of analytic development’* (Charmaz 2006 p 187).

**4.3.5 Sensitizing Concepts**

The role of sensitising concepts has already been alluded to briefly and is elaborated upon more fully here. Charmaz (2006) proposes that the constructivist grounded theory researcher’s background assumptions and disciplinary perspectives “alert them to look for certain possibilities and processes within the data” (Charmaz 2006 p16). This illustrates the notion of ‘sensitizing concepts’ providing the researcher with their initial ideas and concepts to explore and question. Whilst recognising the vantage point from which they start their research and the nature of these ‘sensitizing concepts’, the researcher must still remain as open as possible to whatever is ‘seen and sensed’ from the early stages of the research, being prepared to lay aside initial sensitizing concepts which become irrelevant in the context of initial data collection and analysis.

With regard to this study, my own professional role as a nurse consultant in a memory assessment service, provided a range of pre-existing experiences, impressions and notions of how couples experience dementia, derived from clinical practice and some knowledge of existing literature. In particular I had experience of working with younger people during the processes of assessment and diagnosis of dementia. As Charmaz (2006) has identified, these sensitizing concepts provide researchers with their initial interest, ideas and concepts. These personal concepts as experienced by me as a researcher informed the ‘foreshadowed questions’, which were presented in the initial chapter to this thesis. This formed the basis of my interest and questioning approach to the topic and as such these sensitizing concepts and foreshadowed questions acted as a guide both for the initial purposive sampling strategy for recruitment and also the structure and nature of employed questions in the initial interviews with participants. As previously indicated by the identified foreshadowed questions, I began therefore with an interest in how the presence of dementia impacted on the individual with this diagnosis and those close to them, and more particularly in how they lived with this condition or adapted to it over time.

These sensitizing concepts were consciously recognised, but also deliberately put aside where not relevant or applicable in the context of the emerging data from initial interviews with younger couples during the early stages of the research. As Charmaz (2006) has identified these concepts are useful as ‘points of departure’, in order to form initial interview questions and to begin the process of thinking analytically about the data. This should then be followed by the development of specific concepts through studying and analysing the data from the participants. Charmaz indicates that if these initial sensitizing concepts do not appear relevant to the processes identified through on-going data analysis, this should be recognised and they should be discarded. In GT research it is important that pre-conceived ideas and theories are not made ‘to fit’ with the data and that topics identified as of importance by the participants are recognised and further investigated.

Within this study, the importance of the interview relationship between participant and researcher was recognised in the process of co-construction of meanings and theory grounded in the participants’ and researcher’s experiences (Mills et al 2006). In this way Charmaz (2006) identifies that the researcher shares in constructing the data and that our ‘conceptual categories’ are produced from our interpretation of the data, rather than being exposed or described as they exist through the vehicle of this methodology. The produced theoretical analyses are therefore ‘interpretive renderings’, rather than some exposed and described objective reality.

As a clinician researcher, it was clearly important to recognise how this dual role impacted on the co-construction process of the GT, through memo keeping and reflection and review across the process of data collection, analysis and theory development. It was particularly this aspect of the constructivist GT method that appealed when considering which form of qualitative research to undertake in exploring the experiences of YPWD. The combination of significant personal experience and professional contact with YPWD and the under-developed level of research exploring the experiences of this population could both be addressed and recognised within this constructivist methodology.

Having described the core principles underpinning the GT approach that was adopted, attention is now turned to how these were applied in practice.

**4.4 Methods**

**4.4.1 Purposive Sampling**

The initial sampling strategy was purposive (Holloway & Todres 2010), in that the inclusion and exclusion criteria for the study indicated the discreet population of people (namely YPWD in contact with a specialist service in a district of the North of England), that were sought for the interviews. The inclusion and exclusion criteria are detailed later in this chapter. Individual YPWD and couples (which included a YPWD), were in this way recruited as the initial sample. From these initial interviews the YPWD themselves identified if there were others who were significant in their lives and these individuals were then requested to participate in later interviews, either in the presence of the YPWD, or separately by negotiation and agreement with both the YPWD and other person being interviewed.

**4.4.2 Theoretical Sampling Strategy**

Data was analysed from these initial interviews which from that point on informed the subsequent theoretical sampling strategy (Charmaz & Henwood 2008, Draucker et al 2007 & Strauss & Corbin 1990), employed throughout the remaining interviews with; YPWD, their partners, their adult children, the specialist nurse and a self-help support group run by YPWD. Following the initial stage of data analysis after the first round of interviews, there was consideration at each subsequent stage of interviewing of what further data appeared to be required and from which participants, in order to achieve an adequately deep, rich and exhaustive exploration of the experiences of YPWD and those close to them.

Four rounds of interviews were conducted over a three year period and the specific characteristics of the participants that were recruited through this process are described in chapter 5, ‘Introducing the key characters and the temporal stages’. As will be detailed in the chapters to follow, this theoretical sampling strategy indicated the need to both follow up previous participants (where they agreed to this), to explore their experiences over time and also to continue to recruit more recently diagnosed YPWD, to build on the previous data and draw on a diversity of experiences from a broader range of YPWD as far as was possible within the limitations of the study.

Through conducting repeat interviews over time where this was possible (with 8 of the YPWD and 6 of their partners), identified categories and proposed theoretical constructs could be re-evaluated in the context of ongoing additional data over time from these participants. This was combined with the data from additional new participants recruited across the time span of the study, to analyse whether any proposed theoretical constructs additionally adequately represented and accounted for the themes and categories that emerged from this ongoing data analysis with new participants.

**4.4.3 Recruitment of Participants**

Individuals aged between 18 and 65 years of age with dementia and couples (where one partner had a diagnosis of dementia within that age range), were recruited to the study and interviewed at intervals 6 months apart to gather qualitative data for analysis. The person with dementia was also asked to identify any other people with whom they had close significant relationships (such as with siblings or adult children) who could also be requested to participate in the study.

Participants were recruited via the caseload of a specialist team working with younger people with dementia (YPWD) in the North of England. This service formed part of a specialist NHS Mental Health Trust. Ethical approval was obtained from the appropriate Local Research Ethics Committee and the relevant NHS Trust research approval group (see appendices 1,2,3, & 6).

Previous consultation with the team prior to commencing the research had identified that they were typically working with approximately twenty couples where one was a YPWD at any one time, in addition to a smaller number of individual YPWD who did not identify themselves as having a partner.

It was not initially anticipated that I would be likely to recruit more than 15 YPWDin total over the course of the study and it was recognised from the outset that there was significant potential for the final figure for recruited participants to be less than this, due to the relatively small population of potential participants who would meet the inclusion criteria (see below). Ethical approval was obtained to recruit up to 20 participant YPWD overall however, if this was achievable within the scope of the study. For recruited staff participants from the younger people with dementia team, it was not expected that this would exceed 12 participants and this was anticipated from the outset as likely to be determined by the theoretical sampling strategy in use and the number of staff members identified who were in contact with the YPWD recruited.

Inclusion Criteria for YPWD participants.

* Formal established diagnosis of dementia.
* Diagnosis has previously been made known to the person and their partner.
* Age within the range 18 to 64 years.

Inclusion criteria for the YPWD’s partner, close friend or relative

* Identification of a partner, close friend or relative of age 18 years or over.
* Partner, close friend or relative has consented to participate in the research at the point of recruitment**.**

Inclusion criteria for staff participants

* Member of younger people with dementia team with current or previous involvement with the YPWD already recruited to the study.

Exclusion Criteria for participants with a diagnosis of dementia

* Severe dementia (identified from clinical opinion). Due to concern that the presence of severe dementia may lead to distress and significant difficulty for that person in expressing themselves in an interview setting.
* People with dementia of age less than 18 years of age
* People with dementia of age equal to or more than 65 years (as this study was focused specifically on younger adults experiencing dementia).
* Severe generalised mood disorder and/or severe behavioural disturbance or psychosis (as this was identified likely to lead to increased difficulty for the person to consent and also to participate without distress in any planned interviews).

Exclusion criteria for partners, close friends or relatives of participants with dementia

* Where the YPWD did not consent to participate in the research at the point of recruitment.

Exclusion criteria for staff participants

* Staff who were not (or had not been) working in direct contact with YPWD recruited to the study.

**4.4.4 Data Collection**

Process for Collection of the Data

Semi-structured interviews utilising open ended questions were employed, to invite the participants to describe the presence of dementia in their lives. Semi structured interviews were used as this approach allows for a degree of appropriate flexibility in the interview process. A structured interview would have a pre-determined specific set of questions and process that would clearly not allow or lend itself to flexibility in allowing the participant to direct or alter the topics described. Semi structured interviews enable the researcher to have proposed topics to discuss and questions to ask, but also to retain the flexibility to adapt the loosely structured interview process in light of what emerges as of significance to the participant (Tod 2010). As such semi structured interviews fit well with a grounded theory methodology in allowing for a level of focus on emerging topics of interest, while enabling new or unexpected directions to be taken ‘on the spot’ during data collection. I therefore embarked on each interview with guideline or prompt questions, such as ‘When did you first notice something was changing?”, or “How did it feel when you received a diagnosis?” and often the participant would take the lead in directing the content of the interview and highlighting key aspects of their experiences. All interviews, with consent were audio recorded for later analysis.

Mills (2006) describes how constructivist enquiry requires the researcher to prioritise analysis of the interaction between the participant and themselves. In this way that interaction is seen as inherent to the data that will be produced. Mills argues that the data from the research interview must reveal, “depth, feeling and reflexive thought” (Mills 2006 p 4). In part this process is aided by removing wherever possible any unequal sense of a power relationship, where the researcher has more control over the interview setting. This can be promoted by ensuring the participant exercises choice over where, when and how the interview will take place. For the current study all participants requested to be interviewed in their own homes, with the option of daytime or evening interviews, so that family or friends could either be present or absent according to the participant’s wishes.

Use of terminology in the interview setting

Hellstrom et al (2007a) describe the initial use of the term ‘memory problem’ when interviewing couples where one partner had a diagnosis of dementia, and did not use the word ‘dementia’ until this was introduced by the participants. The term dementia is suggested as a cause of unnecessary harm and distress for some individuals where its use is not at the discretion of the participants (Hellstrom et al 2007a, Bartlett & Martin 2002). This demonstrates the loaded power of certain phrases and terms that may carry highly negative or (perceived) stigmatising effects.

Through allowing the participants to introduce and discuss their own terminology and language in the current study, aspects of descriptive language and metaphor were identified and explored in analysing the experience of dementia. This meant that the use of specific language or terminology was led and informed by the participants, rather than the researcher introducing terminology that was potentially loaded with pre-conceptions of value and meaning such as ‘dementia’ or ‘Alzheimer’s disease’. The presence of these terms and the meanings they were understood to convey did indeed emerge as important and powerful issues for some of the participants.

The initial interview guide for the semi structured interviews with participants was formed so as to reflect the foreshadowed questions for the study, taking account of feedback on the initial research proposal that had been obtained from YPWD and their partners through the Alzheimer’s society and my own increasing preliminary awareness of potential areas of interest. This initial interview schedule is set out below and reveals my early thoughts on relevant important areas of enquiry at that stage.

Interview schedule (August 2007)

1. How did you first become aware of any difficulty with your memory?
2. What was your experience of receiving a diagnosis for your memory difficulties?
3. Has anything changed for you in your life since you have experienced these memory difficulties?
4. What information, advice and support have you received?
5. Has this (memory difficulty) altered how you think about yourself?
6. Do you think this has altered how other people are with you?
7. Has this affected your relationship with each other? (asked in the presence of a partner)
8. Has this affected your; work/career, social life, hobbies and recreation?
9. What has been helpful to you in coping with any changes related to your memory difficulties?

This initial interview schedule included the following caveat:

‘The design of the study will allow for the researcher to analyse data from initial interviews (with participants), in order to identify significant emergent themes, returning to these and exploring these more fully in later interviews.’

In practice the majority of participants had their own clear thoughts on what aspects of their experiences they wished to describe and in what depth. Frequently the participants led the course of the initial interview spontaneously describing their own biography and the course of significant events from first noticing changes, to diagnosis of their dementia and beyond. Reflecting back on this initial interview schedule, the data obtained does very much answer these questions and more. This is not due to any slavish following of the schedule however, more that the issues of importance to participants, (both at initial interview and when returning for repeat interviews with outcomes from previous initial data analysis), did address these initial foreshadowed areas of enquiry.

At subsequent interviews with participants, it was the data analysis from their own and other interviews that comprised the potential areas of discussion and questions. It was usually the case that reflecting back on earlier transcripts and presenting a summary of the outcome of data analysis to that point, was a sufficient point of departure from which the participants would expand further on previous topics, or discuss new thoughts and feelings, or changes over time since the previous interview. In this way the interviews were very reflexive, yet centred very much on key themes and issues, such as; the impact of diagnosis, changes in work and recreation and almost always issues with regard to relationships; with family, friends and the wider community. As outlined previously these subsequent phases of analysis informed the theoretical sampling strategy (Draucher et al 2007, Strauss & Corbin 1990), for further recruitment of new participants and repeat interviewing of previous participants.

Interviewing YPWD and those close to them took place in phases. An initial four month period of data collection was followed by a two month period of formal analysis. Initial perceptions were identified immediately following each interview and used to inform the developing interview guide. Further interviews were then completed in a cycle, with periods of interviewing and data collection followed by periods of data analysis. Following the initial phase of interviewing, subsequent cycles of interviewing included both follow up interviews with previous participants and initial interviews with new participants to the research. In total four phases of interviews were conducted over a three year period. The length of time between any repeat interviews was from a minimum period of 6 months to a maximum of 9 months, dependent on what was convenient for the participants and when the initial analysis from the previous round of interviews had been completed.

It was initially anticipated that YPWD and those close to them would be interviewed together, where this was agreed to by both parties. Where individual participants expressed a preference to be interviewed separately this was arranged as appropriate. This situation required the agreement of both parties to proceed on this basis. Where this agreement was not demonstrated by both of the potential participants, neither was recruited, due to the potential for any distress for the individual not participating. In practice there were three occasions where one member of a couple did not wish to participate and so were not recruited to the study.

During the initial development of the research proposal, I had received feedback from volunteer couples (where one younger person had dementia), on draft versions of the ‘information for research participants’. This was facilitated by the Alzheimer’s Society in a geographical area outside of the study recruitment site. This feedback had indicated that some couples might potentially express a preference to be interviewed separately, as was indeed the case during the recruitment to the study. I had additionally consulted an YPWD team from a different geographical area, during the development of the research proposal, for their input on planning the data collection process. I had met with this team to discuss the proposed research and gain their advice on issues such as recruitment of potential participants and the feasibility of the study.

Approximately two interviews were conducted each week during each interview phase. An in depth interview with the specialist nurse from the local NHS YPWD team was also conducted within the second interview phase, once initial interviews with participant individuals with dementia and those closeto themhad been completed and analysed, in line with the theoretical sampling strategy for the study. This enabled additional exploration of the relationship between the specialist nurse, YPWD and those close to them, from the nurses’ perspective. This interview with the specialist nurse was arranged by negotiation with the staff team and their line manager, in order to minimise any negative impact of data collection on staff time and service delivery. In practice there was only one specialist nurse in contact with the YPWD recruited to the study, so this individual constituted the totality of staff members interviewed during the data collection process.

Interviewing People with dementia

In planning and undertaking semi-structured interviews with YPWD, account needed to be taken of how the presence of dementia may impact on the participants’ ability to engage with this method of data collection (Wilkinson 2001). The specific issues in relation to the YPWD’s consent to participate in the research are discussed later in this chapter, but beyond this there was a need to consider how as a researcher I could promote and facilitate the involvement of the YPWD recruited to the study during the conducted interviews. In considering these issues Hellstrom et al (2007b), have previously posed the question, ‘Do the benefits of inclusion outweigh the risks of causing harm?’. This was a key consideration and from the outset the expressed purpose and nature of the study necessitated the direct involvement of YPWD wherever possible. It was clearly essential for the current study to access directly the ‘voice’ of the person with dementia (Keady & Nolan 2003) and to promote the voice of these participants, rather than relying purely on the ‘proxy accounts’ of carers (Clarke & Keady 2002).

From my own professional background in working with YPWD, I was very aware that people at all stages of dementia might potentially be able to contribute to and actively participate in research. It was however clear that where someone may be experiencing severe cognitive impairment in the presence of dementia and where this was impacting on their ability to express themselves clearly, that this could potentially limit their ability to participate in the proposed research process The core consideration was therefore to promote the active inclusion of YPWD, while minimising possible harm or distress (Hellstrom et al 2007b). As a researcher with the benefit of significant previous clinical experience of communicating with YPWD across the diversity of sub-types of dementia and forms and stages of cognitive impairment, my core presumption was that until I met the person to be interviewed I could not predict how they would engage with the research interview. In practice, the majority of YPWD participants in the study were able to actively and directly engage in the study. Even when there were examples (as described in more detail in chapter 5), where the YPWD did not directly frequently verbally contribute to the interview dialogue, there remained the data from observation of non-verbal communication and my own memo keeping, that could hopefully capture some element of direct data from these participants. In most cases over the time span of the interviews the YPWD was able to directly contribute and provide rich and detailed accounts of their experiences.

Negotiating interviews with carers

During interviews with one couple, it became clear that there was some divergence in how they individually viewed and reflected on the impact and presence of dementia in their lives. The partner of this YPWD indicated that there were issues that she was not able to discuss in front of, or with the YPWD, as this would be too harmful or distressing for them. In this situation the YPWD did themselves identify that they did not want to discuss or think about the future, but wished to maintain a focus on the ‘here and now’, ‘living for today’. At the conclusion of the first interview with this couple, the researcher therefore discussed whether it would be acceptable to the YPWD and their partner, if the partner could be interviewed separately, in addition to the joint interview. A delicate balance had to be struck in this negotiation, as it was clearly important not to create any perception of exclusion for the YPWD, while their partner evidently wished to describe and disclose other information of significant importance to them in their role as the partner or carer for a YPWD.

This was managed through offering the YPWD an equal separate opportunity to be interviewed alone (which they did not wish to do) and also identifying that further repeat interviews would continue to be arranged with their agreement, with them as a couple. This was acceptable to both parties and the further interviews went ahead on this basis.

Interviews with the partner alone (from the couple described above), took place on two occasions, twelve months apart, in addition to further interviews with them both as a couple. It was clear that in the interviews with the partner alone, she did feel able to describe her perceptions of moving into a role of carer and feelings of loss (of a husband). She identified she could not have disclosed or discussed this in front of her partner. Had both parties not agreed to these additional separate interviews, very significant and powerful data would not have been obtained. It was also apparent for this partner, as with a number of other research participants, that they were very motivated to discuss and describe their experiences and she reflected at the end of each interview, that this had been personally beneficial in enabling her to consider changes she was experiencing in her relationship and choices she was making in the context of this.

During the study there was no occasion where one member of a couple wished to withdraw from the interview process, while another remained involved. In total there were two couples (including the previous example), where the initial interviews had been completed jointly with the YPWD and their partner, but during later contact the partners identified they would also like to be interviewed alone. In each of these instances the YPWD identified that they would not be upset or distressed by a separate interview with their carer alone and frank open discussions were had with both couples, where the partners identified they were issues of significance to them that they wanted time to discuss. It was apparent as with the example described earlier, that during these later interviews with the partners of YPWD alone, this was because they wanted to talk as openly as possible about their own journey and experience of changes in their relationship and feelings towards the YPWD, as their symptoms had progressed. This was a complex negotiation and the potential for the YPWD to feel excluded (as in the couple described earlier), or ‘talked about’ was evident, but balanced in each case with the partners’ need to tell their own story. This was the main ethical issue that occurred during data collection, but by taking an open approach with both YPWD and their partners, there was promotion of choice and negotiated outcomes were achieved that were acceptable to all parties in this situation.

**4.4.5 Management of the Data**

Initial notes were made from audio-recorded interviews with research participants. These recordings and word-processed notes were identifiable by an allocated participant number and stored securely on an NHS Hospital site. Data was only accessible to me. Anonymised data was accessible to me and shared with members of my supervisory team. The personal details of respondents were known only to me. Electronically stored data was held on a password-controlled laptop for my sole use, owned and managed by my employing NHS Trust.

Individual interview data was integrated with notes from many other intervieweesto develop theories and explanations of people’s experiences. No names or participant addresses appear in any published or presented research results. The use of quotations and specific described examples of research participants’ experiences in the presentation of the findings, could still theoretically enable someone who knew them well to recognise their involvement in the study. This was clearly stated in the supporting information for research participants as part of the consent process (Appendices 7,8 & 9).

**4.4.6 Procedures**

Participant information leaflets (Appendices 7,8 & 9), were distributed by staff from the Younger People with Dementia Team to individualswho met the inclusion criteria for the study. Potential participants who had expressed an interest in the research were then seen at an agreed time and place, given the opportunity to ask any questions and provided with consent forms and stamped addressed envelopes, returning these to myself if they chose to participate. Staff members were recruited as research participants through contact with the team manager, with provision of an information sheet, consent forms and stamped addressed envelopes for return of completed consent documentation to myself.

There was a cooling off period of at least 2 weeks from completion of the initial consent documentation to the first interview with any participant. The principles of process consent were maintained, with consent checking at each subsequent contact during data collection. The participant flow chart for the study is shown below.

Participant Recruitment Flow Chart

Team staff members provided with inclusion/exclusion criteria and participant information leaflets.

Team member contacts potential participant couples and provides information leaflet.

Potential participant identifies willingness to be contacted by researcher.

Researcher provided with name and telephone number of couple.

A researcher provided with

Researcher arranges time/place to meet with potential participant couple.

Provide consent forms and pre-paid envelopes.

Interested participants return consent documentation to researcher by post.

First interview with couple arranged (with minimum cooling off period of 2 weeks between initial consent and first interview).

**4.4.7 The challenge of recruitment.**

In total three separate YPWD teams from three separate NHS Trusts agreed to participate in recruitment to the study. Initially, only two teams were recruited to participate, but over the duration of the study, neither team had identified any potential participants for the research. Both teams had appeared motivated to participate and although contacted on a number of occasions over the first nine months of recruitment, on each occasion declared that they did not have any YPWD under their care who would be appropriately able to participate. It was not reported by these teams that potential participants themselves had declined to participate, but rather that either through the application of the inclusion/ exclusion criteria, or as a result of clinical judgement, they could not identify anyone that they thought would be suitable for the study.

One team identified that although they had a number of “new referrals”, during the period of recruitment, it was “too early” for them to be involved, while it was identified that for other people on the caseload, their dementia was now ”too advanced”. This gate-keeping role, with the reliance of the researcher on clinicians in the teams to identify potential participants, appeared to be a major barrier to recruitment for the study. Through reflecting on this process, a number of potential contributory mechanisms that may have negatively affected recruitment were identified:

1. The clinicians in the team may have been concerned about the possibility of a negative impact from participation in the research for the YPWD. It may be that they were concerned that participation would be an additional source of stress at a difficult time (such as soon after receiving a diagnosis of dementia). This could have been a protective or paternalistic approach by the YPWD team to recruitment.
2. It was difficult to gauge what value the clinical teams placed on the research and so it is unclear whether there was any lack of motivation to recruit, due to a perception that the research would not be useful. During initial meetings with YPWD teams, staff members had however appeared interested and motivated to act as a point of recruitment and had not openly voiced or expressed any negative opinions about the proposed study.
3. YPWD specialist teams often have small staff numbers and the pressure of day to day clinical work may have resulted in recruitment to the research study being a low priority in comparison to maintaining essential clinical activity. One of these teams reported having staff members who were experiencing long term sickness during the recruitment period, while another team identified that they were experiencing a significant re-organisation and changes to the staffing team and structure.
4. It is possible that some members of the recruiting clinical teams may have been averse to the idea of their work being under ‘scrutiny’ in some way through the researcher interviewing people from their caseload, although this was not identified by the staff as a potential concern, during the research planning stage.

The initial study design had been to interview couples where one person had dementia at a younger age, but feedback from the clinical teams identified that many people on their caseloads where living alone, divorced, or separated and that other friends or family were now significant figures in their lives rather than partners.

It was therefore agreed to alter the study design, protocol and recruitment process to explore the experiences of YPWD and ‘those close to them’, whoever the YPWD identified as fulfilling this role in their lives. Approval was then obtained from the relevant ethical committees and research governance bodies to amend the research design in this way. The researcher then returned to the clinical teams to identify that the recruitment criteria had in this way been broadened, to more accurately reflect the actual social and relationship status of many YPWD and also to allow for a larger pool of potential participants

Despite the broadening of the potential population of YPWD recruited to include those who did not have a partner, it remained the case that no participants were recruited from the first two sites. As a result of the lack of recruitment of participants to the study over the first nine-month period of recruitment, a third YPWD team in a different geographical area and different NHS Trust was recruited to the study, following the necessary ethical approval process (Appendices 3 & 6).

The third YPWD team in the new geographical area was very active in identifying participants for the research, over a further two-year period of recruitment. This potentially indicates that it was the attitude and perception of the clinicians acting as gatekeepers to recruitment, (as well as their capacity and scope to allocate time to this activity), that were the vital elements in successfully engaging participants in the research. These clinicians from the third recruitment site were willing to invest time in considering which people on their caseload met the inclusion criteria and then pro-actively contacting these individuals to ask whether their contact details could be provided to the researcher.

Once potential participants were contacted and provided with detailed information on the study (Appendices 7,8 & 9), recruitment levels from this group were high, with only three potential participant couples from this group declining to be involved.

The significant challenges in recruiting participants to the study highlight one of the difficulties faced in seeking to identify participants from a relatively small population (in terms of the total numbers of YPWD), with reliance on clinicians from small specialist teams as gatekeepers. While some clinicians will have a good understanding of research processes and the importance of research for improving evidence, understanding and service development, others may have less knowledge or understanding of this and therefore not be as motivated to assist with the processes of recruitment.

Due to the potential ethical complexities of recruiting people with dementia to research, there is necessarily a relatively complex process to be followed in preventing harm or distress and in ensuring that appropriate consent processes are in place. These requirements and the inevitable bureaucratic elements that they entail, may in themselves appear cumbersome and overly complex for some clinicians to apply when recruiting potential research participants. The nature of the professional role and relationship that clinicians working in these teams will have with YPWD may also be a barrier, if it is perceived that they are working beyond their usual professional roles and relationships by engaging them in, or in some way promoting their involvement in research.

I was clearly very dependent on how recruiting clinicians initially approached the topic of proposed research participation with any potential participant YPWD and whether they encouraged or discouraged involvement in the research at this point, before I had any opportunity to directly provide information or answer questions about participation.

My clinical role, working as a consultant nurse with people experiencing dementia (including crucially YPWD), may also have had some effect on the recruitment process. The usual clinical work role that I undertake may have either increased the motivation of recruiting teams to help a colleague or peer, or conversely increased any potential feelings that the teams’ work would, in some way, be scrutinised or examined by a senior clinician from outside. Overall it appears more likely however that this clinical background may have increased confidence for the YPWD teams that the researcher would be able to identify any distress or discomfort experienced by YPWD during the research interviews and respond appropriately to this.

**4.4.8 The role of clinician/ researcher.**

For the research participants themselves, it was unsurprisingly usually important for them to understand the context and purpose of the research. Many of the participants began by asking where my interest had originated from and what my own clinical background was. This may have increased potential participants’ confidence that I would understand what they described, but equally could potentially have had an inhibiting effect for some people, if this led to them perceiving that they needed to focus during interviews on aspects of their experiences that they thought would be of interest to a clinician. This could be through a focus on diagnosis or treatment for example, rather than perhaps on the issues that were of greatest importance to themselves such as relationships or their social life.

For these reasons it was of significant importance that I clearly explained my role as a researcher and my purpose in conducting the interviews and collecting data, emphasising throughout the interviews that issues of significance and importance needed to be identified by the YPWD and those close to them, rather than imposed or directed by me. From reflecting on the responses of research participants to being informed of my clinical role and background, it appeared that in many cases this encouraged participants to have greater confidence in being understood when explaining and describing complex and often sensitive experiences and emotions.

Such tensions were raised by Reed and Procter (1995) who described a continuum, contrasting the nature of conducting research as an ‘insider’ or practitioner working day to day with people experiencing what is to be studied, with an ‘outsider’, such as a researcher with no specific current or previous background of clinical practice in the area under study. These authors identify the benefits of reflecting on where as a practioner/ researcher one sits on this continuum, with recognition of the potential benefits of fresh eyes and objectivity that an outsider may bring, in contrast to the insights and previous detailed knowledge an experienced ‘insider’ practitioner/ researcher may bring, to the conduct of the study. They conclude that it is important for the researcher in these circumstances to recognise this potential broad range of influence of their clinical background on collected data and to reflect this in the process of analysis.

**4.4.9 Data Analysis Process**

I listened to audio recordings of interviews within 24 hours in order to review each interview, with memo writing to capture any additional observations, impressions or ideas. If appropriate these were used to help develop the interview guide for subsequent interviews. Each interview was then transcribed verbatim.

Coding

The first stage of analysis employed open coding using a line by line analysis of the text (Glaser & Strauss 1967, Charmaz 2000, Ward 2005). Charmaz (2006) describes qualitative coding of the data within constructivist grounded theory research as;

“naming segments of data with a label that simultaneously categorizes, summarizes and accounts for each piece of data” (Charmaz 2006 p43).

Each line of text was examined and allocated a descriptive code to condense and conceptually represent that piece of data. This included *in-vivo* coding where possible, with phrases or specific language used by the participants themselves employed to form the identified codes (Holloway & Todres 2010). From this stage of analysis onward gerunds were used, where words and phrases ending with an ‘ing’, representing an active process in the data (Glazer 1978, Charmaz 2006). Charmaz (2006) has described how line-by-line coding engages the researcher in a detailed examination of the data, where subtle nuances and implied meanings as well as explicit statements become apparent. She has described strategies that can be usefully employed at this stage to assist with this line-by-line coding.

* Breaking the data up into their component parts or properties
* Defining the actions on which they rest
* Looking for tacit assumptions
* Explicating implicit actions and meanings
* Crystallizing the significance of the points
* Comparing data with data
* Identifying gaps in the data (Charmaz 2006, p50)

These codes were used to select, separate and sort the data to begin an analytic account of them. Simultaneous memo writing enabled the capture of thoughts, concepts and questions arising from the data.

A process of constant comparative analysis was employed in comparing themes identified across individual transcripts, and in comparing the relationships between data from; people with dementia, their partners (or significant other people in their lives) and the specialist nurse. Data analysis in grounded theory is ‘iterative and interactive’ (Holloway & Todres 2010). It is iterative in that the researcher moves back and forth between earlier data, codes and themes and subsequent collected data utilising a process of constant comparison. Differences as well as similarities in the data are identified and emergent patterns across and between the data recognised to enable theory development.

With each subsequent phase of interviewing I returned to those who were participating in follow up interviews, with a summary of emergent themes and concepts from their individual previous interviews and also a summary of key themes from across all of the interviews to that point. This provided an opportunity for the participants to consider and discuss the progress of the analysis to that point and comment on this. Keady et al (2007b) has described the use of ‘co-constructed’ inquiry in working with people experiencing dementia, where involvement of the person with dementia in key stages of the research process, “lent a greater authenticity and representativeness” (Keady et al 2007b, p1). For Keady et al this approach of ‘co-authorship’ also demonstrated that for meaningful engagement to occur for the participant with dementia in the research process, the social research methods and language need to be transparent and understandable to the lay person. In order to test out the findings and proposed grounded theoretical model, I additionally presented this to the YPWD support group (set up and run by YPWD themselves and their partners), in order to ensure that the language, terminology and form of the theory was recognisable in the group participants own experiences of living with dementia at a younger age. This group was partly comprised of previous interview participants in the study, as well as other partners of YPWD, who were now in 24 hour care settings or deceased, who had not previously participated in the research interviews.

Emergent themes and concepts were considered on completion of each phase of interviewing. Through working with the data to make constant comparisons, develop categories and explore these through theoretical sampling, an analysis of the data was developed (Charmaz 2005, Lalor & Begley 2006).

The following example shows how some of the clustered descriptors were grouped under initial identified themes from the open coding of one of the initial interview transcripts. This process was applied to all transcripts in each cycle of research interviews completed.

Getting a Diagnosis

Feeling it’s the start of the end

Not knowing younger people get dementia

Experiencing a crisis at work

Blaming it on stress

Suspecting its something else

Worrying about personality changes

Hoping professionals know what they are doing

Waiting for a diagnosis

Getting anti-dementia drugs

Worrying other drugs might be better

Identified themes were subjected to constant comparison across each transcript and were gradually refined and focused until terms were achieved that adequately enabled a representation and summation of the data.

By the end of the first year into the two and a half year cycle of interviews, specific themes had been identified and were then further reviewed as the cycle of interviews and analysis progressed.

The following is an example of some of these early identified themes:

Theme

Getting a diagnosis

The family context

Getting support

Keeping things normal

Sharing the diagnosis

Managing finance/work

Recognising a problem

Theory development

At this stage in the data collection and analysis cycle, it was evident that there was much rich data, but there was no clear overarching theoretical structure or model to capture the range, breadth and depth of the participant’s accounts.

Where possible at this point previous participants were being re-interviewed and additional more recently diagnosed YPWD who had been referred to the specialist YPWD team, were also being recruited to the study. This cycle of recruitment enhanced the richness of the data in accessing accounts from people in the earlier stages of adaptation to diagnosis, in combination with other participants now dealing with symptom progression some years on from initial diagnosis. The theoretical sampling strategy at this stage had therefore indicated the need to explore further both the;

1. experience of some YPWD and those close to them over time and,
2. the experience of additional participants who had received a diagnosis since the commencement of the study.

Repeat interviews with participants at first provided data that was clearly distinct from initial interviews, in revealing how progression in the symptoms of dementia was experienced by these participants. By the time of the third cycle of interviews with some individuals and couples however, it began to appear that a level of saturation may have been reached, as the data collected at this stage often had little variation in content from the second interview previously conducted 6 to 12 months earlier. This was of use in possibly representing aspects of the participant’s adaptation to the presence of dementia, but did not appear to be significantly enhancing or diverging from previously identified themes or the tentative theory development at that stage.

Over the time span of recruitment of newly diagnosed YPWD as participants in the study, a level of saturation also became apparent in the similarities of some elements of the different participant’s accounts. Due to the diverse nature of the participants recruited to the study (and the relatively small numbers of people diagnosed with dementia at a younger age in one geographical district over a two year period), it was less clear that saturation had been achieved in terms of capturing the full extent of potential variation in how YPWD and those close to them could experience the period around diagnosis. It did become clear though that the proposed theoretical categories proposed at that stage, did encapsulate the codes and themes identified in analysis of transcripts from these participants recruited towards the latter end of the interview cycle.

Focused coding

As the process of data collection progressed over time and previous coded and themed transcripts were compared with those from a growing number of other participants, (in addition to repeat interviews with previous participants), more focused selective coding was undertaken. Charmaz has described how through this more focused coding process the researcher begins;

“weaving two major threads in the fabric of grounded theory; generalizable theoretical statements that transcend specific times and places and contextual analysis of actions and events” (Charmaz, 2006, p 46).

This later process of focused coding enabled identification of the most relevant elements in the growing volume of interview data. This was a necessarily lengthy and time consuming process, with the researcher producing theoretical categories and models to represent the participant’s data and then evaluating these across transcripts, returning to earlier codes and checking whether these categories adequately and appropriately represented the participant’s experiences, without excluding any significant components from the data.

Following a period of further on-going data collection and analysis, a tentative theory was then proposed. This was helpful in attempting to distil the apparently diverse experiences from the participant’s accounts into a meaningful describable model, but was at this point too linear and narrow. This initial tentative theory did not allow for a full explanation and representation of the diversity of ways in which aspects of the participant’s experiences, relationships and self-concepts had changed over time. As such this theoretical model did not allow for a sufficiently rich or inclusive representation of the data at this stage. As further more developed theoretical models were proposed, these were examined again through constant comparison with both the previous data and on-going new data obtained as part of the repeat interview process of data collection.

During the process of data collection, I presented developing codes and themes from the data, with tentative categories, to the supervision team, alongside the primary data sources from the transcripts. This enabled the experienced supervising qualitative researchers to actively interact with and comment on both the primary data sources, identified codes, themes and emergent theoretical constructs that I was proposing. Two examples of codes and emerging themes from the second round of interviews are shown below.

**Interview 1 with YPWD & Partner**

**Getting a diagnosis**

Noticing problems at work

Sometimes wish you didn’t know

Not expecting a diagnosis of dementia

Being shocked by the diagnosis

Benefiting from early diagnosis

Having limited contact with doctors

**The family context**

Being closer as a couple

Making the most of time together

**Getting support**

Valuing specialist nurse input

Importance of explanations/ education

Knowledge is key

Getting tablets for memory loss

Helping others with knowledge of dementia

Not ready for support groups yet

**Keeping things normal**

Being a normal man, doing DIY

Keeping working & adapting work role

Having a supportive employer

Not coping with social events

Having no patience

Keeping fears at the back of your mind

Not being sure how the PWD feels

**Sharing the diagnosis**

Being open with others

Feeling supported by others acceptance

**Interview 2 with YPWD and Partner**

**Getting a Diagnosis**

Significance of specific event (car accident)

Pushing for tests to be completed

Having cancer surgery/treatment while obtaining a diagnosis of dementia

Feeling angry with professionals over delayed diagnosis

Getting diagnosis over the phone from a non specialist

Bing kept waiting 2 hours at a clinic

Getting anti-dementia drug

**Getting support**

Valuing specialist nurse input

Getting social services help when at breaking point

**Keeping it normal**

Valuing informal community support most highly (supermarket café & working men’s club)

Losing touch with friends

Importance of normal routines and social contact

PWD not being bothered or worried by anything

**The Challenge of Caring**

Accessing carers support group

Seeing massive change over 2 years

Seeing care breaks as essential

Seeing negative effect of respite care

Getting practical support

Expecting future challenging behaviour

Feeling irritated by teeth grinding

Missing out on own hobbies and interests

Having own health problems

Being old before your time

Through these on-going processes over time of repeatedly refining the proposed theory and then testing out whether it enabled a sufficiently meaningful representation of the data, a theoretical model emerged that appeared to encapsulate the key identified elements in the participants’ data.

I maintained a conceptual log throughout the study to record when and how concepts, memos and theories emerged from the process of data analysis and what specific transcribed material this related to. A methodological log was also maintained identifying how data was obtained, selected and analysed. This is particularly important within the context of a constructivist grounded theory study, to enable clarity and transparency of the methodological and analytical processes undertaken (Locke et al 1993).

Taking account of previous theory.

During the process of data analysis, I recognised where data appeared to link to or reflect existing theory, particularly that arising from Keady’s work on ‘the dynamics of dementia’ (Keady 1999). Potential links to existing theory were acknowledged and recorded as a memo where this was apparent during the various stages of data analysis. Although this existing theory (which often related to previous research with older rather than younger people with dementia) was recognised, I tried to put to one side these previous theoretical constructs and categories at this stage, to enable an open approach to the data from the YPWD in the present study and to recognise the potentially broader social and relational context in which the current data was being collected. These previously identified theoretical concepts and research categories from earlier research (such as research with older couples where one person had dementia), were therefore neither avoided, nor formally analytically applied to the current data at this stage. During the on-going processes of interview data collection and analysis, these previous theoretical constructs were noted and then set aside in order to inform later evaluation and discussion of the theory developed from the current study with YPWD. The clear links that emerged between existing theory and the theory developed here, as already alluded to in the literature review chapter 3 (page 20), is returned to and discussed in later chapters of the thesis.

**4.5 Memo Writing**

Memo writing was employed throughout the process of data collection and analysis to capture thoughts and ideas at the time they occurred, so these could be recorded and returned to later. As mentioned previously memos were used to identify any apparent linkages with existing theory during the process of analysis. Memos were also used throughout the data collection interviews in order to record any observations I had made. These observations included my thoughts and feelings at the time of the interview and immediately afterwards. This enabled me to reflect on and identify awareness of any filters that I may have unwittingly employed in conducting the interview (such as by moving on from some topics or not exploring these more fully through further targeted questioning), such as in the following example:

*Memo*

*Participant refers to importance of accessing anti-dementia medication. I have moved away from this topic with the next question however, rather than exploring this further. In trying to act as a researcher and not my usual role of clinician, am I avoiding exploring issues of treatment and focusing too much on relationship dynamics?*

Charmaz (2006) has identified the crucial role of ‘memo writing’ between data collection and writing up, in catching thoughts, comparisons and connections the researcher has made. By writing down these thoughts and processes, ideas and concepts can be returned to and re-considered in later analysis and writing up.

Capturing these thoughts and perceptions during the process of initial analysis was viewed as a critical element of recognising how the interview data and analysis was co-constructed between myself as researcher and each participant, as well as informing the identification of potential further areas to be explored in later interviews to be conducted.

Memo writing at the conclusion of each interview also allowed for other impressions, ‘gut’ feelings and perceptions to be identified that where then were noted during interviews, including the nature of any non-verbal communication used and the communication dynamics between couples who were interviewed together, as in the following examples:

*Memo*

*PWD (Person with Dementia) largely silent but using nods of assent when partner speaks and frequently looking to partner to answer for them, even when the question is specifically asking about their personal perceptions of what it was like at the time of diagnosis.*

*Memo*

*Four years now from diagnosis – very real pain and distress describing finishing work – trying not to let it overshadow previous work achievements – wife was supported by her work colleagues at another school better than the YPWD by his own colleagues – wants to tell the full story from the beginning, with the correct chronology of dates and events – partner very calm only adding information when prompted directly by YPWD.*

Memo writing therefore served a range of functions, from capturing data that could be missed through audio recording alone, to identifying and recording the thoughts and ideas that occurred at different stages of data analysis and links to existing theories. Charmaz (2012), has described how memo-writing increases the pace of analysis, maintaining momentum and clarifying for the researcher what is happening in the data. For the researcher, memo writing was also a form of reflection on and clarification of feelings and impressions experienced across the process of data collection and analysis.

**4.5.1 Diagramming**

The use of diagramming in constructivist GT assists in the process of analysis itself, through refining core categories and making inks across these categories. Producing these diagrams and then critiquing these in light of further analysis, enables the researcher to test out the applicability and relevance of these diagrams when developing and proposing tentative theories (Birks & Mills 2015). In this way diagramming enables the researcher to map the data and make connections between categories. By refining diagrams the researcher can continually test out whether theoretical constructs represent the data and importantly whether these conceptualisations can be clearly explained and represented. Within the current study the ‘sharing model’ (see chapter 6.1), was particularly useful in draft form when returning to previous research participants to ‘test out’ the validity of the model in relation to their own previously described experiences. This diagrammatic representation of the ‘sharing model’, was then gradually developed and refined until this formed a coherent visual representation of the key elements of the proposed theoretical model.

**4.5.2 Strategies for co-construction**

A number of specific mechanisms were employed to achieve and seek validation for a co-construction of the theoretical model that emerged from the data analysis. The first of these was in consciously remaining alert and open to possible meanings from transcripts and interview memos. These apparent meanings could then be returned to in subsequent interviews to test them out with participants and encourage elaboration on these themes and meanings. Reflecting on each interview and formally reviewing the transcript to identify where discussion was led or influenced by the researcher and when by the participant, also enabled recognition of how the data was influenced by the process of partnership between interviewer and interviewee (or interviewees). The sharing theory that was eventually co-constructed by this process was then formally presented to a group comprising some of the previous research participants and other YPWD or the families and partners of YPWD. This was a self-organised club/support group for YPWD and their families in the district from where the participants had been recruited. Rather than comprising a lecture, this was a very interactive and lengthy meeting where it became clear that the different elements of the sharing theory had a strong resonance with both previous research participants and other YPWD or their families. This is returned to and elaborated on further in the discussion chapter of this study.

A constructivist grounded theory approach has been described as requiring;

“1. the creation of a sense of reciprocity between participants and the researcher in the co-construction of meaning and ultimately a theory that is grounded in the participants’ and researchers’ experiences;

2. the establishment of relationships with participants that explicate power imbalances and attempts to modify these; and

3. clarification: the position the author takes in the text, the relevance of biography, and, how one renders participants’ stories into theory through writing” (Mills, 2006 p10).

Within the current study the systematic process of returning to participants with the outcome and apparent meanings from previous transcripts, together with the more formal eventual presentation and discussion of the full ‘sharing’ theory, does hopefully demonstrate the ways in which there was a true element of co-construction in the current study.

**4.5.3 Judging the quality of a grounded theory study.**

For the current constructivist study, Charmaz’s questions to be asked of data to ensure this is ‘rich and sufficient’ were applied during the process of data analysis and subsequent theory development:

“Have I collected enough background data about persons, processes and settings to have ready recall and to understand and portray the full range of contexts of the study?

Have I gained detailed descriptions of a range of participants’ views and actions?

Do the data reveal what lies beneath the surface?

Are the data sufficient to reveal changes over time?

Have I gained multiple views of the participants’ range of actions?

Have I gathered data that enable me to develop analytic categories?

What kind of comparisons can I make between data? How do these comparisons generate and inform my ideas?” (Charmaz, 2006, p 18)

As a researcher actively engaged in a constructivist grounded theory study, it was important to strive to ensure that these questions were sufficiently satisfied by the data collected and analytic process conducted within the study. By the nature of constructivist grounded theory research, it was recognised that this remains challenging to assert conclusively and that it is the rigour and depth of the analytic process and how this is presented that attests to the quality of a study.

Charmaz (2006) has identified additional specific criteria as a framework for evaluating the quality of a grounded theory study and has named these; credibility, originality, resonance and usefulness as detailed below. In evaluating the current study the researcher strove to ensure that these criteria were met to confirm that the data, analysis process and presentation of findings were of sufficient quality.

***“Credibility***

* Has your research achieved intimate familiarity with the setting or topic?
* Are the data sufficient to merit your claims? Consider the range, number, and depth of observations contained in the data.
* Have you made systematic comparisons between observations and between categories?
* Do the categories cover a wide range of empirical observations?
* Are there strong logical links between the gathered data and your argument and analysis?
* Has your research provided enough evidence for your claims to allow the reader to form an independent assessment – and agree with your claims?

***Originality***

* Are your categories fresh? Do they offer new insights?
* Does your analysis provide a new conceptual rendering of the data?
* What is the social and theoretical significance of this work?
* How does your GT challenge, extend, or refine current ideas, concepts, and practices?

***Resonance***

* Do the categories portray the fullness of the studied experience?
* Have you revealed both liminal and unstable taken-for-granted meanings?
* Have you drawn links between larger collectivities or institutions and individual lives, when the data so indicate?
* Does your GT make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?

***Usefulness***

* Does your analysis offer interpretations that people can use in their everyday worlds?
* Do your analytic categories suggest any generic processes?
* If so, have you examined these generic processes for tacit implications?
* Can the analysis spark further research in other substantive areas?
* How does your work contribute to knowledge? How does it contribute to making a better world?”

(Charmaz 2006, p182-183)

The quality criteria will be returned to in the discussion chapter to evaluate whether the data was ‘rich and sufficient’ according to Charmaz’ criteria and specifically how successfully the current study met the evaluative questions outlined in the framework above.

**4.5.4 Ethical considerations**

Key Principles

When conducting research with human subjects it is important to consider key ethical principles and how these apply to your own role as a researcher. These key principles are now discussed.

Beneficence or the promotion of wellbeing can be applied to research with regard to how the researcher can ensure the research is of significant benefit to the participants. This could be considered on an individual basis, where the interview process with participants itself is of potential benefit, as well as more broadly where a group with particular shared characteristics such as YPWD, could benefit from increased knowledge and understanding about their experiences (Beauchamp & Childress 2009). This potential for direct benefit from participation in the interview process is returned to below and there was also a clear intention at the outset of the study to utilise this research to the broader benefit of YPWD and those supporting them, through adding to a growing body of knowledge regarding their experiences and what forms of health and social care support may be required to meet their needs, once these needs are better understood.

Non-maleficence refers to doing no harm, (either intentionally or unintentionally) and it was important to consider how involving YPWD and those close to them in research would be experienced by the participants and how this could impact on issues such as their relationships, self-concepts and self-beliefs (Beauchamp & Childress 2009). This issue was addressed with the ethics committee approving the study and the safeguards built into the study are discussed further in the following consent section below.

Respect for persons as a principle can be applied to research in recognising that each potential participant is a unique individual and in ensuring that the research process allows for individual difference and promotes choice, consent and self-determination. These issues should always be paramount in the researcher’s mind and require even more careful consideration and planning where the participant’s capacity to consent may be compromised, such as with more advanced stages of dementia. The nature of this qualitative constructivist grounded theory study in placing the YPWD at the centre of the research and data collection process, sought very much to affirm their personhood. The interview and data analysis processes employed were also from the outset intended to enable this potentially marginalised group of people to express their individual voice and for issues of significance *for them* to be captured and considered within the study findings.

The specific consent issues for this study will now be discussed to demonstrate how choice, consent and self-determination were promoted for the individual participants and more specifically how the consent issues were approached if participants were experiencing more advanced stages of dementia at a younger age.

Consent

Where YPWD were experiencing mild to moderate cognitive impairment (by clinical assessment), the researcher initially worked from the premise that potential participants retained sufficient cognitive ability to demonstrate capacity to consent to participate in the research process. The degree of cognitive impairment was measured or estimated by staff from the YPWD team from their access to the persons’ most recent specialist mental health assessment and from their own clinical opinion.

Where there was concern (in the presence of moderate cognitive impairment), regarding the person’s ability to consent, their carer was requested to additionally support the participation of the person with dementia in the study. Due to the nature of dementia and cognitive impairment, particular attention was paid to providing all information in a written format that was easy to understand and to the use of summarising and repeating of information at all stages of the research, to promote the individuals capacity to effectively consent to the research process. For some people dementia may result in symptoms, which affect their written or verbal communication and interpretation skills. Partners, close friends or relatives recruited as participants**,** were additionally required to consent to participation in the study (Appendix 10).

Throughout all interviews with participants, the principles of process consent were applied (Usher & Arthur 1998), with the researcher remaining alert to any potential expression by the participant that they did not wish to continue, or were experiencing significant emotional distress. This process of continual renegotiation of consent has also been described as useful where there is reflexivity between the data to be collected and that already collected, or where participants may wish to place any limits on the information to be available as research data (Clarke & Keady 2002).

The YPWD teams and the team managers, identified they were willing to act as a point of support and information for service users and their partners, who participated as research participants. The potential for distress resulting from discussing thoughts, feelings and experiences relating to dementia was recognised and the researcher concluded all contact with participants by establishing opportunities to discuss issues further if needed with the identified service contacts. This was not requested in practice by any of the participants. Through the previously described mechanism of on-going process consent, the researcher maintained close attention to any potential display of distress through both the verbal and non-verbal communication of participants (McKillop & Wilkinson 2004).

The study necessarily involved exploration of relationships between people with dementia and those close to them, and also their relationship with members of care staff from the Younger People with Dementia team. In such circumstances it was essential that the researcher maintained confidentiality within the bounds of anonymity provided by the data collection processes. The participant information sheets (Appendices 7,8 & 9) had been developed with review and feedback from younger couples where one person had dementia. This was co-ordinated through the Alzheimer’s Society with participation by volunteer couples from outside of the proposed geographical district for this study

Hellstrom et al (2007a) have identified three generally recognised basic requirements regarding consent to research by people with dementia:

“Potential participants should be fully informed of the study, and any attendant risks.

Participants should have capacity to understand the implications of taking part, and any potential future impact.

Any decision should be entirely voluntary, as should the right to withdraw at any point without prejudice” (Hellstrom et al 2007a)

When completing interviews the researcher needs to be aware that people with dementia may have much greater capacity for understanding when describing feelings and experiences, rather than in recalling specific facts (Hellstrom et al 2007a). From this perspective the application of inclusion criteria may be complex, especially when relying on a third party to clinically determine or predict the potential ability of a person experiencing dementia to effectively and comfortably participate in the research.

Memory function can be divided into three categories; procedural memory (recall of routine procedures), semantic memory (facts and figures, grouping and categorizing), episodic memory (life events and details), (Hecker & Mapperson 1997). Procedural memory is often well preserved in dementia, while episodic and semantic memory is often affected. Information with a strong or significant emotional content may be more likely to be retained. Diagnostic processes and assessments are often designed to highlight the gaps or shortcomings in someone’s memory performance, since an absence of normal functioning may be an indicator for the presence of neuropathology. This approach can appear to de-value the person with dementia in being dismissive of a potentially good longer term recall of earlier life events and focused only on the person’s cognitive weaknesses and deficits. From the perspective of self-identity and feelings of self-worth in the presence of dementia, it may be the episodic past events, relationships and experiences, that are more essential or core to a person’s sense of identity, than the more practical inconvenience of short-term memory loss.

Potential benefits of interview participation**.**

The research interviewing process itself has been described as enjoyable and enriching for many participants experiencing dementia (Hellstrom et al 2007a, Dewing 2002 & Clarke & Keady 2002). People with dementia participating in research have previously described a value in having time and space to tell their story (Pratt 2002, Clarke & Keady 2002). In this way recent research involving people with dementia as active participants, has indicated that inclusion can be beneficial and even therapeutic, boosting self-esteem and demonstrating that the experience of people with dementia and their capacity to express and describe this is valued (Hellstrom et al 2007a).

**4.5.5 Chapter Conclusion**

This chapter has described why a qualitative methodology was identified as most appropriate to explore the experiences of YPWD and those close to them. A justification has been made for why constructivist grounded theory was specifically selected as the best method of enquiry. The processes for undertaking the research and for analysis of the data and theory development have also been described. In the next chapters the research findings are presented, beginning with the biographies of the participants as a way of introducing their diverse individual lives and relationships, which provides the context in which data collection, analysis and theory development occurred.

**Chapter 5**

**Introducing the Key Characters and the ‘Temporal Stages’**

Introduction

This chapter presents the anonymised biographical details of the study participants including information on the social settings and dynamics, personal histories and relationships between these individuals. As can be seen from these biographical vignettes, the life histories, social and relationship contexts within which each of these younger people with dementia (YPWD) were living, during the course of the research, were complex and demonstrated great variety. This reflected the reality of the complex mix of younger people with dementia accessing a specialist dementia service, where individuals do not form a clear homogeneous group and there are significant variations in age, income, employment status, sexual orientation and ethnicity, amongst a relatively small qualitative sample of participants. The tables below set out the number of interviews conducted by participant, type and format.

Number of Interviews Conducted (**Table 3**).

Total number of interviewed participants 32

|  |  |
| --- | --- |
| YPWD | 16 |
| Partners | 11 |
| Adult Children | 3 |
| Professional Carer | 1 |
| Specialist Nurse | 1 |

Total number of interviews by type (**Table 4**):

|  |  |
| --- | --- |
| YPWD | 25 |
| Partners | 20 |
| Adult Children | 3 |
| Professional Carer | 1 |
| Specialist Nurse | 2 |

Total number of interviews by format (**Table** **5**):

|  |  |
| --- | --- |
| YPWD Alone | 6 |
| YPWD & Partner | 15 |
| Partner alone | 3 |
| YPWD & Professional Carer | 1 |
| Adult Child Alone | 1 |
| YPWD & Partner & Adult Child | 3 |
| Nurse | 2 |

Repeat Interviews were completed with 8 YPWD and 6 partners.

Age/Gender range of YPWD at the point of recruitment (**Table 6**).

Age range: 42 to 64

Females: 6 Males: 10

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| F | M | M | F | F | M | M | M | M | F | M | F | M | M | F | M |
| 42 | 49 | 53 | 53 | 54 | 55 | 57 | 58 | 59 | 59 | 60 | 60 | 63 | 64 | 64 | 64 |

The nature and importance of the biographies.

The biographies below are viewed as more than simple descriptions of the participants and their relationships. Rather they are viewed as very important data that locate participants within a certain temporal and historical context and as such provide invaluable insights into the nature of their dementia experiences and how these can best be interpreted and understood.

Some of the biographies are more lengthy and detailed than others and this reflects the amount and depth of information that was provided by each individual YPWD and those close to them. In some instances where the YPWD had difficulties with aspects of communication or with recall, this sometimes had a limiting effect on the detail of biographical information that was obtained. The biographies of those close to the YPWD again showed significant variability across the research participants with regard to the level of biographical detail that could be obtained. Where a YPWD was interviewed alone (for example where one participant was divorced with infrequent contact with adult children), it was not always possible to obtain supplementary biographical detail. This was dependent in part on whether the YPWD wished to suggest other people they felt close to who could be recruited and then whether those identified were willing to be recruited to the study as participants.

The level of biographical detail provided by individual YPWD and those close to them also reflects for some individuals the length of time that they remained as active participants in the repeat interview study, together with the willingness of people identified as close to them, to remain engaged in further interviews and data collection over time.

The biographies represent a significant component of the co-construction of the findings from the data. These descriptions reflect those aspects of the participant’s lives that they identified as being significant for them and their personal story of their unique journey living with dementia at a younger age. In this way, rather than having a pre-formed ‘checklist’ of the type of biographical information I wished to obtain, I strove to be open to participants having the time and space to tell their own story and identify which aspects of their personal biographies formed a significant context for them in how they experienced dementia.

The biographical descriptions also reveal the nature of the relationships and social contacts of importance to each YPWD. Where these involved a number of significant others (such as an inter-generational family network), this is reflected within the biography, whereas for some others the relatively brief biography provided reflects their description of much more limited social contact with, or support from, others.

Following these biographies the next chapter presents the detailed ‘findings’ from the study and the theory that was developed using verbatim quotes and examples from the participants’ data. A temporal model will be presented and discussed in more detail within the subsequent findings chapter, but as these phases are also reflected in the biographies that follow, they are also identified below. The following four temporal stages summarised below, were identified as having been experienced by participants across the journey of dementia and these will also be referred to in the following biographical summaries within this chapter.

**Four temporal stages**

Noticing something unusual

What’s happening? Seeking a diagnosis

Receiving & sharing the diagnosis

Where do we go from here? Getting on with it

The majority of participants described moving from initially ‘noticing’ that something had changed, to increasingly questioning ‘what’s happening?’ and then actively ‘seeking a diagnosis’. This was followed by ‘receiving and sharing a diagnosis’ and the events and emotions surrounding this. The ‘where do we go from here? Getting on with it’ phase, encapsulates the participants’ descriptions of how they responded to the diagnosis in the months following this and how they managed their lives in the presence of dementia at a younger age. These temporal stages are described briefly below and then discussed in more detail in Chapter 6, the findings chapter.

Noticing something unusual

For the majority of participants a period, often protracted and not necessarily immediately obvious, of ‘noticing’ was apparent from the data. This was often when either the YPWD themselves noticed some change that caught their attention, or something had been noticed by others around them.

What’s happening? Seeking a diagnosis

This was the period when symptoms became recognised as being of significant concern and professional assessment was sought. This period was often lengthy and complicated for many of the YPWD and those close to them. Any significant delays in achieving an accurate diagnosis could impact on the person’s employment and their relationships with family and friends.

Receiving & sharing the diagnosis

The time at which a formal diagnosis of dementia was shared with the YPWD and those close to them, marked a significant point of transition for the majority of participants. The ways in which the diagnosis was, (or was not) shared with family, friends and employers or co-workers, was a key focus for YPWD and those close to them. Where this diagnostic sharing was recalled as traumatic or problematic, this could remain significant over time. Where this diagnosis was shared with positive results and adaptation however, this could be a significant factor in constructively moving forward.

*‘Maintaining’, ‘modifying’* and *‘abandoning’,* emerged as the main ways in which participants reacted to and lived with younger onset dementia across the four temporal stages described above. These processes characterised how YPWD and those close to them experienced the described temporal stages of dementia and how these were reacted to. Participants could be; maintaining existing roles and relationships, modifying them in some way, or abandoning them, taking on new and differing activities and relationships. These maintaining, modifying and abandoning elements were by no means always sequential over time. For example a YPWD could be *maintaining* contact with children and grandchildren, *modifying* their hobbies or social life and *abandoning* previous formal paid work roles, all simultaneously at any one time. Similarly they may have a partner who was *maintaining* or *modifying* aspects of their relationships and shared social and domestic activities with the YPWD, while *abandoning* other aspects.

Sharing

*Sharing* was the core social process within and across these processes of maintaining, modifying or abandoning and it was the nature of what was or was not shared, with whom and in what way, that emerged as the key overarching element across the temporal stages of dementia at a younger age. In addition to introducing the temporal stages described earlier, these biographical accounts will also show aspects of how *sharing* was central to processes of maintaining, modifying and abandoning, before returning to relate these to specific examples from the data in Chapter 6 and then discussing the overarching significance of *sharing* to the study in Chapter 7.

The Key characters

**Jane, Mick, Sharon & Lucy**

Jane was 42 years old and had a diagnosis of Lewy Body Dementia. She was diagnosed the year before her interview, although she had ‘noticed something’ and experienced deteriorating cognitive symptoms from the age of 37. Jane lived in a rented local authority home, with her husband Mick who was employed and her 18 year-old Daughter Lucy who has a learning disability and was not able to be left alone for any period of time. She had an older daughter, Sharon who was in her early twenties and lived independently nearby as a single mother with a three-year old child. Up until the year before the interview, Jane had been caring for her granddaughter (who was aged three), while Sharon her eldest daughter was out at work. At the time of the onset of her symptoms, Jane had also been caring for her dad who was in his eighties and had also experienced Lewy body dementia. Her dad had died two years before the interview.

Jane was no longer able to take responsibility for her granddaughter during the day and her eldest daughter Sharon had given up her own paid employment, to care for her own child, provide care support to Jane, and also to her disabled eighteen year old sister Lucy, while her dad (Jane’s husband) was at work. Jane described feeling very guilty that she was in receipt of benefits due to her disabilities and that her eldest daughter (who had always worked from the age of sixteen), could no longer work in paid employment due to adopting significant caring responsibilities. Jane made it clear that it had always been an important part of her families’ identity and a source of pride that they had always been in paid work. Jane also expressed concern that her husband Mick was often coming home early from his job to check on her and that this could jeopardise his employment.

Jane had clearly always been at the centre of her family’s life, as the person supporting and caring for others and had seen herself very much as having been the person ‘holding everything together’. At the time of the interview she now viewed herself as having become as dependent as her disabled eighteen year old daughter Lucy, in relying on her eldest daughter, husband and close friends for significant support each day.

From Jane and her family’s description, it appeared that many people living on their estate were dependent on benefits and that there were relatively high levels of socio-economic deprivation and unemployment. Jane had clearly always seen her family as being less dependent on the welfare state than others in her local community and this self-perception was a source of pride that was being severely challenged, even though objectively Jane and her youngest daughter clearly met the eligibility criteria for substantial benefits and support.

Jane had experienced a lengthy period of worsening symptoms, prior to receiving a diagnosis of dementia. She was initially thought to be depressed and her symptoms were attributed to the stress of her lifestyle and multiple caring responsibilities. She even began to doubt herself and feel that she was a “hypochondriac”. For a period her family had suspected that she may have been secretly drinking alcohol as some of her symptoms mirrored the effects of alcohol intoxication and this had led to suspicion and mistrust for an extended period between Jane and her close family. For Jane therefore the ‘What’s happening? & Seeking a diagnosis’ period was lengthy and complex.

Jane was prescribed anti-dementia medication and was receiving regular input from the YPWD Specialist Nurse and attending a YPWD support group each week. Jane was interviewed together with her husband Mick and eldest daughter Sharon, while her younger daughter Lucy played a computer game in the corner of the room without directly engaging in the interview, and her granddaughter played with some toys on the floor.

**Phillip, Jean and Beth**

Phillip was aged 64, living with his wife Jean in their owner occupied bungalow. This was his second marriage. He had previously cared for his first wife for an extended period (who had a degenerative illness) while in his early forties, prior to her death. His current wife Jean had described her belief that it was now Phillip’s turn to be ‘cared for’, after all the care and compassion she recalled him showing his first wife. He had a married adult stepson who lived a few miles away from his own home. The stepson had two young children of his own, one of whom was disabled and for whom Phillip and Jean had previously provided care and support, until Phillip’s symptoms of dementia had worsened. Phillip had a step-daughter who was a single mum and who was living in Asia Her daughter, (their granddaughter) Beth aged 18, was temporarily living with them and seeking work nearby at the time of the interview. She had been staying with Philip and Jean for a few months at the time of their first interview. This was identified as a source of stress for them, as they felt she was demanding and unhelpful in the house. Over the period that Phillip and his wife were interviewed, his wife described how she felt resentful that both her daughter abroad and son nearby, did not recognise the level of help and supervision that Phillip required and the stress this placed on her, as they continued to expect parental support to assist them with their own difficulties, rather than ever offering to relieve some of the carer stress experienced by Phillip’s wife.

Phillip had retired from work earlier than planned at the age of 59 and he and his wife had both ‘noticed something’ had changed at that stage. After retirement Phillip had started training as a deacon at his church, but had given this up due to finding it increasingly difficult. Following a number of visits to his GP and treatment for depression, he was eventually referred to a Psychiatrist and diagnosed with Alzheimer’s disease. This had been quite a lengthy and frustrating ‘what’s happening: seeking a diagnosis’, period for both Philip and Jean. He was prescribed anti-dementia medication and had regular reviews with the Specialist YPWD Nurse. Phillip attended a local YPWD support group once a week and had input from a specialist support worker once a week, who accompanied him to go out in the local area. At the support group he described meeting people who had much more severe difficulties with memory than his own and felt that he was able to provide them with some support, but this also caused him to think about how he would be himself in the future.

In the year prior to Phillip’s retirement, his employer had moved his work base to another town and he was finding having to drive further and then locate a parking space at the new work base increasingly stressful. He had a lengthy period of sick leave and treatment with anti-depressants, before finally finishing work on health grounds after a lengthy period that included an appeals process. The decision to stop work came before he had been formally diagnosed with Alzheimer’s disease and this lengthy ‘what’s happening & seeking a diagnosis’ period of trying to keep going as normal and being initially diagnosed during that period as having a severe reaction to stress, with identified anxiety and depression, was clearly very distressing and stigmatising for him. He then experienced a period of eleven months with no income, (during which time he depleted his savings) until he was eligible for his pension at age sixty. This was subsequently augmented with additional benefits in the form of Disability Allowance.

Phillip and Jean described having lost faith in ‘the system’, because of his experiences and the financial hardship they had endured due to both the extended pre-diagnostic but symptomatic period Phillip experienced and the following bureaucratic process of ill health retirement and benefits eligibility. The couple perceived themselves as being dedicated hardworking public servants (both previously worked for the Inland Revenue), paying taxes and being self-sufficient. They also expressed their disappointment in what they felt was the ‘system’ working against them in what they saw as a time that they needed help this had made them feel very cynical in recent years.

Phillip’s religious belief and church involvement had been a significant part of his life and from having been an active member of his local church for many years and planning to become a deacon, he talked about now having a much more restricted role in the church. His wife Jean felt that although the congregation was potentially supportive, she had sensed that the priest did not understand Phillip’s diagnosis and felt Phillip was choosing to be less involved, rather than recognising that he was no longer capable of undertaking responsibility for church activities. Jean felt that often people did not recognise how ‘bad’ Phillip’s memory was, or how much support he needed, as initially on meeting him, his speech was good and he appeared socially normal and relaxed. However in reality he required almost constant supervision with any activities. For Jean peoples’ lack of awareness of the extent of Phillip’s dementia and the impact of this on her own life, was compounding their difficulties at the stage of deciding, ‘Where do we go from here?’ and of finding ways of ‘getting on with it’.

Phillip had also been a very keen gardener, but needed support now in order to undertake tasks in the garden. Phillip had recalled his experience when as an older child he had an Uncle with dementia and of how his Aunt would write notes to help his Uncle remember information. This memory appeared quite powerful for him in making sense of his own experiences now and he referred to this in each interview. Phillip and Jean were interviewed together on a number of occasions and then with his agreement, Jean was also later interviewed alone as she wished to discuss aspects of her developing role as a carer and the impact of this on her own life, but felt this would be distressing and unhelpful for Phillip to listen to.

**Margaret and Steve.**

Margaret was 64 years of age and lived with her husband Steve in their owned semi-detached house. Her husband was a retired self-employed joiner. Margaret no longer expressed herself verbally by the time of the first interview and once awake would often walk fairly continuously and repetitively around all the rooms in the house and out to the bottom of the garden and back. Steve had made the back gate and fence secure, due to concerns that Margaret might otherwise leave and become quickly lost. Margaret had three adult children from a previous marriage. One adult child had died the year before the first interview and the other two lived nearby. Steve thought that Margaret no longer recognised her children and showed no awareness that one of her children had died in recent years. One son visited regularly, with Margaret’s young grandson (aged two), who appeared comfortable in leading Margaret by the hand around the house. Steve’s impression was that although her grandchild was physically affectionate with her, she did not show him any signs of reciprocal physical affection or spontaneous contact.

Margaret had worked for many years as a head cook at a local hospice, which it was reported she had greatly enjoyed, despite the often emotional contact with patients and their relatives. She had retired earlier than expected aged 58, after a period of extended sick leave as the work was, “getting her up tight”, according to Steve. This was three years before her diagnosis with Alzheimer’s disease and, with hindsight her husband could see this was related to the onset of her Alzheimer’s disease although at the time he recalls that he wasn’t particularly ‘noticing something’ was wrong. Steve had retired a few months earlier than he had planned, due to Margaret’s Alzheimer’s disease and his need to support her. They had always planned to sell their home and live in a caravan at the coast after their retirement, spending the winter months living abroad, but the caravan had now been sold as Steve felt he could not keep her safe when away from home. Steve also felt that while she must have been experiencing increasing memory problems well before her diagnosis, he was still continuing to work long hours. He now thinks that, on reflection, some of her behaviour was odd. One day she was found by a neighbour in a confused state having been incontinent of urine, sitting in her car for many hours at the lane behind the house. At the same time he discovered that she had acquired large quantities of specific items of shopping such as large bars of chocolate. He had suspected that she was spontaneously taking these items from shops without paying for them.

For Margaret and Steve therefore the’ noticing something’ period was only recognised in hindsight and the full extent of Margaret’s difficulties only became apparent when they could no longer be ignored. Only then did they enter the ‘what’s happening? Seeking a diagnosis’ phase, which therefore was very short before they entered the: ‘Receiving and sharing a diagnosis’ phase.

Initially after Steve’s retirement, they had visited their caravan at the coast. These visits became problematic for Steve, as Margaret would begin to ask him, “when are we going home?” soon after their arrival. It was clear to him that she could not tolerate being there. Margaret was prescribed anti-dementia medication and her progress was regularly reviewed by the specialist nurse. She attended a specialist day centre twice a week. Steve used to attend a YPWD carers support group but said that this had “dwindled away”. By the second interview with this couple (a year from the first contact), Margaret’s husband had himself been diagnosed with Parkinson’s disease and was concerned about how long he would be able to continue caring for Margaret. Because of these changes in his own health by the time of this second interview, Steve was actively questioning ‘Where do we go from here?’ and becoming concerned about ‘Getting on with it’ and caring effectively for Margaret in the future.

Margaret and Steve were interviewed together, but Margaret would often walk around the house, re-joining us for brief periods. Steve explained that this was her usual habit whenever awake. At the second interview, Steve felt that Margaret no longer recognised him as her husband and reacted to him in much the same way that she would to a carer at the day centre she attended. Steve described feeling very bitter that there was not, “more help” for him. Moreover he was saddened that they had worked hard planning for their retirement, only for their plans to be taken away and for their savings to be spent on Margaret’s current and future care. Steve was aware of the range of services and support that was available through social services, the voluntary sector and the NHS, but felt that these services did not fit his particular situation and needs as a carer.

**Mary and Bill**

Mary aged 60, lived with her husband Bill in their owner occupied bungalow. They had no children and Mary had looked after their home for many years. She had always had her own set of friends separate from Bill, with whom she socialised. They had both been very comfortable with their own separate social lives. She had been diagnosed with Alzheimer’s disease two years earlier and had experienced a significant deterioration in her memory and level of independent functioning since that time. According to Bill, the first sign of a problem or ‘noticing something’, was an accident that she had in her car, which she could not then recall later that day nor when the police called at the house to interview her about the incident. Bill recalls that following this, after seeing a specialist, she was awaiting the results of a brain scan and that despite chasing this up over a number of months, during the ‘What’s happening & Seeking a diagnosis’ period, he found it difficult to gain access to information about the outcome of the scan. In the meantime Mary was admitted to hospital for surgical treatment of breast cancer. While there, the Anaesthetist said to her husband, “By the way, your wife has got Alzheimer’s”. He could recall feeling very shocked by this and continued to feel bitter about the ‘matter of fact way’ that this was communicated to him, almost as a side issue. This demonstrated the significance of how ‘Receiving & sharing a diagnosis’ is experienced and how difficulties during this period provide enduring and distressing memories for some participants.

After surgery for breast cancer, Mary returned home and had received personal care support with carers calling twice a day since that time, due in part to her additional chronic arthritis. She also attended a day centre three times a week. At the initial interview Mary and Bill did appear to be ‘getting on with it’ well, but Bill was clear in terms of ‘Where do we go from here?’, and believed that if her care needs increased he would be unable to manage to continue to care for her at home.

Mary had continued to maintain some of her usual routines at the time of the first interview, and was being very well supported by the local community. She would sit in the supermarket café chatting to the staff, while her husband Bill did the shopping and on another evening each week she would be driven by Bill to the local social club, where the regulars would “keep an eye on her”, while Bill went for a drink with his own friends. Bill had been attending a support group for the carers of YPWD from the time of her diagnosis. Bill stated that once this weekly routine could not be maintained, or if Mary developed significant additional physical care needs (such as problems with incontinence), he would arrange for Mary to move into residential care, as he did not feel that he could provide her with significant personal care. Within six months of the first interview Mary had moved into a care home.

Mary and Bill were interviewed together. Whilst the informal care arrangements they had put in place had worked well for a number of years Bill was frustrated by the restrictive and inflexible nature of formal care provision, citing the example that Mary had to travel to the day centre on ‘official’ transport, rather than being allowed to use a taxi, that could be driven by a longstanding family friend (who worked as a taxi driver) to take her to the day centre. This would have been much preferred as it was both ‘more normal and natural’ as well as ‘more comfortable, flexible and convenient’.

**Aisha, Hussan, Safia & Razak**

Aisha who was 54 and her Husband Hussan, lived in a two bedroomed rented terraced house. She was described as having previously raised the family and looked after the home while her husband had been in paid work. They had four children; one who had just left University, a Son Razak in his late teens living at home and a Daughter Safia in her early twenties with mild learning difficulties, who now managed the domestic tasks in the house. Another young adult daughter was estranged and they had not had contact with her for eight years since she was eighteen. Aisha was originally from Pakistan, having moved to the UK as a young adult. She shared a number of relatives with her husband, as they were cousins. She had been close to her sister who lived in Pakistan, speaking regularly to her by phone each week, until this had become more difficult due to her memory and communication difficulties. Aisha had been diagnosed with Alzheimer’s disease two years before the first interview.

Aisha did not contribute very much to the interview conversations, generally leaving her husband Hussan to answer any questions. Hussan felt that their Daughter Safia was not able to be very organised and that the house has become chaotic and “a mess”, since Aisha’s Alzheimer’s disease had worsened. Hussan felt that he could not discuss Aisha’s Alzheimer’s with the wider family, especially in Pakistan, as they would think, “she has lost her mind” and had no clear concept of what dementia is. He was also concerned that Aisha would no longer cope with travelling to Pakistan to visit her family as she had done in the past. Due to the stigma associated with Dementia he was avoiding contact with their wider family and knew Aisha’s sister wondered why she hadn’t telephoned her. He did not, however, feel he could discuss these issues with anyone. He was also worried about the impact of his caring responsibilities on his employment as he felt that his work would use “any excuse”, to terminate his employment.

Hussan described how he had ‘noticed something’ had changed over quite an extended period and that initially he and the GP had thought that Aisha’s symptoms were due to depression, caused by loss of contact with their estranged daughter. After a lengthy period of ‘what’s happening & seeking a diagnosis’ Aisha was eventually referred to a specialist after a period of treatment with anti-depressants. She was prescribed anti-dementia medication and had regular reviews with the Specialist Nurse. Aisha and Hussan were interviewed together, while their youngest daughter was also present in the room, but not contributing to the conversation. It took a number of months to arrange an interview with Aisha and Hussan, with agreed appointments that did not go ahead, due to her husband not being available, or the date becoming inconvenient at short notice. He was understandably very clear that he could not prioritise the time for a research interview over his other work and caring responsibilities. Hussan was obviously very concerned regarding ‘Where do we go from here? And despite support from his daughter, described a range of pressures that made ‘Getting on with it’ very difficult for him, Aisha and their daughter. Hussan appeared very guarded and concerned about any possibility of Aisha’s family being made aware of her diagnosis and clearly felt that this would be seen as shameful and a source of embarrassment for his family, although he personally felt this view was very wrong. This sense of needing to ‘hide’ Aisha’s diagnosis and symptoms appeared to make the family very cautious and ambiguous about participating in the research and after two interviews, they declined any further contact.

**David, Rebecca & Matt**

David aged 60 was married with two sons and a daughter, who all lived independently away from the family home. One adult son Matt had recently moved from London back to Yorkshire, but continued to work as a pilot from London during the week. David’s daughter had two young children that he and his wife Rebecca visited regularly. David retired early on ill health grounds from an assistant director role in town planning, which he had held for many years. He described a difficult extended period of years ‘noticing something’, before his diagnosis, where he had periods of sickness absence from work and was treated for stress and depression, before eventually being assessed for dementia and diagnosed with Alzheimer’s disease. In common with a number of other participants David & Rebecca felt they had to push and fight to find out, ‘What’s happening & to seek a diagnosis’. David was diagnosed 2 years before the first interview, but had stopped working for 2-3 years before that, as it was clear to him and his wife that he could no longer cope at work. His employer offered him more menial roles, but his wife Rebecca recognised that even then, he would not be able to retain information sufficiently to undertake these new tasks. The loss of income at a time when they still had dependent children at home and a child at University, meant that Rebecca returned to work full time, which she had not planned to do. They recall that David had seen up to seven different doctors over a three-year period, before eventually receiving ill health retirement status. In terms of ‘Receiving and sharing a diagnosis’, they described the diagnosis of Alzheimer’s as a relief, because he could start anti-dementia treatment and they at least knew, “what we were dealing with”. This extended period of David’s difficulties being related to work stress and bereavement, was described as having really knocked his confidence and changing the dynamic of his relationship with Rebecca. From previously perceiving himself as a joint decision maker in their relationship and equal partner with Rebecca in making decisions about their family, home or finances, this extended period where he appeared to ‘not be coping’ had begun to alter how he viewed himself and also how Rebecca viewed his role in their relationship as there was even at this early stage some level of shift, with David relying more on Rebecca to make significant decisions.

With David’s agreement, Rebecca was interviewed separately on a number of occasions, as she identified she would be able to talk more freely about ‘Where do we go from here? & Getting on with it,’ and her perception of her role as a carer when alone. David and his wife were also interviewed jointly on a number of occasions and with his and his wife’s agreement, his son living nearby was also interviewed alone. During the interviews, David continually described his abilities in negative ways, suggesting he had always been a ‘slow learner’, while his wife consistently disputed this, citing how he had held a very responsible job for many years, as well as being very able with DIY, gardening and constructing things as a hobby. Over the 2 years he was interviewed I noticed that David gradually became more focused on simple physical activities and tasks, such as stamping his feet or swaying to music, rather than verbalising his feelings in any detail.

Matt was also interviewed separately in his own home with David & Rebecca’s agreement. From Matt’s interview it was apparent that Rebecca had not shared with him the full extent of the stress she experienced, nor her sense of loss about her husband and their previous relationship. It was clear that she was trying to protect her son and reduce the impact on his life, although Matt stated that he had decided to come back and live near his parents in order to provide more support if needed.

**Allen and Hazel**

Allen aged 53, lived with his wife Hazel in their owned detached house. They did not have any children. He was working as a deputy head teacher at the time of his diagnosis with vascular dementia. He described a difficult and extended period of ‘noticing something’, which lasted for years, before receiving a formal diagnosis of dementia. This was punctuated with lengthy spells of absence from work and a diagnosis at that time of stress and depression as the cause of his difficulties. At the time of onset of his symptoms of memory loss, he had been bereaved with the death of his father the year before and both he and his wife were initially hopeful that his symptoms would resolve after a period of treatment for depression, but there was no improvement and this then led on to them questioning; ‘What’s happening? Seeking a diagnosis’.

Allen remembers an extended period of trying to cope at work and to manage his forgetfulness by using post-it notes, (such as on his desk, at home, or on his car dashboard), but of having an overwhelming feeling at that time that things were ‘out of control’. He was diagnosed three years before the first interview and at that time was still officially employed. He described a difficult and protracted process of achieving ill health retirement and the whole period around, ‘Receiving and sharing a diagnosis’. He described his sister (a head teacher) as having been very helpful in this process at a practical level, but that she and her husband could not directly discuss his dementia with him, as they found this terminology or any discussion about his future, too uncomfortable and could only focus on specific practical support.

Allen described the trauma of being asked not to enter the grounds of the school by the head teacher (where he had worked for twenty years), after declaring his diagnosis of dementia and having to collect his belongings at night with a locum caretaker, without being able at any time to, “say goodbye to the children”. This difficult extended period before diagnosis and the distress of how his employment had ended, clearly impacted very heavily on Allen, who continually referred back to this episode on each of the three occasions when he was interviewed over an eighteen month period.

When describing his thoughts and feelings about, ‘Where do we go from here? And getting on with it’, Allen described feeling that his neighbours and acquaintances might doubt that he had dementia, as his symptoms were not like Alzheimer’s and that the vascular dementia which he experienced was poorly understood. He described living with a dread, that one day his symptoms could suddenly dramatically deteriorate. Allen and his wife Hazel were interviewed together on each occasion, with Allen doing most of the talking and his wife only interjecting when specifically asked by Allen to do so. Allen agreed to contact his sister to ask if she was willing to be interviewed, but she declined this.

**Dominic and Tom**

Dominic aged 64 was living with his same sex partner in their owned terraced house, at the time of the first interview. A year later they had sold this home and moved to a rented local authority bungalow. Dominic was a registered nurse, who had finished work earlier than planned, but described this as having been a great relief due to the difficulties he was having at work because of his memory. He was diagnosed a year before the first interview after a very difficult period. Around the time of ‘What’s happening? And seeking a diagnosis’, he was also dismissed from work by the hospital. This was due to a police investigation and court case surrounding allegations that he had mismanaged a bank account he had been administrating for a friend. His diagnosis was accepted as a mitigating circumstance by the court, as it was acknowledged that due to his dementia, he had difficulty with decision-making and organising financial affairs.

At the time of the first interview, Dominic had no pension income due to the dismissal and had lodged an appeal. A year later at the second interview, this had been resolved and he was in receipt of his reduced pension. Simultaneous to this process, his partner Tom was experiencing progressive physical health problems and had been off on long term sick from work. By the time of the second interview they had reduced their outgoings, and were claiming appropriate benefits and pension entitlements, as his partner had also retired younger than he had expected, on ill health grounds.

Dominic found it difficult to discuss his diagnosis with his family, as there was a family history of people experiencing dementia at a younger age “a couple of aunts and an uncle”. An uncle, a headmaster had “just disappeared” and had no further contact with the family until years later it became known that his uncle had, “died from dementia”. Dominic was prescribed anti-dementia medication and saw the specialist nurse regularly. He described how he and his partner complemented each other, as he could provide physical care for his partner, while Tom provided him with help organising tasks and recalling information. At the time of the second interview he had ceased to have any contact with his mother, as it was too difficult to talk about his dementia with her.

Dominic was interviewed alone on each occasion. His partner Tom was present in the house, but did not wish to join the interview. At the second interview noted that he and his partner were now closer than ever, and that they were enjoying their bungalow, (which they had moved to between the first and second interview) and their early retirement, as they had more time in each other’s company. Dominic believed that his work history as a nurse encouraged him to face illness as a fact of life to be managed and accepted. He clearly also felt that he was supporting his partner as a carer in terms of physical support, just as his partner was supporting him with organisational support. This was clearly important in maintaining his sense of making an equal contribution to a successful partnership.

**Andy and Deb**

Andy 55 was living with his partner Deb in their owner occupied bungalow. Deb had a son from a previous marriage who Andy had raised, “as his own”. This adult son now lived with his own young family in the North East and they visited him fairly regularly. Andy was diagnosed with Alzheimer’s disease two years before the interview and attended the local day centre for younger people with dementia once a week. He was visited by a specialist support worker, who he went for a walk with one day every week. Andy had seen his time with this young support worker as an opportunity for him to show the younger man routes and walks he knew, rather than seeing in any way that he was dependent upon the younger support worker for any guidance or support.

Andy had worked as a miner before being made redundant from the colliery some years earlier. He had seen a friend from his working days once each week. Deb was continuing to work full time at the time of the first interview, but was considering reducing her hours or stopping work, as she was concerned that Andy could no longer manage for long periods alone at home. She was worried however about the financial implications of this and also about letting down her colleagues and employer by reducing her hours or giving up her role at work. She also recognised that she obtained a lot of social benefits from her contact with others in the workplace, that she would not have staying at home as Andy’s carer. When discussing their feelings about ‘Where do we go from here? And getting on with it’, Deb did not feel that she could fully or openly discuss problems with Andy any more, as she felt he was not able to recognise the difficulties that she faced as his carer. Deb described problems such as the fridge door being left open and Andy taking the dog out for a walk and leaving the front door open when he was alone at home and that these issues were becoming more frequent.

Andy was prescribed anti-dementia medication and his progress was regularly reviewed by the specialist nurse. Deb described her contact with another carer as her main informal source of support. Andy and Deb were interviewed together. She appeared to indicate that there was more she could say during the interview about her feelings and experiences as a carer, but did not wish to say this in front of Andy or agree to any separate interview without Andy present, although he stated that he would have no difficulty with this. Deb indicated that in terms of support for, ‘getting on with it’, her informal contact with other people who understood her situation was far more beneficial to her as a carer than any support from health or social care professionals no matter how well informed they were.

**Dave and Angela**

Dave was 49 years of age and married to Angela. They did not have any children. At the time of the first interview he described ‘getting on with it’, in very positive terms and was still working full time in an adapted work role, for a highways company. He was diagnosed two years ago with Alzheimer’s disease and described a relatively short period of ‘noticing something’, quickly followed by him and Angela questioning ‘What’s happening and seeking a diagnosis’. In marked contrast to many other participants the diagnostic process was very quick, “about six weeks in all”. He described becoming aware there was a problem when he became unable to learn new tasks at work, needing to be shown day after day what to do but unable to remember. He went to see the GP who ruled out any physical cause and referred him straight to a specialist. After an MRI scan they said, “there is nothing else it could be” and diagnosed dementia. He was prescribed anti-dementia medication and had regular reviews with the specialist nurse. At the time of the first interview, he had worked for the same firm for thirty years. He had a positive experience ‘receiving and sharing a diagnosis’, with his employers having gradually adapted his role. He had continued to drive, although when driving at work he was always a passenger, rather than driving any colleagues. Eighteen months later he had now had to retire from work due to the progression in his symptoms and changes in his work relationships, with a new firm taking over his workplace.

Dave had always been very good at DIY and as part of ‘getting on with it’, continued to maintain aspects of this at the first interview. He and his wife also had previous organising roles with the local caravanning club and remained very involved in this. Dave had been very open with work colleagues and caravan club members about sharing his diagnosis and found that people had generally been very accepting and supportive. Dave and his wife were interviewed together, with Dave often relying on his wife to answer questions, while he would contribute with nods and occasional brief interjections of his own. This was quite in keeping with his long-standing personality traits.

**Martin**

Martin was 63 and lived alone in his owned semi-detached house. He had worked as a miner before being made redundant in his fifties, when the mine closed. He was diagnosed two years before the first interview with Alzheimer’s disease and recalled that in terms of ‘receiving and sharing a diagnosis’, immediately after receiving the diagnosis, his wife had said, “I can’t cope with that” and had left him, which he found very surprising and difficult as there had been no prior indication of a poor relationship. He had a daughter who was a single mum living nearby and a brother who worked abroad, but with whom he went out regularly when he was back in the UK, which he enjoyed very much. Martin was prescribed anti-dementia medication and was in regular contact with the specialist nurse and attended the local support group for YPWD, where he described how he “helps out” the other YPWD. He continued to drive. When describing ‘getting on with it’, he discussed how he maintained contact with his friends at the local social club and they would go out fishing or to the horse racing together quite regularly. During the repeat interviews he remained effectively independent without any outside support, relying on his calendar and post-it notes on his fridge to remember appointments.

Martin was interviewed alone on both occasions. He was described by the specialist nurse as a real “success story”, as after a shock diagnosis and his wife subsequently leaving him, he had adapted very well to living independently and successfully managing his memory problems while maintaining his social life.

**Geoff**

Geoff was 57 and lived alone in a ground floor rented flat. He retired some years ago having worked as a building site labourer for many years. He was diagnosed three years before his interview with Alzheimer’s disease and was prescribed anti-dementia medication, with regular reviews from the Specialist Nurse. He had separated from his wife before his diagnosis, but as part of ‘getting on with it’, she continued to support him by visiting each week and doing his shopping and laundry. He has two daughters and a son, the daughters had their own homes and families and the son in his late teens was living with his ex-wife. He described seeing them occasionally as they all lived fairly close by. He heated up his meals and generally organised himself day to day, spending his time watching TV and looking through the paper. He described feeling content and safe in his flat and knew he could ring for any support if things were too difficult for him. Geoff was interviewed alone and despite quite significant problems with his short-term memory, appeared to be very comfortable and confident living alone with clear structured routines each week. He did not appear overly concerned with thoughts of ‘Where do we go from here?’ and showed little recollection of any previous period of ‘noticing something’, or any clear recollection of the time around, ‘receiving and sharing a diagnosis’. Throughout the interview Geoff was very focused on the ‘here and now’ and on practical arrangements and routines that he had developed. He did not seem interested in focussing on his feelings or thoughts about the future, preferring to ‘live for today’.

**Frank and Tracy**

Frank aged 63 had been diagnosed three years before the first interview. Once he and Tracy had ‘noticed’ his increased forgetfulness over a number of months, they had questioned ‘What’s happening? And sought a diagnosis. A process they recalled as being fairly straightforward. They lived in their own home during the winter months and they spent the warmer months, from Spring to Autumn, at their mobile home on the coast. He and Tracy were interviewed together as a conference telephone call to their mobile home. Frank described having already taken planned retirement before receiving a diagnosis of Alzheimer’s disease and did not feel this had significantly impacted on his lifestyle in terms of ‘getting on with it’ after diagnosis. He continued to drive. He was prescribed anti-dementia medication, with regular reviews from the Specialist Nurse and neither he nor his wife felt there had been any deterioration in his condition over the previous three years. They had children and grandchildren, with whom they had been very open in ‘sharing’ a diagnosis. He could recall how his mother (who had died six years earlier with Alzheimer’s disease), had developed memory problems when in her eighties and noted that he did occasionally think about this at night and worry what the future may hold in terms of, ‘Where do we go from here?’. Day to day he described getting on with the retirement he had planned for, regularly playing golf and socialising with others at the coastal caravan park. Overall he felt that so far Alzheimer’s disease had not significantly impacted on his life. Day to day neither Frank nor Tracy focused very much on his mild memory problems and felt these were very much in the background, with their lives carrying on pretty much as usual.

**Neil and Michelle**

Neil was 59, married with two young adult children; a daughter living at home working in a temporary job prior to attending university and a son in the sixth form. His wife Michelle was is in full time work with a professional career. He and his family lived in an owned detached modern house in a sought after country village. Neil had retired early from an academic university post in engineering. He described how for a period of approximately a year, he had struggled at work ‘ noticing something’ was wrong and how this had become increasingly stressful for him due to concentration and memory lapses, until he had questioned, ‘What’s happening?’ and sought and received a diagnosis which led to early retirement.

Neil was interviewed alone on one occasion and declined to be interviewed on any further occasions or for any of his family to be interviewed. Neil focused very strongly on describing how after retirement he had sought new challenges to focus his attention and energy away from thoughts or worries about the future. His main focus during the interview was on his successful completion over the previous year of charitable events, including half marathons and distance cycle challenges, all of which were for international charitable causes (such as breast cancer research), that were not linked to Alzheimer’s disease or dementia. Neil did not wish to discuss or focus on any of the negative impacts of his diagnosis or the period of ‘receiving and sharing this’ with others. His focus was very much on the achievements of his previous academic career and in terms of, ‘Where do we go from here and getting on with it’, his focus was on further planned charitable challenges. Although Neil talked very freely at this single interview about topics he was comfortable to discuss, it was clear that any focus or discussion on the emotional, psychological or social impact of his dementia on himself or his family was not comfortable for him. I had a strong feeling that any further interviews with either himself or his family were perceived as potentially threatening or harmful.

Neil was seen alone at home, while his family were all at work or school and it did not appear that he had informed his family about the interview or that he necessarily planned to discuss this with them. For Neil, living with his dementia appeared to very much be focused on shutting out the symptoms from his own and his wider families life for as long as possible, with a focus on relatively short term targets and achievements, that gave him a sense of purpose and fulfilment. This was his way of, ‘getting on with it’. It was clear that Neil had very ambivalent feelings about the research interview and wished to limit both the focus of the interview and his level of involvement in the research.

**Sophie**

Sophie was 53 and living in a local authority group home for people with a learning disability, who were able to live semi-autonomously with daily input from support staff. There were two other residents, who were out at the time of the interview. Care support staff were present at the group home during the day, 7 days a week. Sophie was accompanied by a paid carer during the interview. The combination of Sophie’s learning disability and memory problems appeared to make it difficult for her to give a clear description of the chronology of significant events in her life. For example she struggled to recall or describe any previous period of ‘noticing something’ or of how she had ‘received and shared a diagnosis’. Sophie had been living at this group home for approximately seven years and liked it because it was, “nice and quiet”. She described how where she had lived previously local teenagers would shout and call her names. She described feeling much safer and more comfortable in her current home. In terms of ‘getting on with it’, Sophie attended a day centre four times a week which she enjoyed and also described how she would go out for meals to the pub with her care workers or to the supermarket. Being able to complete these activities was very important to her. Sophie was not able to talk directly about her experience of dementia and did not appear to recognise or recall being told she had this diagnosis or what that might mean. She was much more focused on describing what she enjoyed, the things she could do independently and the activities the care staff assisted her with. The care worker accompanying Sophie during the interview had not known her long and did not feel she could talk meaningfully about the impact of Sophie’s dementia on either Sophie or those she lived with.

**Rachel and Pete**

Rachel was 59 and living in a local authority rented home, with her boyfriend Pete. Rachel had worked successfully in a number of occupations up until her early 50’s including many years as a waitress and then a publican and bed and breakfast owner. Five years ago her sister and neighbours had ‘noticed’ that she was struggling to cope with everyday life. Eventually she lost her business, was declared bankrupt and was no longer in a long-term relationship. She was admitted around that time to a mental health unit and was diagnosed with Bi-polar disorder and later on in the admission (following a brain scan), with Alzheimer’s disease. This complex set of circumstances had made ‘noticing something’ more difficult, in terms of distinguishing any mood difficulties from other underlying problems related to dementia,. However as the admission period lengthened there was increasing questioning of, ‘What’s happening and seeking a diagnosis’. The admission lasted for 11 months and there was concern that she would not manage if she attempted to return to living independently after discharge from the mental health unit.

While Rachel was an in-patient she was befriended by her current partner Pete (who had been visiting a friend there) and the two began a relationship. With Pete’s support she was discharged to her current home where they now lived as a couple. In many ways Rachel described how her life had improved significantly over the past 4 years since ‘receiving and sharing a diagnosis’ and moving in with Pete.

In terms of Rachel and Pete’s description of ‘Where do we go from here? Getting on with it’, after Rachel had returned home from hospital, a friend of Pete’s suggested that they go to a support group for younger people with dementia and their carers. They both attended this group one day a week and also went on regular trips with this group, travelling round the country once a month as well as on longer holidays occasionally. Rachel also attended a specific group once a week that was solely for YPWD, linked to the same not for profit organisation, as well as an NHS support group for YPWD once a week.

During the interviews with this couple, Pete did much of the talking with Rachel intervening to clarify specific points or add additional information about her past life before she and Pete met. It was clear that the support group for YPWD had become a focal social point for both of their lives, which they saw as a major positive step that had taken place after Rachel’s diagnosis. Unusually Rachel had been put in touch with the NHS team for YPWD through their fortuitous contact with the volunteer YPWD group, rather than having been initially referred by their GP for diagnosis or support by this team, as the other research participants had.

**Specialist Nurse**

The specialist nurse worked within an NHS Trust providing specialist mental health services including dementia services. She would be asked to see people with suspected dementia at an early age from anywhere around the geographical district that formed the third successful recruitment site. She had qualified in her early 20’s as a mental health nurse and had over 20 years’ experience of working in the field of dementia, and more specifically over the previous decade with YPWD. Her role included initial assessment of younger people with suspected dementia and she worked in tandem with the Consultant Psychiatrist who specialised in diagnosis of YPWD (as part of a broader role). As such she would gather information for the diagnostic appointment and support people to attend this, then provide follow up support post diagnostically to the YPWD and their family. Her role also encompassed regular monitoring and cognitive testing of YPWD who were prescribed an anti-dementia medication. She would engage with wider family, friends, employers, benefit, care and housing agencies where this was identified as needed or beneficial by the YPWD. The nurse had in the previous ten years completed a post registration nursing degree and had focused her dissertation on the state of service provision at that time for YPWD. It was clear that she had a passion for her role and work. She was described by the majority of the research participants as a significant source of advice and support, especially through the often difficult period of diagnosis and adjustment to life after this.

**5.1 Chapter Conclusion**

During the interviews with YPWD and those close to them, it was very apparent that the majority of individuals wanted or needed to describe their journey when living with dementia, and that this could be understood in terms of the four phases described earlier. For a significant number of these individuals the processes of first ‘Noticing something’ and then asking ‘What’s happening’ and ‘Seeking a diagnosis’, up until the point of ‘Receiving and sharing a diagnosis’, was and had remained highly significant episodes in their lives. The stress and uncertainty that often accompanied this period before diagnosis, remained prominent in many of the participant’s minds and was often a subject that dominated initial interviews and was also returned to in subsequent interviews. The difficulties surrounding not receiving a correct diagnosis of dementia and the attribution of symptoms to other causes such as stress or depression, was described as having been stigmatising and distressing for many of the participants and those close to them.

As well as the process of seeking and obtaining an accurate diagnosis, the impact of then sharing this diagnosis with others (such as employers, friends and family), also emerged as highly significant for many of the participants and a focus of many of the interviews. As further interviews were conducted with new participants and repeat interviews were conducted over time

with initial participants, clear stages of a temporal journey in the presence of dementia became apparent. This progression from; ‘Noticing something’ to ‘What’s happening? And seeking a diagnosis, ‘Receiving and sharing a diagnosis’ and then, ’Where do we go from here? And getting on with it’, captured this temporal journey (as agreed with the participants) in a way that enabled their diverse individual experiences to be identified and understood without losing individual variation.

The following findings chapter explores this temporal model in more detail, drawing on examples from the accounts of YPWD and those close to them. Key processes that help to explain how participants ‘navigated’ their lives with dementia are proposed and discussed. ‘Sharing’ (or not as the case might be) is identified as the core category that largely mediated and shaped the extent to which participants were able to engage in ‘maintaining’, ‘modifying’, or ‘abandoning’ aspects of their lives across the temporal journey of dementia at a younger age.

**Chapter 6**

**To Share or not to Share…**

**The findings chapter**

This chapter will present and discuss the main findings from the study and the resultant mid-range theory of living with younger onset dementia that was co-constructed with the participants. At the heart of the theory lies the ‘temporal’ model. This emerged clearly from the data and whilst I was aware of earlier temporal models of the dementia experience these were not explicitly drawn upon when constructing the one presented here. However, as will become apparent there are points of similarity and overlap with existing models, especially that proposed by Keady (1999) and these will be explored more fully in later chapters. As well as describing the temporal model in greater detail a major focus of this chapter will be to introduce and elaborate upon the core category of ‘sharing’ and the role that this played in helping participants in either ‘maintaining’, ‘modifying’ or ‘abandoning’ aspects of their prior lives and relationships.

As outlined briefly in the prior chapter the temporal model was seen to comprise 4 broad and distinct but often overlapping phases as outlined below and in the diagram on the following page.

**Four temporal stages**

**Noticing something unusual**

**What’s happening? Seeking a diagnosis**

**Receiving & sharing a diagnosis**

**Where do we go from here? Getting on with it**

This temporal model captures the major ‘transition’ points that marked participants’ journeys with dementia at a younger age in a chronological fashion from first noticing signs or symptoms, through to the impact of the progression of dementia on their lives and the lives of those closely connected to them. This presents a rather neat and orderly account, which does not fully reflect the often chaotic and fragmented experience of a number of participants. This is inevitable when developing a model of this sort but nevertheless the participants and I feel that the model provides a useful way of capturing often disparate experiences sufficiently, to identify shared markers within their journey. This was reinforced when presenting this model to the group comprising some of the previous participants as well as more recently diagnosed YPWD (see page 76, ‘strategies for co-construction’). The next section of this chapter expands on these temporal stages and illustrates them with examples drawn from the accounts of the participants. Each of these temporal stages will be returned to later in the chapter to reveal how at each stage participants were engaged in either ‘maintaining’, ‘modifying’ or ‘abandoning’ aspects of their lives depending on the extent to which ‘sharing’ was in operation.

**6.1 Sharing Diagram**

Noticing something unusual

Maintaining

What’s happening? Seeking a diagnosis

Modifying

Abandoning

Receiving & sharing a diagnosis

Where do we go from here? Getting on with it

**6.2 Noticing something unusual**

For the majority of participants a period, usually protracted and not necessarily immediately obvious, of ‘noticing’ was apparent from the data. This was often when either the YPWD themselves noticed some change that caught their attention, or something had been noticed by others around them. This is seen as separate from and preceding the ‘what’s happening?’ or pre-diagnostic period, as at this point participants were not specifically concerned about what they had ‘noticed’ and certainly didn’t see it as suggesting a diagnosis such as dementia. Consequently there was no attempt to actively seek any answers, nor indeed to even ask any questions, at least initially. Nevertheless, even at this stage the ‘uncertainty’ that was often created could result in subtle changes in dynamics or attribution.

For example Aisha’s husband Hussain, described a period of uncertainty when he initially noticed changes in Aisha, which still, over time caused a number of emotions;

*“Well you could actually say it’s got to be over two years now. We’d noticed that she kind of kept on telling the same thing. First of all I just thought she was being clever you know……..so then of course I was a little angry……..doing the house and everything else and thought, ‘what is the problem?’”*

Hussain went on to describe the discussions that took place between his eldest son and himself around this time, that were not ‘shared’ with Aisha but rather the unusual behaviour was attributed to other causes;

*“Then we kind of said her memory was a bit absent when you’re talking to her, she’s not really showing any willingness or eagerness and she just seemed to be disconnected. Well the thing is I actually thought….we had a bit of a tragedy because of my daughter like as we’ve not seen her for nearly 8 years…..so at first I thought she was upset and it was kind of the cause”.*

Following this family discussion help was sought and Aisha was treated for depression for an extended period before there was any suspicion of dementia possibly being the cause. This process mirrored the experiences of a number of the other YPWD participants, who had also been treated for stress and/or depression for an extended period before any other cause for their symptoms was considered.

As with Aisha, so Philip, Jane, David and Allan were all initially treated for stress or depression. Stress, anxiety and depression are commonly experienced mental health problems, while dementia at a younger age is rare. These factors appeared to lead to GP’s, families and the YPWD themselves all either assuming (or possibly hoping), that symptoms were related to stress or depression, which while still often associated with a level of social stigma, also offer the potential for full recovery. It was also the case that for some participants such as Dave, possible treatable physical health problems were considered first before dementia was suspected, although in Dave’s case the ‘noticing something’ period was relatively short, because the GP was thorough but also quite decisive as Dave’s wife Helen described:

*“It was (Dave) who flagged it up, he’d been given promotion at work and when they were trying to teach him the new job, day after day he said I can’t remember what they’ve said, he couldn’t take in the new instructions, so he went to Dr’s…nothing was being retained at all. Three years ago started the investigations, from GP instantly said, ‘could be thyroid etc’ that were all ok, then to rule anything else out MRI scan and then said, ‘there is nothing else it could be’.*

This relatively short period of ‘noticing’ before dementia was suspected was not reflected in the accounts of other participants who more often described this as quite an extended (and stressful) period of time. Differing events often triggered this ‘noticing’ period.

For example, during his role as a trainee Deacon at his church, Phillip’s wife noticed that he had increasing difficulty with the paperwork for the role and as she described it, “that was what got to him”. Jean also noticed at this time that he was ‘more irritable’ and that eventually he made an appointment to see his GP who initially said, “I think you’re just a bit depressed”.

Jean described the difficulties that changes in Phillip were causing at this early stage before there were any formal investigations of what he was experiencing. As was the case with Hussain and family these often resulted in subtle changes to relationship dynamics:

*“I could see him getting more and more uptight about it and I said I think you ought to go to the Dr’s and he did, it was August bank holiday before he finally agreed and the Dr put him on sick and gave him antidepressants, but it was the following May before they actually finished him at work”.*

Allen had described becoming increasingly worried at this stage that something was wrong, but was also avoiding seeking any help, despite what he recalled as significant changes:

*“It was year of world cup and children were coming in early to watch the match, I can’t remember when, I was rushing around to set up projector onto big screen, suddenly as if I’d been hit with sledgehammer…that’s odd, sparkling lights and whatnot. Put TV on, felt something had happened, then went to back of my mind.*

*“A little while later, while head was off child had a serious accident, head injury and parents were going to sue, nobody could find accident forms, my wife said to me, ’You’re in serious trouble’. This was a significant thing, I was sure I would have done (the forms), but couldn’t remember”.*

For another couple, Mary had recalled noticing herself how she was becoming forgetful:

*“I noticed things and then I went to see the Dr, the GP and he asked some questions and said I was alright, but I wasn’t satisfied”*

Mary’s husband Bill added:

*“He didn’t feel it was that bad, but Mary went for a check for breast cancer and we went to see a different GP…a what do you call it……locum and I mentioned it to her and she asked a few questions and then she put us in touch with the Consultant, but in the meantime Mary had a slight road accident”.*

In this way Mary and Bill felt that it was really only through a chance encounter with a locum GP that things progressed on from noticing changes to a more active process of identifying what was happening and seeking a diagnosis.

This ‘noticing something’ period was therefore very variable in terms of how long it took YPWD, and those close to them, to suspect what might be the cause of any noticed changes and to ‘share’ these thoughts and feelings with each other or their GP. The role of the GP was often central in terms of how long it then took for specific investigations for possible dementia to be undertaken, sometimes extending from months into years, with other ascribed causes (such as depression) being treated before referral to a dementia specialist. As previously indicated, the significance of this period and its impact on participants will be returned to later in the chapter in considering how the social process of ‘sharing’ was central to how participants at this initial stage of the temporal model, and at every subsequent stage, engaged in ‘maintaining’, ‘modifying’ or ‘abandoning’ aspects of their lives.

**6.3 What’s happening? Seeking a diagnosis**

‘What’s happening?’ captures the period when symptoms became recognised as being of significant concern and professional assessment was sought. This period was also often lengthy and complicated for many of the YPWD and those close to them. As noted above, in many cases an initial mis-diagnosis and attribution of the symptoms to causes other than dementia led to significant delays in achieving an accurate diagnosis. This in turn could impact on factors such as the person’s employment and the nature of their relationships with family and friends. At the same time the YPWD tried to introduce strategies to ‘maintain’ an element of normality.

For instance Allen described this period in the following way:

*“I was terrified of what was happening so I was just stumbling along really, whenever it was I used to make copious notes about things. I always had in my hand….what do you call it…a filofax also with my laptop, anything that I had to do was always put in to remind me, it was like bells and whistles. I mean the car and my keys were covered with sticky notes…on my forehead almost. It was bad and then I always felt, I was obviously getting very stressed and thought all I need is a good night’s sleep then I’d be alright, then I got a massive migraine on the way to work one morning……..and then I thought, ‘I can’t go on’. I made an appointment at the Dr and told him this headache wasn’t going away.”*

This marked the turning point for Allen leading him to actively seek an explanation and diagnosis. However, he was subsequently treated for a lengthy period for stress, depression and a suspected problematic grief reaction relating to the death of his dad a year earlier, rather than dementia being considered. Allen recalled that the lack of investigations into his physical health may have meant that his blood pressure had been raised for a significant period, especially with the stress and anxiety he was experiencing for more than a year, as counselling and anti-depressant treatment did not improve his symptoms. Over an extended period he was struggling first with managing at work as a deputy head teacher and then with seeking and organising early retirement on ill health grounds, before vascular dementia was eventually diagnosed and his high blood pressure identified and effectively treated.

Martin described how some time before seeking a diagnosis his close friends, with whom he went to horse races or fishing, had commented on the extent to which he was forgetting information or conversations he had previously had with them. Before he had received any formal diagnosis, they had nicknamed him, *“Mr Alzheimer’s”.* Although he said he had not been upset by this and had shared in this as a joke with his friends, he mentioned it a number of times during both of his interviews and this nickname did in part prompt him to seek an assessment through his GP.

Phillip and his wife recalled that although their GP was treating Phillip’s symptoms as depression, that they were becoming increasingly suspicious that something else was wrong and eventually after many months paid to see a Neurologist privately. Unfortunately they still experienced further delays of many months before investigations were completed.

*“They said, ‘I’ll put you down for an MRI scan’…we waited from June to September (for the scan) and then were, ‘Ring again in December’. I eventually contacted the Consultant’s secretary who arranged for the scan in 2 weeks’ time and then referred to the Psychiatrist.”*

Dominic described how after difficulties with his employment and a complicated court case, referral from the GP to the specialist YPWD team and access to a diagnosis was a major turning point:

*“There were a couple of GP’s I saw…one who I knew a bit and she was really good, we went through a few things and she then referred me….and then the (specialist nurse) came round to see me and did some tests…and it was obvious there was a problem and then I had a brain scan and got a call the following day to say that something was found at the front of my brain, there was some blood supply problem there. And that explained part of it they thought as well, and I saw a consultant…..I then got obviously not straight away but it was fairly quick and I actually got a diagnosis which at first actually pleased me because I wanted to know and obviously by now with my GP, we’d realised what it probably was and I felt I wanted to be told what it was and now there wasn’t a doubt, so I thought, ‘We can deal with it now, he said I can start on some medication which I did and I think it was after that it sort of really hit home….”.*

Access to a formal dementia diagnosis was therefore very variable in terms of the time from initial symptoms noticed by the YPWD and those around them, to the point of sitting down with the Consultant Psychiatrist (in most cases) to be told the diagnosis. While some participants described fighting and battling to receive an answer to their questions, sometimes over years, there were a small number of examples of much speedier access from the GP to the specialist and receipt of a dementia diagnosis, such as for Dave where this process took six weeks and Frank who did not recall any barriers or delays in accessing a specialist and a diagnosis.

**6.4 Receiving & sharing a diagnosis**

The point at which a formal diagnosis of dementia was shared with the YPWD and those close to them, marked a significant point of transition for the majority of participants. The ways in which the diagnosis was, (or was specifically not) shared with family, friends and employers or co-workers, remained as a key focus of both the YPWD and those close to them across the span of the repeat interviews. Where this diagnostic sharing was recalled as traumatic or problematic, this often appeared to colour the YPWD’s on-going self-perception sometimes years later. This was certainly the case for Allen and also Jane. Conversely where this was shared with positive results and adaptation, this represented a constructive turning point from which to positively move forward.

For some of the YPWD, such as Geoff who was living alone with fairly advanced memory problems, it appeared difficult for him to think back to or describe the point of diagnosis some years earlier, although he was very able to describe his current situation. It appeared likely that it was the impact of his experienced dementia on his cognitive functioning that made significant events from recent years difficult to recall, rather than any deliberate avoidance of the subject or suppression of a previous distressing experience. For others interviewed alone, such as Neil, Martin and Sophie, it appeared of far more importance for them to focus on the here and now and without someone significant present as a co-interviewee, there was not the opportunity for someone who knew them well to prompt or remind them of such past events.

For Rachel and her partner Pete, her diagnosis of dementia had been obtained during a lengthy (11 month) admission to a mental unit due to her bi-polar disorder. This diagnosis of Alzheimer’s did appear to have impacted significantly on her discharge plans from hospital, but in this context Rachel herself did not recall receipt of this particular diagnosis as significant in itself, although her partner described this as the catalyst for access to the YPWD team, support group and a useful social network that they both engaged fully with after her discharge home from the mental health unit.

The majority of participants had received a formal diagnosis of dementia after referral to the YPWD team and they were informed of their diagnosis during a clinic appointment with the team Consultant Psychiatrist. Those participants who had a diagnosis of Alzheimer’s disease or Lewy Body dementia (as distinct from vascular dementia), were then prescribed anti-dementia medication and received on-going regular reviews from the specialist nurse within the YPWD team. Formal diagnosis also often impacted on; the YPWD’s employment (if still working at that stage), benefits and entitlements and access to support groups and social networks that existed for YPWD, their partners and carers in the local area. Access to appropriate anti-dementia treatments (which participants hoped would slow down the progression of dementia), was an important aspect of and outcome from diagnosis for the participants, but did not constitute a significant focus of the participant’s interviews. Of far more importance to many YPWD and those close to them, was achieving a greater understanding of what was happening and why through receipt of a diagnosis. As will be returned to later in the chapter when the temporal stages will be explored in more detail, the manner in which a diagnosis was obtained and how it was delivered and then shared with others, remained a highly significant event for the majority of the participants. It was clear that for many of the YPWD and those close to them that the delay in accessing an accurate diagnosis had been painful and distressing and memories of that period remained foremost in some participant’s minds, often years later.

**6.5 Where do we go from here? Getting on with it**

Following the receipt of a formal diagnosis the ‘where do we go from here period?’ was characterised by YPWD and those around them making decisions on how to use this information, such as deciding who to ‘share’ this information with, and what plans to make for the future.

In the initial interviews with David and his wife, there was a description of the ways in which they faced the challenge of his dementia together, despite the lack of a shared agreement on the best approach to adapt to his symptoms and the impact of these on their lives.

*“Made us closer if anything, (YPWD nods in agreement), we vary a bit on plans for the future, I want to do what we can while we can, do it to the full and get the most out of it and you’re (gesturing to YPWD) sort of ‘let’s do it as we would have done, everything as normal’.”*

Although David and his partner adopted a different approach to the presence of his dementia, this was an open and shared process at this stage with mutual recognition that they were each dealing with issues in their own way, but as part of a unified and agreed approach.

The ‘getting on with it’ period was often shaped by the extent to which the YPWD’s dementia progressed over time and the ways in which they and those close to them were able to successfully adapt to these changes. Forms of sharing continued to be a key social process in how YPWD and those close to them continued their lives after diagnosis. There were examples of couples continuing to share in close intimate relationships and also sharing in how adaptations or changes were made to their lifestyle and share of relationship responsibilities. For other YPWD, progression in their symptoms led to a reduction in how they participated in or maintained ‘their share’ of responsibilities and activities in the home and family.

At the point at which some couples were first interviewed, such as with Andy and Deb, they had clearly been ‘getting on with it’ for some time after receiving a diagnosis of dementia, but this was becoming increasingly difficult due to the progression in Andy’s dementia. This appeared to mark another turning point for this couple, where Deb described Andy as being less self-aware of the problems his dementia was causing and of his increasing reliance on her as a carer. Deb was at this point therefore reviewing her options in terms of whether to continue working. For this couple, as with Phillip and Jean and David and Rebecca in their later interviews, the person without dementia indicated that there were subjects, emotions and experiences that they no longer felt able to share or describe in front of the YPWD. Rather than describing a shared decision of ‘Where do we go from here?’, with the YPWD, these partners at this stage were increasingly recognising that they were now a carer and would in some ways be ‘getting on with it’ without necessarily openly discussing or agreeing this with the YPWD, as they would automatically have done previously.

Having considered the temporal stages in a little more detail and ‘hinted’ at the role that sharing played in this process attention is now turned to the extent to which ‘sharing’ occurred and how this influenced the ways in which YPWD and those close to them engaged in maintaining, modifying or abandoning aspects of their lives and relationships.

**6.6 Maintaining, modifying and abandoning**

*‘Maintaining’***,** *‘modifying’* and *‘abandoning’* emerged from the participants’ accounts as the main ways in which they reacted to and lived with younger onset dementia. These processes characterised how YPWD and those close to them experienced the described temporal stages of dementia and how they and those around them reacted to these stages. The meaning of these processes are fairly self-evident and capture the extent to which participants sought to either maintain existing roles and relationships, modify them in some way in response to dementia or had to abandon elements and look to new and differing activities and relationships. These maintaining, modifying and abandoning elements did not however follow a neat clear linear course that was necessarily aligned with the temporal stages previously outlined in the model above. There were some examples of individuals who did describe engaging in activity (or inactivity) that comprised ‘maintaining’ normality initially, followed by ‘modifying’ aspects of their lives in the presence of dementia and later ‘abandoning’ elements of their lives due to symptom progression. However for many participants it was not the case that each of these aspects took place in a neat chronological order over time.

Furthermore, whilst in most cases decisions as to whether or not, and how, to maintain, modify or abandon established patterns, roles and relationships were made primarily by YPWD and those close to them, in some instances these decisions were taken by others, particularly those that revolved around work roles. Examples of these will be given later. Moreover, how decisions were made by YPWD and those close to them depended primarily on the extent to which ‘sharing’ occurred. When decisions were made jointly then sharing was a prerequisite. If decisions were made by either the YPWD or those close to them separately, then sharing did not feature as key elements. In other instances ‘decisions’ were made tacitly, without full discussion but based on implicit ‘agreement’ as to the way forward. These scenarios can best be understood as comprising two continua. In one there is full sharing at one end and limited or no sharing at the other. This largely shaped the extent to which there was participation in decision making, as illustrated in the lower continuum. When full sharing occurred then YPWD and those close to them where able to engage in shared decision-making, with both parties playing a full and active role. When sharing was partial then the part that either the YPWD or those close to them played in decision making varied. Sometimes it was the YPWD who chose not to share everything with other people but more often, as the dementia progressed, it was others who felt unable to share all their thoughts and feeling with the YPWD. At the opposite end of the continuum there was little or no sharing and here the YPWD played an increasingly small part in decision making and key decisions were made by others. This is illustrated in the figure below.

Sharing Continuum figure 1

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The following sections will illustrate how these processes operated to shape whether or not participants sought to maintain, modify or abandon aspects of their prior roles and relationships.

As described earlier during the early stages of noticing and seeking a diagnosis there was little change to peoples’ behaviour and relationships, although as they began to realise that something might be amiss some participants began to modify aspects of their lives that might be proving problematic. For most participants as the YPWD’s symptoms progressed, there was an increasing likelihood that aspects of their lives would be ‘modified’ in some way to accommodate dementia. Simultaneously some aspects of their lives might be very effectively ‘maintained’, while others were ‘abandoned’ altogether. In particular it was recognised that participants often strove to ‘maintain’ a wide range of characteristics that comprised aspects of their; unique sense of themselves and self-identity, roles and relationships (in the broadest sense) and their interests and activities. These efforts were often challenged by the impact of their experienced dementia over time, necessitating modification or even abandonment of these highly significant aspects of their individual, or shared, lives and identities. The major process that influenced these activities and the core category within the theory is that of ‘sharing’.

**6.7 Sharing**

As noted above ‘sharing’, emerged as the key mediating process across the temporal model from initially ‘noticing something’ right through to ‘getting on with it’ for all participants. Whether participants were engaging in ‘maintaining’, ‘modifying’ or ‘abandoning’ aspects of their lives, ‘sharing’ (or the absence of sharing), was the critical and core social process that largely determined the degree of active participation that people, especially the YPWD, could make. This sharing took a variety of forms and altered across the temporal phases.

For example the act of sharing could be apparent in the ways a YPWD and their partner jointly agreed who they would, or would not, share the diagnosis with in the earlier stages of dementia. This decision could then significantly influence the extent to which they maintained relationships with friends and family. At a later stage in the journey of dementia during the ‘getting on with it’ period, an absence of shared goals or the adoption of separate (unshared) priorities by a YPWD from their partner (and also by this stage carer) could significantly influence the quality and type of their relationship. An example of this for one couple was where David became more focused over time on direct immediate sensory experiences such as walking or stamping his feet, while his partner Rebecca was increasingly and simultaneously focused on planning for her own anticipated future and increasing caregiving responsibilities.

Sharing occurred both within close relationships, (for example such as between a YPWD and their partner or child) and also in broader social relationships, such as the sharing (or absence of sharing), of a diagnosis of dementia with work colleagues or neighbours. Sharing also comprised less explicit forms, such as shared understandings or shared experiences, often rooted in earlier relationships and a shared history together based on shared expectations, hopes, aspirations, or fears for the future.

The absence of ‘sharing’ was also very significant in terms of its impact on roles and relationships and the influence this exerted on how decisions were made about maintaining, modifying or abandoning aspects of participants’ lives, and importantly, who primarily made such decisions. Within the overarching temporal framework a number of forms of ‘sharing’ and ‘not sharing’ were described as significant by participants, although they were not exclusive to any specific stage of the temporal model. These are elaborated upon below and primarily comprised:

**Sharing of**

Noticed changes/Concerns

The diagnosis

Activities, Plans, Goals & Aspirations

Roles and relationships

**Not Sharing of**

Noticed changes/Concerns

The diagnosis

Activities, Plans, Goals & Aspirations

Roles and relationships

‘Sharing’ activities were therefore key to shaping the ways in which YPWD and those close to them acted together (or separately) to ‘maintain’, ‘modify’ or ‘abandon’ aspects of their lives during each temporal stage of the journey of dementia, from ‘noticing’ something through to ‘getting on with it’. This way that sharing was enacted enables a better understanding of the highly individual accounts of the participants, shedding light on the complex and shifting processes, relationships and forms of engagement that participants described during the process of data collection. Teasing out and describing the various forms that this ‘sharing’ or ‘not sharing’ took, provides a way to better understand how, as the symptoms of dementia progressed over time, many varied and important aspects of the participants’ self-concepts, relationships and social experiences also changed. By making these complex individual experiences of dementia more transparent and recognising how such processes shift, interact and alter over time, it may be possible to assist people to more fully recognise, understand and adjust to what they are personally experiencing. Increased understanding of the shifting dynamics of ‘sharing’ or ‘not sharing’ and how these relate to ‘maintaining ‘modifying’ and ‘abandoning’ aspects of the lives of the YPWD and those close to them, may also potentially inform the provision of health and social care interventions that more appropriately target the YPWD’s and their carer’s needs at particular times as they live with dementia. This aspect is considered more fully in the next chapter. Here the varying forms of sharing are considered in more detail.

**6.8 How ‘sharing’ was experienced.**

The following section describes in detail the ways in which the social process of sharing (or not sharing) occurred for participants throughout their journey across the temporal stages from initially ‘noticing something’ and early changes of dementia before diagnosis, through to the ‘receiving and sharing a diagnosis’ period and later life in the on-going ‘where do we go from here? Getting on with it’, period after diagnosis. The relevance and impact of ‘sharing’ and ‘not sharing’ activities and the relationship between this and processes of ‘maintaining’, ‘modifying’ or ‘abandoning’ are presented and discussed. Examples and quotations from the participant’s data are utilised to reveal how the ‘sharing’ model enables a greater understanding of the ways in which participants lived with and experienced the presence of dementia at a younger age in their lives. Although each younger person with dementia (and those close to them), experienced their own unique journey and pathway the four discrete but overlapping stages as previously summarised, were identified as present for all participants in some form. How sharing manifested itself during these periods is now considered.

**‘Sharing’ & noticing something unusual**

As described earlier in this chapter, for the majority of participants there was a period of ‘noticing’ apparent from the data, where either the YPWD themselves had noticed some change, or this had been noticed by others around them. Typically at this stage, these initial noticed changes were not actively shared with others by the person subsequently diagnosed with dementia, as discussed in the following examples. Nor, in most cases was it necessary to modify activity. However in some cases as partners or others ‘suspected’ that something might be wrong they might ‘monitor’ the behaviour of others more closely.

Not sharing noticed changes

Dominic described the period when he first noticed that he was experiencing difficulties, but this was not something which at this stage that he focused on or considered sharing with either his partner or his work colleagues as it was not considered important.

“*Probably going back even a couple of years, I just noticed because I’ve always had a really good memory, a couple of things ….that I was surprised, I worked as a nurse and so there were certain details, things that I was forgetting and at first I didn’t really notice it an awful lot, just it was happening and I didn’t really think much of it, it was just as it went on and became more of a concern really.”*

Margaret’s husband Steve also recalled that for quite an extended period before seeking any diagnosis, he did not share any thoughts or concerns regarding any changes in Margaret with her, or with anyone else, as he attributed these to other, explainable causes:

“*Yes, there were a few little signs that I didn’t* *take a lot of notice of, but I just put it down to…she’s getting a bit older and a bit forgetful, then…we’d bought a static caravan on the coast ready for retiring, because I should have retired same year…and I used to come home on a Friday and she wasn’t in which was strange and the plastic box which she used to pack the food and clothes in wasn’t there.”*

Some changes were more dramatic but still not shared. For example Allen, who had been working as a deputy head teacher, recalled how traumatic the period before seeking a diagnosis had been when he was noticing the changes in himself, but rather than sharing this with his wife friends or colleagues, he kept these thoughts to himself at this stage, possibly through fear of what they might mean.

*“I used to drop a colleague off in a big council estate and one day something distracted me and then I thought, ’where am I?’ I had a desperate panic, I didn’t know where I was, the next day I thought it’s the same route, I’d been doing it for several years, I could not recognise where I was, but I still didn’t do anything at that point. I was getting really worried about it all and that paralysed me into doing nothing…I was terrified of what was happening.”*

Despite these difficulties Allen still tried to maintain his normal pattern of behaviour.

For others maintaining became more difficult, even if they were not fully aware of it at the time. For example, Jane recalled how she had first noticed the impact of changes on her role as a parent. She described how, with hindsight, she could see now that years before formally seeking a diagnosis, she had noticed problems when helping her youngest daughter with schoolwork, but this had not yet been shared or discussed with the wider family. Rather she made excuses whilst worrying about the changes herself:

*“I just got through skin of me teeth with that level 1 but it were with me concentration I were trying to help her with her homework and I just couldn’t do it could I? I had to go… ‘wait till your sister gets in’,…….. and it were horrible because with her learning difficulties I’d always helped and helped her and then it come to a point,…….. it were like a different language to me, nowt would sink in, I’m thinking bloody hell what they learning at school these days?”*

This example also illustrates how Jane’s eldest daughter Sharon had begun to take on additional responsibilities with her younger sister Beth (while herself still living at home as a teenager), while Jane struggled with understanding her symptoms in the period prior to seeking a formal diagnosis. In terms of Jane’s role as a parent, this was clearly being modified even at this early stage, as her eldest daughter had begun to share in the responsibility of providing some aspects of a supervisory and educational role with her younger disabled sister, adopting these activities due to Jane’s increasing difficulty in maintaining this role herself. This example demonstrates how the act of sharing (in this case of a parental role) is simultaneously characterised by Jane no longer fully ‘maintaining’ this role and how family roles are therefore ‘modified’ with her daughter Sharon taking on elements of a parental role. Even at this pre-diagnostic stage therefore it can be seen that the processes of maintaining and modifying are not linear and sequential, and how in just one family group, different characteristics of these processes can begin to occur even prior to any formal diagnosis.

For others a form of monitoring came into play. David’s wife Rebecca recalled a key incident around this time which prompted her to begin to look more closely at her husband’s behaviour :

*“And he also forgot his pin number for the bank and that’s when I started noticing”.*

At this stage Rebecca was beginning to look for any changes in David, but these concerns were not shared with David and therefore neither David nor Rebecca were actively and openly seeking answers to the changes in him, although they were both noticing something was different. David at this stage was focused on maintaining life as normal, but Rebecca had begun to modify aspects of her behaviour, taking on a watchful and observational role, noticing something was wrong and trying to quietly gather information to understand what was happening, without this being shared with the wider family.

Whilst these patterns of, and reasons for, not sharing varied it seems that the initial ability to ‘discount’ the changes was apparent in a number of cases and that as this became more difficult a reluctance to share, for some, was attributable to fear as to what the changes might mean. As indicated earlier a failure to share concerns could lead to changes in relationships or as in Jane’s case above an early and subtle change in roles within the family.

Sharing noticed changes

Some YPWD recalled that others around them had shared noticed changes with them before they themselves formally began to seek an explanation or diagnosis for what was happening.

David had undergone an extended period of years where he was experiencing symptoms but had not yet been diagnosed with dementia. He recalled how his difficulties at work in a senior public sector job became increasingly noticeable to colleagues, who did share their concerns with him.

*“ And uh….you know people were you know starting to tell me that I was becoming extremely stressed and uhm”*

Of the participants interviewed, Andy and Deb were the only couple who said that they had both noticed and shared with each other their awareness of problems for years before seeking a diagnosis. However, despite the sharing of these concerns, they did not seek help until the symptoms were quite significant. It appeared they had made a conscious choice as a couple to maintain their sense of normality, through shared management of Andy’s difficulties, until his problems had progressed to a level where they both agreed they needed external support and advice.

*“It weren’t so much your memory, it were writing your signature the wrong way round and getting your clothes on back to front, didn’t have any idea did you….[addressing Andy] what it was? We knew something weren’t right but it didn’t connect….”*

This demonstrates a shared approach and understanding between Andy and Deb in striving to maintain life as usual for as long as possible. However it also indicates that delays in seeking help were not only due to a failure to share information or the vagaries of the system.

For the majority of participants the point of shared recognition with others that problems had been ‘noticed’, was a catalyst for formally seeking a diagnosis or assessment. For a number of the participants initial changes had been noticed, either by the YPWD or those close to them, but either the YPWD attempted to ignore and manage any difficulties at this stage, or in some cases their family members adapted to or ignored (consciously or sub-consciously) signs that something significant had altered. It was only once the difficulties were too obvious to ignore, or impacted significantly on the person’s employment or family responsibilities, that these became a subject of shared discussion, outside the immediate family or couple. This usually led to contact with the GP, in order to have these issues professionally assessed. The beginning of the journey towards diagnosis had begun.

**‘Sharing’ & What’s happening? Seeking a diagnosis**

The ‘what’s happening?’ and ‘Seeking a diagnosis’ period was the time where symptoms had been recognised as of significant concern and professional assessment was now sought. As noted earlier this period was often lengthy and complicated for many of the YPWD and those close to them. In many cases initial mis-diagnosis and attribution of the symptoms to causes other than dementia, led to significant delays in achieving an accurate diagnosis. This in turn could impact on factors such as the person’s employment and the nature of their relationships with family and friends.

‘Sharing’ (or the specific absence of sharing) also occurred as a key process for YPWD and those close to them during the ‘what’s happening’ period. For some, shared discussion and recognition of the symptoms experienced by the YPWD with their partner or wider family, often marked the beginning of actively seeking a diagnosis or explanation. During this period there was for some YPWD significant support from their partners in dealing with the challenges of the diagnostic process and issues such as modifying roles at work or in the family. For others this period was characterised more by the loss of previously shared goals and aspirations for the future. The ways in which sharing occurred as a significant process during the pre-diagnostic period will now be explored with examples from the data.

No shared discussion.

For Jane the period from onset of the symptoms of dementia to establishment of the diagnosis, was recalled as a very traumatic time, from her own perspective and also those of her eldest daughter and husband. The attribution of the changes in her behaviour to causes other than dementia had clearly begun to have a negative impact on relationships in the family:

*“…that’s how they were making me feel, like an hypochondriac saying it were depression…and then they were putting it down to me lifestyle because daughter has …problems and then I had me dad living with me cause he’d got this Lewy Body thing….at one bit it sounded like I were drunk all the time and not had a drink…that’s it slurred, when I went to Dr’s he said, ‘you could have had a mini stroke’ but I were fit as a fiddle, so I thought he were wrong”.*

Jane described having had to fight to get a diagnosis made;

*“I were about 37 then….they signed me off from Neurologist, she put it down to stress, I went kicking and screaming, I weren’t happy, but I thought they’re professional people give em benefit of doubt and it got more worse progressing, I couldn’t do me daily tasks I were leaving cooker on, putting salad in frying pan …things in freezer…..should have been in cupboards and everything back to front weren’t it?”*

Jane recalled that the family were also suspicious of the cause of her problems at that time, such as thinking that she may be hiding an alcohol problem. This was not openly discussed between Jane and her family and it appeared that this may have had some longer term impact on the nature of their relationship with her, as this in some ways damaged the trust she had in her husband and eldest daughter. This suspicion was threatening Jane’s ability to maintain her previous close supportive relationship with her husband Mick and eldest daughter Sharon, as they modified their previous open trusting relationship with her and began to share the role of monitoring Jane’s behaviour

*“He [husband] used to ring me up in afternoon, ‘you’d better not be drinking’ and I adn’t touched it, so that made me more frustrated.”*

*“I were getting a bit paranoid wi’ it and it were more aimed at him [husband] than anyone else and they sent me to see a cognitive behavioural? Cause they still put it down to depression, but I were adamant. I went I did everything jumped through hoops, upside down …but it weren’t till I went back to Drs and I explained and said I’ve got to be a full quid, I’ve got to be on the ball cause I’m looking after [daughter] I said listen cause I were main carer, I said if I go down they’re all going to go down , you’d got baby and everything [indicating elder daughter] and I were like me hands were in every pot, I were helping everybody, but I like that… I did a lot of busy things and I knew I weren’t coping, so I said you’ve got to sort it out cause I weren’t managing.”*

It was evident that during this ‘what’s happening?’ period a split had occurred between Jane and her close-knit family, where she was actively seeking to maintain her independent functioning and to push for a diagnosis, while her eldest daughter Sharon and husband Mick had doubts and suspicions and were separately seeking answers and explanations, without this being a shared open process discussed between all of them. Jane described having been very persistent with her GP and the hospital specialists insisting that her symptoms were recognised and further tests completed until she finally obtained a diagnosis. Jane’s description of this period is very much that this was her fight alone at this stage, where she would not accept that a cause for her symptoms could not be identified.

Phillip’s wife Jean had noticed that he was increasingly struggling with work commitments but she did not share these concerns with him until she realised he was deteriorating badly and that he could not carry on without seeking help and an explanation,

*“He finished work at 59, he was moved first to a base further away and he used to be going at 6.30 am to get a parking space and getting agitated about it, I could see him getting more and more uptight about it and finally I said, I think you ought to go to the Dr’s and the Dr put him off sick and gave him antidepressants.”*

There was therefore an initial period where Jean had adopted a monitoring role regarding what was happening, while Phillip was striving to maintain his usual roles and routines and they were actively ‘not sharing’ these concerns with each other at this stage.

Actively sharing concerns.

Allen recalled the point at which he realised he had to share his concerns with someone else and seek professional advice and help. It was clear to him that his increasingly desperate efforts to maintain a veneer of normality were starting to fail.

*“I was terrified of what was happening, so I was just stumbling along really….I mean the car and my keys were always covered in sticky notes on my forehead almost..it was bad…and then I got home and that is when I thought I can’t go on, I made an appointment to see the Dr…from around then things started to slip”*

At this point Allen openly discussed his concerns with his wife Hazel for the first time. This enabled Hazel to support him, but this also marked the start of a long phase of increased stress and uncertainty, due to the extended period that was to follow before an accurate diagnosis was obtained. This ‘sharing’ did however enable them to maintain a close supportive relationship in facing these difficulties together as a couple.

During the ‘what’s happening?’ period David and Rebecca began to share their awareness of his problems and this enabled Rebecca to provide him with some support in making shared decisions. Critical issues around work, income and retirement were all being addressed at this pre-diagnostic stage and sharing in this awareness was a key source of support for David at a highly traumatic time. After an extended period of absence from work (when David had been receiving no pay for many months), he was offered the opportunity to re-train and return to work in more menial jobs. An example of his work being willing to modify his role in response to his current abilities. However as Rebecca recalled they knew they had to resist this offer, as it was clear to both of them that he would not cope even with reduced responsibility. At that stage David still did not have a diagnosis of dementia, but despite this he and Rebecca had a significant shared understanding of his difficulties and knew he would be unable to retain the new information that would be required to adjust to any new role.

*“And they didn’t understand. I understood by then that processing information, retaining it, sequencing [David] was finding challenging and therefore we had to stand our ground and that was it…the first couple of years I would say were quite stressful”*

Rebecca described a particular critical incident which cemented her recognition that a change had to be made and David had to leave his employment, despite the absence at that stage of a clear diagnosis.

*“ he was sitting one day in the car park…he had lots of files in the car and he was sobbing….he didn’t know what to do with the files and then I realised well he has to stop work, so he stopped work straight away”.*

Rebecca was suspicious at this stage that David’s problems were clearly more than depression or work related stress. She was sure that there was some physical neurological cause for his problems. David’s recollection of that time is of being overwhelmed with his difficulties and related stress and anxiety, rather than any specific concerns about the possibility of dementia. Therefore whilst David became overwhelmed by what he was experiencing Rebecca adopted a pro-active role, making decisions for David regarding his employment. A modification of roles had taken place and although sharing had occurred the modifications that followed provide an example of tacit agreement. Even before diagnosis therefore Rebecca had already taken on the role of making some significant decisions on behalf of David, as he was struggling to maintain his previous level of autonomous independent decision making, having to modify this due to his symptoms and related stress and anxiety.

The ‘what’s happening?’ period had significantly challenged David’s sense of being able to effectively meet targets at work and also to maintain his role in generating household income. This marked a clear change for David and from this time on he was unable to take on his previous share of responsibilities in the home and in family life. There was therefore, even at this early stage, a clear shift in his ability to maintain ‘goals’, and fulfill ‘roles and responsibilities’, both at work and in his personal life.

This time was recalled by both David and Rebecca as being especially difficult, as there was a lack of clarity as to whether he was depressed, overly stressed at work, or there was some other problem. The impact on his sense of self identity, particularly from relinquishing his work role was returned to a number of times by David in his initial interview, as he identified this as a painful loss and one that was still painful to him now a number of years later:

*“But you know it was the age old human thing weren’t it, that you know you’re doing your part and I felt that….well I always felt that…I think we all think that we’re always going to be able to work don’t we?”*

*“ In some ways at my end it was feeling of letting people down. Not in a mega way, but this is my job, I should be doing it”.*

This inability to maintain work roles and for David to do his share of responsibilities had clearly been very negative for David and continued to frame aspects of how he regarded himself and of his sense of self-worth over an extended period of time.

Margaret’s husband Steve, had not recognised or been aware of the gradual onset of her dementia and described an unusually sudden transition from Margaret appearing to be fully independent (while he was out working long hours), to a sudden and dramatic realisation that she was now highly dependent on him for care and support. After many years of working towards their retirement plans, his recollection was of how these were suddenly and catastrophically abandoned with the realisation of the severity of her problems and the impact of these on Margaret’s ability to manage independently when alone for any period of time. There was no sense that any conscious attempt had been made to modify any aspects of their work, home or relationship roles, with Steve describing a sudden realisation and subsequent abandoning of aspects of their previous life and future hopes.

From Steve’s description, it appeared that he was previously focused solely on the goal of retirement and after working long days, often six days a week in a physically demanding job, was somehow unaware (or potentially in denial) regarding the onset of Margaret’s dementia. Having eventually realised there was a significant problem, he only then recognised the changes that had been occurring over previous months, such as her hoarding particular foods or products in the house and not cooking or cleaning the home as regularly as usual. With this sudden realisation, he became aware that there had been significant problems over many months that he had not recognised.

This was not typical of other participants’ accounts and shows that for Margaret there was an unusually rapid progression from apparently managing alone for long periods each day, to requiring constant support from her husband Steve. This occurred without any period of shared discussion and understanding, or of any process of adjustment in either their relationship or share of responsibilities in the home.

*“The trouble is I used to go to work at 6.00 am and not get home till 7.00 pm, so then I were in and out, didn’t spend a lot of time with her really, only at caravan, we didn’t go to the caravan at all that weekend….she wouldn’t go to doctors, she were going mad about going to doctors, I knew doctor well and explained and he said, ‘don’t worry, I’ll just call in this afternoon on the off chance’, and he came and she were alright and then he got [the specialist] involved and he diagnosed her…I was supposed to be retiring in the August, but the doctor gave me a sick note from the April because I couldn’t leave her on her own.”*

For Margaret and Steve there was therefore no period of ‘noticing’ any significant change, but rather a sudden transition so that aspects of her dementia were already quite advanced by the time she received a diagnosis. There was no discussion between Margaret and her husband about these issues after diagnosis either. Steve described having been so pre-occupied with work, that he did not recognise her progressive deterioration until it was unavoidable. This was not typical of other participant’s accounts and neither was Steve’s description of suddenly fully adopting the role of carer for Margaret.

Margaret did not engage for any sustained period in the research interviews and so this account necessarily only reflects Steve’s recall of this period. Margaret was therefore not able to provide her own perception of her thoughts and feelings prior to receiving a diagnosis of dementia, such as whether she had consciously chosen not to share any noticed changes with Steve.

**Receiving and sharing a diagnosis.**

The point at which a formal diagnosis of dementia was shared with the YPWD and those close to them, marked a significant point of transition for the majority of participants. The ways in which the diagnosis was, (or was specifically not) shared with family, friends and employers or co-workers, remained as a key focus of both the YPWD and those close to them across the repeat interviews. Where this diagnostic sharing was recalled as traumatic or problematic, this often appeared to colour the YPWD’s on-going self-perception, sometimes years later. Conversely where the diagnosis was shared with positive results and adaptation, this represented a constructive turning point from which to move forward. The following accounts describe the different ways in which diagnosis sharing had been experienced and the impact of this on the actions, attitudes and self-perceptions of the participants.

Positive impact of diagnosis sharing.

After a lengthy period of time and the application of significant pressure on her GP to pursue the cause of her worsening symptoms, Jane was referred for further specialist brain scans and received a diagnosis of Lewy body dementia. She recalls that once the diagnosis had been made support was put into place very quickly and there was a significant transition in her family’s understanding of what she was experiencing and why. As with other participants in the study, the experience of being a younger person with dementia (in Jane’s case in her 30’s) appeared to lead to potential initial misdiagnosis and attribution of symptoms to stress, depression, or in Jane’s case suspected alcohol consumption.

It is clear from Jane and her family’s description, that it was only after diagnosis that more positive transitions could be made and that the family could apply their previous caring experiences (for a disabled child and also an older grandparent with dementia), both to make sense of Jane’s symptoms and to respond to them. This mirrors aspects of data from other participant family carers in the research, where information and advice from professional sources or support groups, did not always appear as powerful as shared personal or family history and experience of either caring and/or dementia, in making sense of what was happening and also in predicting future care requirements. This sharing of family history and personal experience between the members of Jane’s family was in this way identified as a powerful mechanism for all of them to make some sense of what was happening, and to maintain their ways of being together. This only occurred once a clear diagnosis had been made

Although Jane had been clear that something was wrong and that she needed to access a diagnosis, her family did not suspect that it could be dementia (which they associated with old age). The progression of Lewy Body dementia can often have a fluctuating course, with episodes of significant confusion followed by periods of significant lucidity. It was only after a clear diagnosis had been made therefore, that Jane and her family could fully make sense of the nature of her symptoms and her behaviour that resulted from this and know what it was they were dealing with.

It was clear that in the previous extended ‘what’s happening?’ phase, Jane and her family could not effectively share their thoughts, feelings and plans for managing the impact of her dementia. There was instead a growing atmosphere of suspicion and mistrust, with her family ‘monitoring’ her and suspecting that she might be secretly drinking large amounts of alcohol, or be in some way personally ‘to blame’ for her problems. The absence of a diagnosis was in fact a force of separation and had clearly begun to isolate Jane from some discussions taking place in secret between her husband and eldest daughter. Rather than sharing their feelings with Jane, her family were at that time becoming confused and suspicious in relation to her symptoms and their cause, until a diagnosis was established.

David’s wife Rebecca also recalled how important finally receiving a diagnosis had been.

*“That was a Damascus moment for me…..at least you knew what you were battling and he could start appropriate treatments and the one sentence he gave me (the psychiatrist) which we clung onto and keep saying…you must focus on everything you* ***can do*** *(her emphasis)”.*

This illustrates how the diagnostic conversation often remains a powerful memory and context for YPWD and their partners, even years after this event.

Following the receipt of a formal diagnosis the decision to ‘share’ the diagnosis and with whom was also a very important point of transition, and influenced how maintaining, modifying or abandoning unfolded.

For some of the YPWD a deliberate and systematic approach was taken to sharing the diagnosis with friends and acquaintances, so people would understand any changes that they had observed in the YPWD. For example Phillip had been training as a Deacon in his spare time at his church, but began to find this challenging due to his memory problems. So he arranged for the congregation to be informed of his diagnosis by the priest one Sunday while he remained at home.

*“I did stop it at the church and I wasn’t capable of doing the things I should have been, I don’t think the priest understood it, or still does”,[partner now speaks], “ but what we got him to do, the service that he usually attends, we won’t come and if you’ll say it to everybody, so everybody knows, it must be over a year or more, I think everyone sort of gasped, they did say he put it nicely, I mean some people still think he’s alright, but I wanted em to know because they’d been saying, ‘he’s not on alter any more’ and then if he’s a bit out of character they can make allowances” [Philip speaks], “I just think it’s better if people do know, that’s maybe just my personality.”*

He had clearly taken the decision to abandon this part of his life and to modify his relationship with the church. This formal sharing of the diagnosis appeared to serve a number of functions for Philip. It helped to remove inaccurate rumours or speculation amongst his congregation as to why he might appear different in some way and why he was no longer so active in administrative duties at the church. It enabled a large number of people to be informed simultaneously by a third party (the priest), without the potential for emotional distress and discomfort for Phillip if he had to disclose and explain this information on multiple occasions himself. This diagnosis sharing with the congregation can also be seen as one aspect of how Philip was moving from being a fully active member of his church, to a modified relationship, where he maintained involvement, but in a less active form. In this way sharing was positive, with the congregation providing support and understanding as his dementia progressed. Phillip’s wife attended a different denominational church in a different area and as such was not regularly involved in any aspects of his interaction and relationships with his own congregation and faith leaders. This formal sharing of the diagnosis supported Phillip in managing the process of how he abandoned certain of his responsibilities and role in his church congregation, whilst still maintaining some involvement, albeit in a modified form.

Dominic stated that he had been strongly encouraged by his partner to share the diagnosis with others. Dominic had interpreted this as a coping mechanism by his partner and one that he could understand and accept.

*“My partner felt people should know and pushed it that way, so I thought Ok, that’s how he’s coping, I think he is more worried than he lets on, because we rely on each other quite a bit, I do quite a bit for him, but now he has to take on things I did, he has to look out much more for me, because I used to sort the household bills etc.”*

This shows how Dominic was sensitive to the impact of the diagnosis on his partner and this approach set the tone for their clear shared positive adaption to the impact of dementia on their lives over time and across the time frame of the interviews.

One couple (Frank and his wife), were interviewed jointly by phone while staying at their mobile holiday home at the coast. This couple recalled that they were very upset initially when Frank had received the diagnosis, but that since commencing on anti-dementia tablets, he had not experienced any significant deterioration over the past three years. As things had been so stable, Frank thought very little about his diagnosis and focused on day-to-day life.

*“once went to a seminar with my wife about dementia…think about it when I see something on the TV and again sometimes at night….so live for today, have been out playing golf this morning.”*

Despite this lack of progression in his symptoms Frank did say that there was still some uncertainty about the future.

*“But can both get a bit down….fear of the unknown….don’t think about it a lot…laugh it off an’ are very open with people about it…have children and grandchildren, son in London…am very open with them and can talk to them about it and my wife.”*

Frank had been sixty-four years old when diagnosed and was already enjoying his retirement at that point, having retired two years earlier, so he did not feel that his diagnosis or experience of dementia had led to any particular significant financial impact or change of lifestyle to date for either him or his partner. They were able to maintain their current life style. Frank was clear that sharing the diagnosis with the family was beneficial and that the disease had, at least for him and his wife, been very much in the background. Frank and his wife were able to assimilate any problems with forgetfulness experienced by Frank into their daily lives and routines, without any reported compromise or re-adjustment to their retirement plans or expected future together. Sharing this approach in a natural way, Frank’s wife felt that he was still the husband he had always been and there was no sense of her adopting any conscious role as a carer for Frank, or that he perceived any difficulty in maintaining expected roles, relationships and activities. Here was a prime example of how one couple had been able to maintain key aspects of their lives due to the sharing strategies that they adopted.

Dave had received a diagnosis within a short time of first reporting his symptoms of memory loss and his partner felt that being open with other people about the diagnosis was very positive and helpful.

*“We’ve been open with both [friends and family], it’s initially a shock….whoah….they wonder how to approach you, but then…well it’s still him, it’s still the same person and that’s what you need…not to treat you any differently and just accept….if he’s had a bad day, you get on with it and have another day…people have been very understanding.”*

For this couple, sharing the diagnosis and engaging friends and family in support was seen as crucial, reinforcing the importance of early diagnosis and sharing this.

*“Support is a big one…family and friends…from experience he [YPWD] was initially funny about letting people know, but because they’ve been so wonderful, why is there the big stigma? If you’re up front and then he’s snappy, having a bad day, they accept it. His patience runs out quicker than it used to, he does it once and it gets chucked if he can’t do it first time, patience isn’t there and if you understand you think, ‘fine, he’s not being nasty’. All the others [family and friends] have said is, ‘we can help, we’re not going to treat him any differently’, I’d encourage people to be up front, I’m sure early diagnosis is positive.”*

Negative experiences of diagnosis sharing.

While for many participants sharing the diagnosis with their partner or close family and friends was positive, this was not the case for everyone. Sharing the diagnosis of dementia with a partner had, for one participant, had a very negative, indeed devastating, impact on his relationship. Martin described how the diagnosis had led to a dramatic response from his wife, which he had not anticipated, as she made it very clear that their relationship was over.

*“We had no arguments during the marriage, so I were shocked when she walked out, I hadn’t done anything wrong, she ‘got on wrong bus’ she said when she found out [the diagnosis], and said ‘I’m not in here for this’, she’ll come here odd times, but not to see me, to get old photos and stuff like that”.*

Martin had not realised there was any significant marital difficulty prior to obtaining the diagnosis and interpreted his wife’s response as a purely selfish one, where she was avoiding her own fear of dementia and the potential that she would become a carer for her husband. Martin’s wife did not agree to be interviewed, so it was not possible to explore this issue further from her perspective.

Allen described the shock and impact of receiving a formal diagnosis once he had been eventually referred to a specialist service and informed that he had a vascular dementia.

*I sat down and prepared for the worst…this is the end…sat for a long time…many days…then in the end decided I needed to get on with things.”*

Whilst his contact with the specialist service was positive, he recalled that even after receiving a diagnosis, the relationship with his head teacher at work remained difficult and that the process of obtaining early retirement had been very complex and traumatic. Although this interview took place four years from his diagnosis, the issue clearly remained very painful for Allen, as described in the following memo made at the time of the interview:

**Researcher Memo**: [Four years now from diagnosis – very real pain and distress describing finishing work – trying not to let it overshadow previous work achievements – wife was supported by her work colleagues at another school better then the YPWD by his own colleagues – wants to tell the full story from the beginning, with the correct chronology of dates and events – partner very calm only adding information when prompted directly by YPWD]

Allen described how despite having earlier acted up for the head teacher while she had been off work for two years, he did not feel at all supported by her, following his own diagnosis. This accentuated his feelings of isolation and prevented him from having an opportunity to share what was happening with people at the school. He was therefore essentially forced to abandon a cherished role without being able to provide an explanation as to why. Here is a clear example of how the actions of others, beyond the control of the YPWD, can have a devastating impact.

*“She could never understand depression and a wall went up, you don’t get….we found out…you can’t retire from teaching…you are just ill, people keep saying, ‘you need to forget about it’, I can forget what I did yesterday…I can’t forget that….sometimes you need to be cross about things to cope, otherwise I’d be upset. I wasn’t allowed to go back to the school while anyone was there, or say goodbye to the children….she knew things were a mess but didn’t do anything. I think she was more worried about her own situation, people asking, ‘why didn’t you notice etc’. I was told if I wanted to collect my things, the caretaker would let me in while the school was closed (our caretaker a nice chap was off, so another chap came). I’d worked there almost 20 years.”*

Allen’s wife gave an example of the extent to which her husband was suddenly removed from his workplace when she was asked by one of the parents at Allen’s school:

“*How is your husband, he just disappeared, we don’t know anything about him”.*

This exacerbated his feelings of being abandoned, as he had no opportunity to engage with anyone at the school in any positive planned process of retirement or have the opportunity to say goodbye.

One couple who had family in England and Pakistan, (Aisha and Hussein), were cousins and so shared some relatives. Cultural and attitudinal differences meant that they had not been able to share the diagnosis with relatives in Pakistan, although Aisha’s sisters would ask ‘what is wrong with her?’ and ‘why won’t she speak on the phone?’, when ringing from Pakistan. Hussein described how the stigma attached to mental health problems and a lack of understanding from relatives in Pakistan, not only prevented him from sharing the diagnosis, but also led to a degree of isolation and heightened stress by keeping secrets from family members. His perception was that the awareness and understanding of problems like Alzheimer’s was poor in Pakistan compared to England.

*“…because they just wouldn’t be able to understand it. What they would actually describe her in terms is, ‘she’s lost her mind’, but here (in England) you talk about Alzheimer’s and straight away most people know.”*

The change in gender roles with the husband taking on domestic tasks and struggling to manage the home and his employment, was also seen as stressful by Hussein, now that his wife could no longer actively share in maintaining the home. The reasons for this were also poorly understood by some members of the wider family in England. Hussein did not openly discuss or share any of these concerns with his wife, who he felt by that stage did not recognise the ways in which her dementia was impacting on her level of independent functioning in the home.

He described being at a family gathering where he was asked why he ‘put up with her’ and said he was disgusted at this lack of understanding and said that at any family events he would confront anyone expressing these ‘bad’ attitudes.

*“ A cousin of mine started talking and he was so ignorant, so I had to be harsh with him. He goes, ‘and what do you think about it?’ I said what the hell are you talking about, what do I think about it, she is my wife, It could be me tomorrow, it could be you. When it hit home he kind of zipped up and changed the subject but he really kind of bothered me a little bit.”*

There were other ways in which participants described having difficulty in openly sharing either the diagnosis of dementia, or the nature of the experienced symptoms with the wider family. In some cases it was the YPWD themselves who experienced difficulty in openly sharing this information with certain others. For others it was reluctance on the part of family members. For example Allen could not share his actual diagnosis or discuss this with his brother, who refused to discuss the issue.

*“The word dementia is not mentioned….my brother will not say the word, he’ll relate it to Terry Pratchett and talk about that”*

Allen was clearly frustrated at his brother’s apparent reluctance to directly confront the diagnosis and use the diagnostic terminology. Although his brother was happy to provide practical support, he did not engage with Allen in discussing any impact of the diagnosis on Allen’s emotions, fears, or hopes for his future.

Sharing of the diagnosis with the wider family was identified as initially problematic for some YPWD by the specialist nurse.

*“He (Dave) had a hard time coming to terms with the diagnosis and was also very reluctant to even tell his close family about the diagnosis for quite some time, but then he found when he did start to talk about it, life became easier within his social circle as well and they were very supportive. He has a son who I think was eighteen at the time and he was very very wary of telling him and how that would affect their relationship and he does know now and is fine.”*

The specialist nurse described how her role at the point of diagnosis and immediately afterwards often focused on supporting the YPWD to make choices about when and with whom they should share information. This was something that the nurse could support, emotionally, psychologically and also sometimes practically, such as ringing an employer on behalf of the YPWD, or being present when they told family members. In this way the nurse could assist the YPWD to make necessary modifications, sharing as much as they wanted to at any particular time and in the context of any particular relationship, be it social or work related.

Dave had been diagnosed with Alzheimer’s disease while still in full employment and this, in addition to Dave’s retained ability to complete DIY around the home, was seen as significant in maintaining his sense of worth and self-identity in the presence of dementia. Dave would still however have preferred it, if obtaining a diagnosis could have been delayed and normality maintained for longer. Conversely, his partner felt that obtaining the diagnosis early had been critical in enabling access to anti-dementia treatment and flexibility in adapting his work role. His employer had been in contact with the specialist nurse for advice and had made changes to Dave’s pattern of work, such as ensuring he was with a colleague who could drive for him, if he needed to travel long distances on work related activities. This is an example of how sharing of information on diagnosis and symptoms with an employer, enabled positive modifications to be made to the YPWD’s work role. However, not all employers were so accommodating.

Sharing the diagnosis with employers.

The specialist nurse described how sharing the diagnosis with employers resulted in a very mixed experience for many of the YPWD.

*“It’s been very varied to be honest with you, we’ve had both ends of the spectrum. We’ve had (Dave’s) employers who have literally bent over backwards to enable him to continue working as long as possible. They initially introduced a buddy system for him at work so he could carry on doing his job, working in partnership with another chap. They then arranged for him to have a driver because he wasn’t able to actually do his own driving around his area, so he had a driver who took him round and he did the job. Unfortunately just recently the company have been taken over and things have changed somewhat…they have interviewed him and kept him on with this new company, however he’s had to sort of step down several rungs in the ladder if you like. He was an inspector, a motorway inspector in the past and he’s working as what he terms a ‘yard boy’ at the moment, so it’s been a big comedown for him, although he’s still employed and he’s going to review that (soon), to see if it’s viable for him to continue with that role”*

The nurse had worked effectively and constructively with some employers, while others appeared to ‘cut people off’.

*“…we have had the other end of the scale where employers have not wanted to talk or work with us as soon as that person has got the diagnosis they’ve said well that’s it you’re finished, go away we don’t want to discuss it”.*

*“I recently had a chap who’s been a nurse in a general hospital and they were pretty much saying, ‘well I’m sorry but there’s no room for error here, we’ve got to….look we’re sorry but that’s how it is.”*

Some employers were viewed as uncaring and this mirrored the accounts from some YPWD in describing the longer-term emotional impact on themselves of how their employer, and sometimes specific management staff, had treated them after sharing the diagnosis.

*“…he used to work on the railways and his bosses deemed that it was unsafe for him to continue and although he only had quite a short time to go before he would have officially retired anyway they just kind of cut him off and said that’s it away you go we don’t wish to know you anymore and he feels very bitter about that situation.”*

From the examples presented above it can be seen that the ways in which sharing of the diagnosis occurred often shaped how the YPWD and those close to them could make positive modifications or not to their ability to maintain or modify aspects of their lives. Even when there had been a lengthy pre-diagnostic period of years, the formal period of ‘getting a diagnosis’, often marked a turning point, where positive changes of ‘maintaining’ or ‘modifying’ were made for some, whilst for others relationships, roles, responsibilities and activities began to be abandoned. It is clear that for many of the participants the period around formal diagnosis was significant in how they managed their dementia from that point forward. While there were examples of employers, family and friends reacting constructively to sharing of a diagnosis, for others this led to instability in relationships and secrecy, fear or embarrassment in the wider family. It was clear that the ways in which this period was managed by; healthcare professionals, family, friends and work colleagues often shaped the YPWD’s social roles and sense of personal biography and identity from that point forward.

As well as formal paid employment, other forms of ‘work’ such as caring for or supporting an elderly relative, were also affected following diagnosis for some YPWD. David’s wife identified that neither she nor David had shared the diagnosis with David’s elderly mother and David’s family had taken over caring roles he had previously undertaken with his mum. David’s wife described how his mum appeared aware that something had changed for David, but this had not been openly discussed, due to the family’s belief that she would have difficulty understanding or accepting this. There would appear to be an age effect here, where the unnatural situation of someone having an (adult) child with dementia reverses the expected chronology of life events, where the ‘elderly’ are expected to be recipients of care, not their adult children.

*“We haven’t mentioned Alzheimer’s, but she’s picking up on some of the things I think simply because David can’t do them and it isn’t so much of an issue because David’s mum will walk round with him in her garden and as they do things they are doing them together, we have David’s sister has said she would bring her [quoting David’s mum] and she [David’s sister] just says ’it’s too dangerous for him now’, and so I just take over [my son] for the hedges, so little bits that David used to do, we’re doing now”.*

**‘Sharing’ & Where do we go from here? Getting on with it.**

This period was often shaped by the extent to which the YPWD’s symptoms progressed (or not) over time and the ways in which they and those close to them were able to successfully adapt to these changes through modifying their relationships, roles and activities. Sharing continued to be the key social process in how YPWD and those close to them continued their lives after diagnosis. There were examples of couples continuing to share close intimate relationships, whilst modifications or changes were made to their lifestyle and responsibilities. For other YPWD, progression in their symptoms led to a reduction in how they maintained ‘their share’ of responsibilities and activities in the home and family.

For a number of YPWD the presence of their dementia led to significant changes across generations of a family, impacting on their own elderly parents or in some cases on young grandchildren. In some families, adult children were identified as sharing in the caring role for the YPWD, sometimes partially abandoning their own previous individual social roles and responsibilities to achieve this. The role of sharing in these individual on-going journeys of dementia is discussed in the following examples. Sharing was identified from the data as occurring in positive ways, negative ways and sometimes in ambiguous ways, when the form of sharing undertaken had both positive and negative attributes identified by the participants.

Sharing activities

Dominic described how both he and his partner had retired earlier than planned, as his partner had developed a progressive physical disability. Dominic felt that they had both worked to maintain their relationship and shared hobbies and interests by making a range of successful modifications to their lifestyle. They had sold their house during the eighteen month period of the repeat interviews and moved to a rented local authority bungalow which had (unlike their previous home) a garden. They both enjoyed developing the garden and had modified their respective roles and activities to make this successful, despite their difficulties as Dominic describes below:

*“…but sometimes if I’m doing something for a while then I find that I get a headache with it or, concentrating on things…but now we’ve got the garden ……….needed loads and loads doing….everything was absolutely……. A few months ago. We’ve worked a lot, but we like doing that, its slow and partner can’t do much, but he’ll tell me what to do and I do it. We’ve found this quite good really its really something to get on with that we like, so we don’t get bored, feeding lots and lots of birds…. So really things have got better in that way.”*

In this example, despite the couple’s respective difficulties, they have found a successful partnership approach to explore alternative shared activities, with a positive transition described in terms of their relationship, housing, hobbies and interests.

Dave and his wife also demonstrated a shared understanding of the impact of his symptoms and the need to modify their lives, in order to maintain social contact and functioning with other people.

*“It has impacted on other things we do, we do a lot of socialising at caravan club and mostly there are socials…quizzes, gradually, more and more, he can’t cope with that, mentioned it to Psychiatrist and influx of light and sound he says, ‘too much for me, too much info’, and it’s like he’ll blow a fuse, he’ll shut down now, whereas at one time [looks towards Dave], you’d have been the last one to bed and enjoyed it.”*

Despite Dave’s difficulties, they were working together and engaging friends and family in the process of supporting normal social interaction. Rather than avoiding potentially stressful social situations or gatherings, Dave was supported by his wife to participate for only as long as he was comfortable to do so

Sharing of plans, goals and aspirations.

The presence of dementia did not necessarily mean, at least in the short term, that there were dramatic changes to peoples’ future plans. For example, in terms of planning holidays, there appeared to be a willing acceptance from Dominic and his partner that their horizons were possibly more limited, but that this wasn’t a source of significant frustration. They had in previous years both travelled and holidayed abroad together frequently and Dominic had always actively enjoyed planning this. He now recognised that this would no longer be possible, enjoyable nor desirable in the context of his dementia;

*“[Going away together]………I think that’s an important thing to try to do, we don’t go so far…not abroad again…….. used to a lot. Not that bothered now…used to enjoy organising that, whereas now that would be difficult to do, so keep it easier stick to places in this country. I think if I did [go abroad] I’d probably get lost somewhere something like that, it affected……. It does affect decisions, whereas before I always did all the organising and now that would be difficult I am sure I would get that wrong……. But I’m not bothered we’ve done all that before, so it doesn’t matter or bother us.”*

For Dominic and his partner, it appeared that their relationship had, if anything, been strengthened by the mutual difficulties and challenges they had faced and their willingness to accept, adapt and respond to the diagnosis and stopping work. Whilst this had led to some losses including; a loss of income, a need to sell their owned home and move to a smaller property, and restricted holiday choices, this was not viewed as a disaster. From a period of significant stress and uncertainty at the beginning of the interview process, it appeared that later the couple had made numerous successful modifications to their expectations. This revealed a range of very positive adaptations, with their strong relationship being at the core. This demonstrates the possibility of successful transition for a younger person with dementia, in terms of both their sense of personal identity and in their relationship with their partner, despite the overall expectation of some form of increased dependency over time, in the presence of dementia. There was a real sense of this couple’s interdependence at the time of the second interview based on clearly shared goals and achievements despite the challenges they faced.

Positive sharing of the caring role.

There were a number of examples of families and couples positively sharing in fulfilling caring roles during the post-diagnostic period. For one couple (Aisha and Hussain), the husband needed to continue working to maintain the family income, and did not feel he could have managed this, if their daughter aged 20 had not been living in the family home and able to undertake a significant share of the caring responsibilities for his wife who now had dementia.

*“Well this is it you see, that bit’s really gone down the dump now…I mean when she was right [indicating Aisha], like the house was spotless, if anybody did anything wrong, we kind of knew about it, she kept everything right.”*

*“I’m really glad they’ve taken responsibility, especially my daughter and my son has become very understanding…..she’s a godsend [indicates daughter], when I’m not here she’s the one who looks after her.”*

It appeared that the focus for the young adult daughter was now in providing care to her mother, rather than pursuing any individual goals or plans. Hussain described how he expected that his young adult son would soon leave the family home and that his daughter would now abandon any previous life plans and undertake the role of carer for her mother and in this way support him to maintain his employment. I did not interview the daughter so could not gauge her reactions to this situation, which was no doubt in part shaped by cultural expectations. Clearly however this meant major modifications on behalf of the daughter, possibly shaped by cultural factors.

Neither Dominic nor his partner identified themselves as a carer for the other, as each had differing and complimentary roles to play:

*“It’s like we both are the carer….we do things for each other cause we need to do that….he will often do this, do that and he’s looking out for me, reminds me about lots of things as well.”*

Jane, as her dementia symptoms progressed, viewed herself as having become increasingly dependent, sharing with her disabled daughter a need for ongoing monitoring, supervision and support from the wider family.

*“Because between meself and [indicates disabled daughter] we both forget to feed ourselves and daft things like that, so we would get up and just sit there….I don’t get hungry…don’t notice”.*

She described how the family had previously shared the experience of caring for her dad when he had dementia as an older man and how this would influence her own experience now of being cared for herself.

*“But me dad were 84 and he still helped, I gave him tea towels to fold up and put clothes away…I made him just mop floor…I involved him all time and he loved it, so these [indicates eldest daughter and husband] know what to do”.*

Jane therefore expected her husband and daughter to make use of her for tasks she could still usefully perform in the home as her dementia progressed, even though this might require some form of supervision. Jane was therefore quite open and explicit with her family in describing both her expectations of them as carers, but also in predicting how she would act as the ‘cared for’. This open sharing of anticipated caring needs and the caring relationship within the family was only evident to this extent in the interviews with Jane and was not a feature of interviews with other participants.

Jane’s three-year-old granddaughter was also described as participating in this supervisory family caring role with Jane in that she was described as prompting her grandmother when out shopping as a family. The granddaughter was identified as habitually prompting Jane with; *“granny say ta”, a*s Jane had difficulty in remembering to say ‘please and thank you’ during social interactions.

This family’s shared role in caring both for Jane and for her youngest disabled daughter was ambiguous and had both positive and negative impacts. On the positive side this was an example of the family working together across the generations in responding to Jane’s needs. The more negative aspect for Jane was the need to abandon her own role as carer for her disabled daughter and acknowledge her own diminishing level of independent functioning.

Abandoning activities, plans, goals and aspirations

Margaret’s husband said that initially after her diagnosis, they had attempted to maintain the activities they had previously shared and enjoyed, such as going to their caravan, but he quickly realised that Margaret could no longer tolerate this.

*“After that [the diagnosis], we started going to the caravan, because I could go any day then and I’d get there, switch all the water, gas and electric on, get the fridge going and then she’d turn round and say, ‘come on then if we’re going home’, and she’d mither me to come back home, I’d come back home and she’d want to go back [ to the caravan]”.*

After his retirement, Margaret’s husband had attempted to continue with their previously shared goals of long weekends at their coastal caravan, but Margaret was no longer able to enjoy this and this goal was abandoned.

David’s wife talked in later interviews about how he was no longer able to share responsibility for maintaining the home or completing DIY tasks. Her description indicated that David believed he was still contributing to household tasks, whereas in reality she had to provide considerable supervision so that this became a drain rather than a form of support, and the strain was clearly beginning to tell:

*“but sometimes it’s just the little things, like realising I’d have to unblock the shower yesterday! So..absolutely everything..putting up new curtain poles..changing the light bulbs..absolutely everything and David will say, ‘I can help, but then for example he’ll mop the kitchen floor but only mop parts of it and so I’ll just have to leave it…it’s just amazing you have to have strategies for doing everything yourself….yesterday if you’d come you’d have seen my daughter in law brought a lovely bunch of flowers and we’d had them a while, they’d died and I’d put them on the floor, David had taken all the flowers and planted them round the garden..that’s David’s idea of gardening, last year I’d say he would do the garden..”*

Abandoning previous roles and relationships

Jane’s eldest daughter described how she was now acting as her mum’s carer and mourned the loss of a normal relationship with her mum as a daughter, due to the demands of caring;

*“It’s …..like I packed in work to do it………….and I feel like I do more now than when I were working and it’s like I cant come up for a visit…. There’s always summat to do always….but I’m trying…………”*

Jane’s daughter clearly wished to maintain previous normal social relationship of mother and daughter, but in light of the care that she had to provide for her mother and sister this was clearly severely challenged. In this way the normal mother-daughter relationship had been lost or overshadowed due to the impact of Jane’s dementia on the whole family.

Jane herself was also clearly frustrated at the change in her own relationship with her husband, as her dementia had progressed.

*“Me temperaments changed I’m more….. snapping at him and losing me temper, but he’s driving me crazy cause he’s treating me like china whereas otherwise he’d just say, ‘shut your gob’, and he wont have an argument back.”*

*“He keeps sneaking up on an afternoon and checking up on me, before he were doing well on bike to work…. Doing well and since I’ve been diagnosed he’s left bike in house and taken his car he’s coming up at 3 o clock and making me sandwiches and things and I’m saying, ‘I don’t want you coming home, just stay at work’.”*

Jane wanted her husband to continue acting as he always had done in the past, so that she could continue to share a ‘normal’ marital relationship, rather than feeling as though he was only supervising and caring for her.

Adopting the role of ‘Carer’.

During the later interviews David’s wife described the shift in her relationship and feelings towards David and the loss of a shared understanding, as she became his ‘carer’ rather than sharing a relationship as husband and wife. This was described in a number of ways, ranging from the practical aspects of providing care, through to perceptions of identity and attractiveness. She described how a shopping trip with her husband now required her to adopt a supervisory role as a carer, rather than experiencing this as a shared activity for them as a couple.

*“…at the supermarket he picked things out of someone else’s basket…I have to watch him now…because he said, ‘ooh red onions’ and didn’t associate that they were in someone else’s basket and the gentleman just looked..and you just have to apologise and say look…….to be honest I do try to take one day at a time, because I think I’m going to spend the next two decades as a carer…I don’t get depressed, but there are days when I feel sad and I have to give myself a mental shake because I don’t want to feel sorry for myself”.*

David’s wife did not share these concerns regarding her predicted future as his carer with him, although this was clearly a source of some distress for her. She described how she would now need to meet her needs for adult company and recreation by sharing holidays with others, rather than with David (as had previously been the case throughout their adult lives together).

*“…because I need that stimulation as well and for the first time some friends have asked me to go on holiday with them at Easter, so I’m going away for a week [exclamation of stress apparent in her voice at this point]”.*

*“ it’s a very big thing, I’ve known David since I’ve been sixteen, I’ve never been away without him, we’ve done things together you know the things that we’ve enjoyed, going to the cinema or walking we’ve done together”.*

It was also apparent that David was not as able to function as a partner with his wife, as a couple with a shared history.

*“I miss the companionship, I miss the conversations, the fun, the humour and you know when you’ve been with someone a long time and you… you are in a situation, you can look at your partner and you know immediately they understand what you’re seeing. David doesn’t see that anymore”.*

*“He only lived the first twenty years, the forty we’ve been married don’t count believe me (accompanied by a pained laugh)”.*

The above captures how many different elements of their relationship had to be abandoned as his dementia progressed. She also described in a later interview how being a carer and the absence of the usual shared characteristics of a relationship between a husband and wife, had also meant that emotionally and sexually she did not perceive David in the same way. Because of this they no longer shared in an intimate physical or sexual relationship, although she believed that is something that David would still have wanted.

*“ I put David’s clothes out now….and it does affect your relationship because I* ***care*** *(word is emphasised) for David and I’ll always care for David and look after him, but I can’t respond to him physically and we don’t have a physical relationship, it is part of the whole relationship. I feel guilty because I know David would still like a physical relationship, but it’s the one thing I don’t feel as though I can relate to him because there’s nothing else in the relationship. There’s no….it’s just all those little things through the day….there’s none of that so it is a very different relationship now and I didn’t realise how that had affected me until I went for a check up and they said, ‘are you still sexually active’ and I just burst into tears”.*

In the later interviews with David’s wife she gave examples of how the progression in his dementia had led to deterioration in his self-care skills, reinforcing her increasing perception of him as ‘cared for’, rather than a marital partner sharing in an expected marital relationship.

*“for example I put him a new pair of jeans on yesterday and they need a belt and he couldn’t, he couldn’t do that…(tone of voice very sad and tearful expression)..I virtually had to dress him yesterday…but I’ve now worked out that I can’t just get him a new pair of trousers with a different belt, a fastener…he can’t do that.”*

*“I try and make light of it and I try and do it…I’m not perfect and sometimes I get frustrated you know and when I’ve tried to explain for the fourth time that the belt is threaded through the hoops I said, ‘look love I’ll show you where the hoops are’ and then David says,’ you’ve done it all wrong’ and then he’ll take the belt out and put it around him, but it’s not through the hoops, it’s just round him and he’ll say, ‘it goes like this’ and then I have to walk away and I have to leave him for a while….yes…take a deep breath.”*

David’s son lamented the fact that he could no longer share his worries or concerns with his dad and recognised that he had modified aspects of his life in order to share in supporting his mum

*“I wouldn’t talk to him about anything stressful or anything difficult because…still…his gut instinct is…..built in as a man…to try and help sort the problem out and he can’t do it, so all that does is just makes him more stressed for the next few days…it’s a completely different relationship…you talk about things you know he’ll comprehend and won’t make him think to hard”.*

“It was probably one of the reasons I moved back, because I was living in London and if you came back it has to be four days at a time, whereas now I can just nip over for tea, see them for a few hours – give her a break or…..I’ve still got a lot of friends up here and I can buy a nice house…”

No shared awareness of the caring role.

For Andy and his wife, as his dementia had progressed, there appeared to be a lack of shared understanding between them of the impact of this leading to a considerable divergence in their perception of the impact of his symptoms.

***Andy****: “I feel fine….don’t worry about anything cos that’s gonna make it worse, I’m happy me..(laughs and smiles).”*

***Partner****:”(laughs)…..yes it’s Alzheimer’s….i can see a difference from last year to this year….and previous year….a difference……most of the time he’s on his own while I’m at work, you still manage to take the dog out on the walk, where he goes there’s a lot of people who know him, so she’d [indicates dog] bring him back home if anything……….it is getting a bit more like mmmmmmmm…I mean you know….getting dressed, or even doing a bit of dusting or hoovering…can’t do anything like that cos….[tone very quiet]…..your concentrations not there is it?”*

***Andy****:” it takes….yeah out of it a times and then you get so fed up and start to get uppity…and then she tells me off [smiles].”*

***Partner****: [laughs] “I don’t……..you’re always telling me off!”*

In this interview Andy appeared to be ascribing a supervisory or parental role to his wife, rather than seeing her as an equal partner. It appeared that rather than recognising the difficulties he had now, and the extent to which she supported him , this was interpreted as somehow critical, akin to being, ‘told off’. For Andy these changes represented an alteration in his partner’s attitude to him, rather than evidence of her increasing role in acting as his carer due to the impact of his dementia.

David’s wife also felt that while she recognised the support she needed from her adult children now, she simultaneously wished to protect them from sharing too much in caring for David.

*“My daughter lives two hours away and they’re wonderful, we go over there and see them and they want us to go on holiday with them and we’re very close, but she has three young children and a part time job. I know what it’s like being 30 something, with a small family, last thing I want to do is make them worry about us.”*

She felt that it had been natural and positive for her to care for her own elderly father, but did not want her own young adult children to share in caring for David, viewing this both as unnatural due to David’s relatively young age and also impractical due to their own responsibilities with young children and developing careers.

*“Even though I’ve looked after my dad for the last decade, he was never a burden and I loved looking after him and I know my children would be the same, but I want them to enjoy these years.”*

Not sharing perceptions of change.

David’s wife described a particular significant event where he had become lost and it was clear that they did not share the same perception of what had happened or how concerning this had been.

*“….when I got back David wasn’t here, I’d only just missed him because a neighbour saw him, it was 3 o clock and it had just started to go dark and David had gone out in just a jumper, he hadn’t put his coat on, so by 4 o clock I thought I wonder if he just you know nipped…and by 5 it was pitch black and I couldn’t find him anywhere in the usual places, so I phoned the police and it was 9 before we found him”.*

David recalled the incident but described it as a less significant event which he felt he had successfully resolved:

*“ Yes (partner’s name) had said, ‘don’t be long’ and I missed me route, because I went out and having said that, when I knew I was having a problem I actually went and knocked on someone’s door and everything came alright again….they came and fetched me..”*

This shows how in the later interviews with this couple, there was a significant divergence in their perceptions of the same event, rather than the shared understanding and acceptance of the other person’s perspective, that had previously characterised their initial interview some eighteen months earlier.

In later interviews with David it was clear he had formed his own internal coping mechanisms, rather than actively discussing or sharing concerns with his wife in achieving a shared understanding to managing his progressing dementia.

*“I picked up on an interesting concept the other day with Alzheimer’s and it’s keeping yourself as useful as you could and apparently walking and stamping down is supposed to get better stability if you need it, way of walking etc”.*

*“And that’s one thing that’s really interesting you know because it seems that actually helps, pounding around and pounding your legs on the floor”*

It was also clear that David and his wife no longer shared the same perception of his past capabilities, as his own self view had altered in the presence of his dementia*.*

*“In some ways other people who are still in normal mode don’t twig that you are struggling a bit, I was always a slow student, I did well but had to be head down”*

David’s wife disputed this self-description, citing activities that David would have routinely undertaken in the past. However he did not appear convinced or reassured by her evidence of his past achievements, as this information no longer formed part of his own remembered past:

*“[David] says that but he drew our house plans, used to service the car, put furniture together from plans….but says, ‘I’ve always been like this’ but you haven’t, you’re a very talented person.*

This process of not sharing perceptions of change over time, was also present for Phillip and Jean in their later interviews, when Jean requested to be interviewed alone, so she could more openly describe her perception of her increasing role in supporting Phillip, something that he was unaware of. As Jean described it:

“He still looks and sounds normal, in short conversations people assume he’s not that bad”.

Jean also described how:

“He went to a group for younger people with dementia, but complained they were all, ‘In their 50’s”, although they were all a similar age to him”.

For Jean this was frustrating in that friends and family believed that she and Phillip were ‘maintaining’ their normal life, whereas in reality aspects of their previous life and relationship were being constantly ‘modified’ or ‘abandoned’. During this later interview with Jean, she described how she had arranged for his first respite admission to a residential home for a week, to give her a break from her caring responsibilities. Unfortunately she did not feel supported by their wider family in making this decision and was upset that despite this they were not providing her with any practical support.

As with Rebecca and Deb, Jean could not openly discuss these issues with her partner, as she perceived that he was not aware of these changes and would only become distressed to no purpose.

**6.9 Chapter Conclusion**

This chapter has presented a staged temporal model describing how participants experienced the presence of dementia in their lives over time. The importance of ‘sharing’ as a core social process has been highlighted and the different forms of both sharing and not sharing that were evident in the data have been discussed. The ways in which ‘sharing’ was central to how participants engaged in ‘maintaining’, ‘modifying or ‘abandoning’ aspects of their lives across the highly individual temporal journey of dementia at a younger age has also been presented. In this way the complex and multi-layered manifestations of how sharing, and not sharing, occurs for YPWD and those close to them has been described. The next chapter will discuss the implications of these findings and reflect on the overall research process and methodology. Consideration will also be given to the ‘quality’ of the study and the extent to which the findings reflect and potentially add to our understanding of living with dementia at a younger age.

**Chapter 7**

**How useful is the Sharing Theory?**

This chapter has a number of aims, specifically it will:

* Consider how well the temporal model presented in the findings chapters addresses the initial foreshadowed questions identified at the outset of the research and how changes and adaptations to these were made over time.
* Present my own reflections as a clinician/ researcher on the research process including the chosen methodology and process of data analysis and theory development.
* Consider whether appropriate quality criteria were met by this constructivist grounded theory study.
* Consider how the findings add to and complement previously published theory, related to relationship dynamics in dementia and acknowledge the similarities and differences between existing theory and the model presented here.

Finally the implications of the study for practice and policy in relation to support for YPWD and those close to them, education and training for health and social care practitioners working in this field and areas for future research will be considered.

**7.1 Revisiting the foreshadowed questions**

The initial foreshadowed questions informing this study were:

1. **What impact does dementia at a younger age have on the person’s life in terms of their social roles and participation?**
2. **Which aspects of how dementia affects their life are most significant to them?**
3. **How does the presence of dementia at a younger age specifically impact on the person’s work and recreation?**
4. **Does the impact of dementia on the person’s life alter over time as symptoms progress?**
5. **How does dementia at a younger age affect the nature of the person’s relationship with their partner (or those close to them) and how does this change over time as symptoms progress?**
6. **How are these relationship issues experienced from the perspective of the younger person with dementia’s partner and/or carer?**

In addressing the above broad set of questions this study has explored, identified and presented ways in which dementia at a younger age impacted on the participants’ lives. At the heart of the ‘sharing’ theory which developed was the notion of a temporal trajectory which suggested four sequential, sometimes overlapping and individually variable but nevertheless, shared phases beginning with people ‘noticing something unusual’. This was frequently ignored or rationalised in some way until frequent re-occurrence or worsening resulted in people questioning, ‘What is happening’. These processes usually occurred separately for the person who would eventually be diagnosed with dementia and those close to them, until an often ‘pivotal’ event meant that they could no longer be ignored. This then triggered the search for a diagnosis. This process was frequently protracted and stressful, and because of the young age of the participants causes other than dementia were offered and excluded before an eventual diagnosis was reached. During this early period roles and relationships could often shift in subtle ways, without full awareness of the participants. The receipt of a diagnosis was more often than not the major point of transition as it provided an explanation for previously unexplainable changes and allowed people to recognise what they faced and at least start to ask ‘where do we go from here?.

As was described in the Methods chapter, although initially the foreshadowed questions were in part quite focused on exploration of the experience of YPWD and their partners, it quickly became apparent during the first recruitment phase that limiting the study to YPWD and partners only, would exclude a significant number of potential participants who had either; no partner, ex-partners, or who identified other significant family, friends, social or work contacts as of significance in their lives. While it clearly remained of interest to explore YPWD’s relationships with partners where they had one, this broader range of potential significant relationships was clearly an equally important and relevant avenue to explore. In this way rather than attempting to limit the number of potential participants (from a necessary small geographical pool of YPWD), or attempting to artificially keep the research design straightforward, it was clear that this unpredictable range of potential relationships for any one YPWD should be explored, grounded in which relationships the person themselves identified as of significance in their lives. This approach appeared most likely to be open to the reality of the participants’ lives and relationships and enabled the foreshadowed questions 1 and 3 as detailed above to be addressed, with an understanding of the YPWD’s social roles and relationships more fully explored in light of the additional experience of those close to them, whether partners or people of other significance in their lives.

In terms of considering which aspects of dementia affected participants’ lives the most, the data suggested that the factors involved were more diverse and complex than might have been predicted at the outset of the study, given the relative paucity of existing literature. However, whilst the experience of living with dementia was inevitably an individual one, it became apparent that at any point across the temporal journey of experiencing dementia at a younger age, the key social process and core category that exerted the most influence was that of ‘sharing’. The extent to which a variety of things were shared (or not) such as; the diagnosis, perceptions of dementia and its impact, roles and relationships, hopes and aspirations (amongst others), largely shaped whether YPWD and those close to them attempted to ‘maintain’, ‘modify’ or ‘abandon’ a number of aspects of their lives. When things were shared the above processes were more likely to be the result of at least some (and often considerable) discussion and planning, or an agreement to ‘live for today’. When important aspects were not shared, either between couples or their wider network, then inevitably key knowledge remained, to a greater or lesser extent, hidden.

The findings highlight the ways in which dementia at a younger age impacted on participants’ work/role, social lives/relationships, but the nature of what constituted ‘work’ and/or other roles or ‘social’ relationships was again highly complex and varied. In trying to capture such variability any ‘theory’ will, of necessity, be unable to capture fully each individual’s unique journey. Nevertheless, the temporal phases identified, together with the processes of sharing, maintaining, modifying and abandoning, resonated with the participants and provided them with an overarching framework that ‘made sense’ to them and provided a way of articulating the totality of their experiences in a way that they could relate to. On this basis I believe that the initial foreshadowed questions have been addressed to the extent to which it is possible in what is a relatively small, if intensive, study.

**7.2 Reflecting on the research process**

The challenge of recruitment

As described earlier the difficulties in recruiting participants to the study were more significant and challenging than I would have anticipated. As was described in the Methods chapter, there was a clear gulf between the initial confidence of the recruiting specialist teams for YPWD that they would find time to support recruitment in the first two sites and the reality of actual recruitment. Two of the three geographically separate teams had been confident during research planning meetings that they would have sufficient numbers of people accessing their service who would meet the inclusion criteria for the study and that they would be able to easily gain initial consent for them to be contacted by me. However in practice no potential participants were identified by either of these teams over a 12 month period, despite repeat visits to team meetings and telephone calls. When asked for feedback on how I could support the teams with recruitment, no specific barriers were identified.

These recruitment difficulties were particularly frustrating for myself as a clinician continuing to work day to day with YPWD, but not able to translate this clinical contact into recruitment for the study. In order to keep the ethical boundaries of the research clear, I had from initial planning of the study ensured that no recruitment would take place from the geographical area within which I worked. It became clear once I began conducting the research interviews however, that participants rightly wanted to know what my background was and why I was interested in this area of enquiry. Sharing this with participants increased their willingness to share information, as they considered that I had some credibility and understanding of their lives and experiences. I believe that this increased the rapport during the data collection process and allowed a partnership to emerge.

It was not initially clear why the third recruitment site was so much more successful in identifying potential participants who I could contact, as the apparent pressures on each of the three teams, in terms of caseload size, team size and population served appeared broadly similar. It is likely that the difference with this team was their willingness to actively seek people who met the inclusion criteria. The other two clinical teams appeared to adopt a rather paternalistic and protective approach to YPWD on their caseload, as evidenced for example in comments such as, *“it’s too soon after diagnosis”,* or that a YPWD has, *“ had dementia for years and so would not be of interest”.* My impression therefore was that these clinical teams acted as ‘gatekeepers’ and perhaps did not permit the YPWD to make their own choice as to whether to take part or not as they were not even informed of the study.

Other factors may also have played a part in that I did have a prior connection to the town that formed the third recruitment site, having worked there as a charge nurse ten years earlier. It is possible that this historic relationship and knowing me as a former, and hopefully, trusted colleague gave the third recruitment site team confidence that the YPWD and I could manage any difficulties between us, with the clinical YPWD team as a supportive, rather than controlling factor.

**7.3 Reflections on the role of clinician/researcher**

As someone who has worked as a nurse in clinical practice for many years, there was a need throughout the whole research process for me to reflect on how this background might impact on my role in the co-construction of the data and the process of data analysis. As a clinician working every day with people experiencing dementia and their families, I have inevitably developed certain forms of communication and engagement that, I would hope, assist the development of a therapeutic relationship. In this context when completing cognitive assessments, clarifying a diagnosis, or prescribing medicines, there will be specific information that is relevant to the purpose of the therapeutic interaction and information that is not relevant. These habits and approaches are no doubt deeply ingrained, and have probably become second nature in situations where time is limited and specific factual information or opinions and choices have to be obtained to make a clinical decision. The qualitative research interview is clearly a very different process and has a differing purpose. I needed to take a far less directive and focussed approach than that I would normally adopt in a clinical setting. However the fact that I was a nurse working in the field and that this was known to participants must have exerted an influence.

By the time that I met them the YPWD would often already have had considerable experience of meeting with nurses and doctors to discuss their diagnosis, care, support and medication. This combined with their awareness of my work role as a nurse consultant, could potentially influence what the respondents may have thought I was interested in, and how they should respond. This may have led them to approach the interview with a certain set of expectations rather than talking freely about what was most important to them. Whilst it was understandable that participants would want to talk in detail about their diagnosis and other ‘technical’ details it became apparent after reflecting on some of the initial interview transcripts, that I was not encouraging further discussion of some of these topics, and rather tried to steer respondents away from things that were, in my view, ‘too clinical’. This was something that I subsequently worked hard to avoid doing.

Through memo-keeping and reflection post interview, it was evident that over the course of the study I became more natural and at ease, and was allowing the interview to follow the direction that it appeared to be taking naturally rather than attempting to control it in some way. I soon became less prescriptive and avoided using leading questions and became far more responsive to the overall ‘feel’ of the interview. The process of transcribing, coding and theming the initial round of interviews made these processes more visible to me and I was able to identify and learn from occasions where the transcript showed the participant had mentioned a specific issue, (perhaps more than once) and I had moved onto another subject rather than exploring the issue that the participant wanted to talk about.

Of course there is no ‘right way’ or ‘wrong way’, to be a clinician/researcher, but there is a need to reflect on and be open to what is occurring and why, to allow for a more genuine co-construction of meaning from the data and to develop skills and awareness as a qualitative research interviewer. This was an important learning point for me. Clearly there is a need to learn through experience, reflection and supervision and the benefit of a repeat interview study, is that it allows the space and time to develop and refine such skills. It affords the opportunity to re-visit and explore themes with participants and to expand upon and enrich meaning.

**7.4 Theory development**

This constructivist grounded theory study has presented many challenges and unexpectedly (at least to a novice grounded theorist), the most significant was the process of data analysis and theory development and refinement. The initial frustration at not being able to recruit for an extended period was, with hindsight, far less of a challenge than the development of a credible theoretical model that could capture the diversity of the data and encapsulate it in a way that provided the ‘best fit’ possible. Following each iteration of; codes, categories and concepts, I was concerned that any emerging model might not fully capture the variety, complexity and sometimes contradictory nature of what YPWD and those close to them were describing in their lives at any one point in time. Supported by the supervision team I remained open to this often demanding and painstaking process of re-visiting the data in light of any new addition and the eventual reduction of the elements in the proposed theory. As already described I also adopted a number of strategies to involve participants in this process. The final temporal model did, I believe, achieve the necessary balance between brevity and simplicity whilst accounting for complexity and variability that are the hallmarks of a good theory, whether grounded or not (Charmaz 2006). Importantly I feel that it was truly ‘grounded’ in and supported by the data. Ultimately of course it is for the reader to make the final judgement.

**7.5 Judging the ‘quality’ of the research.**

Quality criteria

As previously referred to in the methodology chapter, the following quality criteria identified by Charmaz (2006) were considered to evaluate the current study both during processes of data collection and analysis and towards the end of this cycle of repeat data acquisition:

“Have I collected enough background data about persons, processes and settings to have ready recall and to understand and portray the full range of contexts of the study?

Have I gained detailed descriptions of a range of participants’ views and actions?

Do the data reveal what lies beneath the surface?

Are the data sufficient to reveal changes over time?

Have I gained multiple views of the participants’ range of actions?

Have I gathered data that enable me to develop analytic categories?

What kind of comparisons can I make between data? How do these comparisons generate and inform my ideas?” (Charmaz, 2006, p 18)

On reflection a considerable amount of background data about the participants was obtained, mostly from the participants themselves as outlined in the biographies chapter and the depth and range of social and relationship processes that have been described within the temporal model for YPWD will hopefully attest to a comprehensive representation of the full range of contexts in the study.

The process of meeting with a group of YPWD and those close to them at a self run support group, was initially daunting but affirmed that the outcomes of the research and the model presented were recognisable and relevant to the group members in the context of their own lived experiences in the presence of dementia at a younger age. Presenting the research findings and giving an overview of the temporal model and the ‘maintaining’, ‘modifying’ and ‘abandoning’ aspects of each stage, with ‘sharing’ as a central process, prompted much debate. Frequently, during what was a lengthy discussion, members of the group spontaneously connected with the temporal model, which prompted them to recount how this had relevance to their own personal experiences. The group were very clear that they could recognize aspects of their own experience, (both from the past and currently), as being visible in the model and this prompted a detailed discussion between the YPWD, their partners and carers who were present in the group. This was a varied group which contained some of the people interviewed by myself over the previous three years and others who had lived with the presence of dementia over a long time and were not previous participants, combined with newly diagnosed group members. The temporal model for YPWD was not identified by the group to be missing any key important elements and the feedback and critique was that it enabled a representation of experiences that occurred often over many years as the dementia symptoms progressed and had a definite resonance with their own lives. The depth and length of the discussion that the theory prompted within the group was certainly reassuring with regard to the relevance of the model. Most striking was how the temporal stages and specific forms of’ sharing’ and ‘not sharing’ in the model spontaneously prompted group members who had been interviewed sometimes years earlier as participants to re-describe their experiences. This made it clear that the categories within the sharing model did have resonance with their experience of dementia at a younger age. For other group members I had not met before, the theory prompted them to discuss and share how these forms of ‘sharing’ or ‘not sharing’ were reflected in their own experiences both now and in the past. Prior to the meeting I had anticipated having to provide quite a careful and detailed presentation of the sharing theory, but as each element of the model was presented, group participants immediately engaged with this and clearly felt a strong need to recount how this reflected in their own experiences.

Charmaz (2006,p182-183) provided a framework for constructivist grounded researchers to complete a detailed and reflective evaluation of their study and each of the elements of this evaluative framework will now be considered in turn:

**Credibility**

Has your research achieved intimate familiarity with the setting or topic?

The research method employed for the current study has afforded the opportunity to achieve an intimate familiarity with the experiences, thoughts, feelings and perceptions of the participants. This in turn has enabled a high level of familiarity with the experience of YPWD and those close to them through data obtained from those directly experiencing the phenomena under investigation.

Are the data sufficient to merit your claims? Consider the range, number, and depth of observations contained in the data.

The total number of participants in the research was 32, 16 of whom were YPWD. As such this is necessarily a fairly small sample, but the process of data collection and repeat interviews did yield a large amount of transcript data, with a broad range, number and depth of observations made. As such the sharing theory developed is grounded in the rich and detailed descriptions by participants of their experiences and the systematic process of analysis that was employed. Line by line open coding of transcripts and memo keeping provided a significant amount of detailed data for analysis.

Have you made systematic comparisons between observations and between categories?

As has been described earlier in the methods chapter, a process of constant comparative analysis was employed during subsequent phases of data analysis across the process of data collection. There was therefore comparison between observations, codes, themes and categories across the interviews and the transcripts.

Do the categories cover a wide range of empirical observations?

The categories identified in the process of data analysis and subsequent theory development, reflect and describe the breadth of reported and observed experience of the participants. The sharing theory is in this way proposed as a means to explicate and present in a meaningful way this wide range of observations from the data.

Are there strong logical links between the gathered data and your argument and analysis?

The process whereby the sharing theory was developed and derived from the data has been presented and every attempt has been made to show how categories were developed and the ways in which data links with and is represented by the theoretical model proposed. The theory is grounded in the data and a detailed process of constant comparison, returning to previous data in the light of new data, to support the credibility of the sharing model and its utility as a means to make sense of relatively diverse social worlds and experiences in the context of dementia at a younger age was employed.

Has your research provided enough evidence for your claims to allow the reader to form an independent assessment – and agree with your claims?

Where possible within this study examples of data have been presented to justify and represent the proposed sharing model and the mechanisms of maintaining, adopting and adapting, that were present across the temporal journey of dementia at a younger age. This does hopefully make visible for the reader how specific examples of participant’s data link with the theoretical constructs derived from that data, with sufficient background biographical data and description of the data analysis method presented, to enable the reader to form an independent view of the credibility of the study and its findings.

**Originality**

Are your categories fresh? Do they offer new insights?

The sharing model does appear to show new insights into the experiences of younger people with dementia and builds on and integrates with previous studies conducted with people experiencing dementia who were not at a younger age. In this way, while the temporal model described has clear links with previous theory, fresh categories and insights have been presented which add to and complement previous work as described within the discussion section of this thesis. The ways in which ‘sharing’ is a key social and relationship process for YPWD, does provide a new insight into their experienced social world. This is clearly distinct from previous study findings in terms of the ways in which this core process of ‘sharing’ or ‘not sharing’ enables a deeper understanding of how across the temporal journey of dementia at a younger age, YPWD and those close to them are maintaining, modifying or adapting aspects of their lives.

Does your analysis provide a new conceptual rendering of the data?

In presenting and describing the sharing model a new and important aspect of how YPWD and those close to them experience the impact of this condition in the context of their relationships and societal roles has been presented. This concept has not previously been described (to the author’s knowledge) in relation to YPWD (or older people with dementia) and is therefore a new conceptual rendering of the data.

What is the social and theoretical significance of this work?

The implications for policy and practice arising from the findings of this study will be discussed in more detail in a later section of this thesis. The sharing model and findings from the current study are proposed as of significance in enabling a deeper understanding of the processes which are inherent in how YPWD and those close to them live with this condition over time and interact with those around them, whether in their work, recreational or personal relationship roles and functions in society. It is hoped that this deeper understanding and the proposed theoretical model can inform YPWD themselves, those close to them and the wider community of how best to support YPWD’s choices and positive adaptation to living with this condition. Key elements of what is shared, when, how and who with, such as of the diagnosis of dementia itself, have been shown to have great significance and impact on YPWD’s lives. A deeper understanding of this can enable consideration of how this journey in the presence of dementia at a younger age can be positively influenced by the responsiveness of supportive health and social provider agencies and the wider community in which YPWD live.

How does your GT challenge, extend, or refine current ideas, concepts, and practices?

The ‘Sharing’ model challenges the concept that the journey of dementia for a younger person (and those close to them) occurs in any neat linear way across the temporal stages from first ‘Noticing something’. through to, ‘Getting on with it’ in the years after diagnosis. The ways in which aspects of the participant’s lives are maintained, modified or abandoned as fluid and very individual processes have been presented and the core social process of ‘sharing’ presented as the conceptual means to make these shifting processes visible and explainable. Typically current practice in organising health and social care responses to the needs of YPWD is structured around key points, such as diagnosis or symptom progression, with relationship changes, loss of employment etc. The ‘sharing’ model makes clearer the deeper, less apparent complex social and relationship processes that can determine how these stages or events are experienced in either positive adaptive maintaining ways, or can lead to abandoning (either through choice or necessity) for YPWD and those close to them. This can potentially enable YPWD, those close to them and those supporting or providing services for these people, to identify a more flexible individual response, based in part on how sharing is occurring in their lives at any particular time in their journey of dementia.

**Resonance**

Do the categories portray the fullness of the studied experience?

The emergent themes and concepts were considered on completion of each phase of interviewing from the transcripts. Through working with the data to make constant comparisons, develop categories and explore these through theoretical sampling (Charmaz 2005, Lalor & Begley 2006), the sharing model was developed containing categories that reflect and portray the fullness of the studied experience. Through returning to participants with these categories in the sharing model, the relevance and adequacy of these categories was checked by participants.

Have you revealed both liminal and unstable taken-for-granted meanings?

Throughout the process of repeat data collection and subsequent phases of analysis and constant comparison across the transcripts, there was recognition of shifting or dynamic periods or stages in the participant’s accounts. The identified temporal stages within the ‘sharing’ model reflect these transitional points, where activities could comprise of maintaining, modifying, or abandoning at any stage with sharing (or not sharing) as the core social process mediating between the form and nature of activities engaged in (within social roles and relationships) at any one time. The model therefore allows for the reality of shifting and unstable meanings that could be present for any one participant at any one time to be revealed.

Have you drawn links between larger collectivities or institutions and individual lives, when the data so indicate?

Where examples were present within the data of participants describing interaction with institutions (such as employing organisations or health care institutions), these were identified and reflected in examples from the participant’s accounts. Sharing of the diagnosis of dementia at a younger age with an employer by YPWD and the outcome and implications of this sharing for both parties, was one significant example of this type of link within the current study. This could also relate to concepts of social institutions such as one example of a participant not wishing to be seen as ‘dependent’ on the welfare state when she and her family had always perceived themselves as self-reliant as a core element of their social identity.

Does your GT make sense to your participants or people who share their circumstances?

The sharing theory has been presented to a group of YPWD and their partners/ carers, followed by a detailed discussion of how accessible the theory was and to what extent did it make sense to the members of this group in the context of their own experiences. The group contained some of the participants from the previous phases of interviews as well as other YPWD and their partners/ carers who had not previously been recruited to the repeat interview process of the study. The group were very positive in affirming that the theory did resonate strongly with their own experiences, giving numerous examples, prompted by the presentation of the model. For some participants previously interviewed, there were examples of these individuals re-telling aspects of their experience of dementia spontaneously having read or listened to an explanation of the sharing model. The sharing theory has also been presented in detail at a national conference to nurses working in this field of practice, where again during open questioning and discussion at the conclusion of the presentation, a number of nurses linked the sharing model to their own experiences of caring for and supporting YPWD and their families (Clibbens 2014). The model does therefore appear to make sense both to participants and people who share their circumstances.

Does your analysis offer them deeper insights about their lives and worlds?

When the sharing model was presented to YPWD, their partners/ carers and nurses working in this field of practice, there was immediate recognition of the temporal staged model of moving through from ‘Noticing something’, right through to ‘Where do we go from here? Getting on with it:’. There was then often recognition of how maintaining, modifying or abandoning had been previously seen or experienced, but the fluid nature of these processes and crucially the core social process of sharing as a mediator between and across these stages and processes was largely viewed as offering a new perspective, but one which did resonate with and reflect in some way their own experiences, although not in ways they may previously have considered according to feedback from sharing the model.

**Usefulness**

Does your analysis offer interpretations that people can use in their everyday worlds?

From feeding back the sharing model to YPWD, those close to them and professionals working in this field, it was evident that the presented theory and interpretations did generate discussion of related personal experience. In this way the sharing model would appear to offer a theoretical framework, that relevant groups and individuals could employ to understand how being a YPWD is experienced in terms of relationships and social roles. This could be practically applied and utilised in supportive discussions, or work with YPWD and those close to them to facilitate maintenance of positive relationships and social roles. This could also have a potential useful role in training and education for health and social care staff working with YPWD, or to generate discussion in support or education groups for YPWD and those close to them.

Do your analytic categories suggest any generic processes?

The analytic categories within the sharing model are identified to clearly link in some ways with temporal staged models of social and relationship roles and experiences for people with dementia at an older age (or any age), rather than being necessarily specific to YPWD. As a progressive neurological disease it is also apparent that YPWD will share some elements of this illness experience with people experiencing other progressive neurological conditions, although factors such as age of onset, pattern and speed of symptom progression and impact on social functioning, remain likely to be quite different in some significant ways across different conditions. The act of sharing or not sharing is inherently a social and relationship process in itself and it is therefore likely that this will be a significant social process more generically in many aspects of human experience, although specifically applied to explain and understand the experiences of YPWD and those close to them in the current study.

If so, have you examined these generic processes for tacit implications?

The analytic process applied to the data and the identified temporal stages and social processes within the sharing model do incorporate an evaluation of the tacit implications from the data, as well as the more immediately evident and explicit social processes that YPWD and those close to them described. The implications for policy and practice arising from the study will be discussed in more detail in the discussion chapter.

Can the analysis spark further research in other substantive areas?

In presenting the sharing model as a mid-range theory that may assist in greater understanding of the social world and relationship changes that occur in the presence of dementia at a younger age, there remains a clear acknowledgement that the experiences of YPWD have not been fully explored and that in the UK the number of people experiencing this condition is much greater than previously thought (Alzheimer’s society 2014b). There is then a continued need for more research specifically with YPWD, as well as an on-going need for greater understanding of the increasingly common experience of dementia at an older age. The sharing model could also be considered in the context of progressively deteriorating illnesses other than dementia, to see whether it has any utility in deepening understanding of social and relationship processes in other less clearly related settings.

How does your work contribute to knowledge? How does it contribute to making a better world?”

The sharing model contributes to a growing but still relatively small body of knowledge that enables a deeper understanding of the social, emotional and relationship experience of dementia at a younger age, for those with this form of dementia, those close to them, supporting them and the wider communities in which they live. Dementia at a younger age affects a significant minority of people in the UK (Alzheimer’s society 2014b) and there is much current work towards promoting dementia friendly communities and social inclusion for YPWD (and those at an older age). The sharing model and other emerging theoretical explanations that provide a greater understanding of the complex shifting social world for YPWD are needed to enable improved commissioning and provision of health and social care provision, that promotes inclusion and choice for these individuals and those around them.

Conclusions regarding the quality of the study

The quality of the study has been reviewed utilising Charmaz’ evaluation questions in order to review the extent to which it has credibility, originality, resonates genuinely with the participant’s experiences and has utility in being applicable in the ‘real world’. The previous presentation of the findings does I feel constitute a detailed description of participant’s views and actions over the repeat data collection period for the study and does reveal not just the obvious ‘facts’ but the social processes that lay beneath the surface of participants’ experiences. There was a genuine and largely successful attempt to gain where possible multiple views of what participant’s had experienced and there was sufficient data to effectively develop and then refine analytic categories. The often complex and challenging process of making comparisons between the data from different participants and indeed form the same participants over repeat processes of data collection, were key to informing and generating ideas and analysis of the data. Overall therefore I do feel that there is a demonstrable and credible quality process that underpins the collection, analysis and presentation of the data and the findings and theory that emerged from this constructivist grounded theory study. In the next section there will be an exploration of specific relationships and links between the current study and previous existing theory.

**7.6 The relationship between the temporal model for YPWD and existing theory that informed the study.**

As mentioned in the introductory chapter of this thesis the existing literature was used to identify both the sensitising concepts and the foreshadowed questions that guided the initial direction for the study. The sensitising concepts provided a broad set of ‘ideas’ that proved useful in shaping the potential direction of the study whilst the latter more specific, but still quite broad and emergent ‘ foreshadowed questions’ shaped the initial contact with participants and allowed at least some structure to early conversations. The extent to which the study has addressed the ‘foreshadowed’ questions has already been considered. Here attention is turned to the role of the sensitising concepts and the influence of, and parity with, the theory that resulted from the study and the literature that existed at the time the study commenced.

Three broad ‘sets’ of sensitising concepts informed the direction of the study. Given that, at the time the study commenced, there was very little existing theory relating to YPWD these concepts were derived primarily from the broader literature on living with dementia, which whilst inclusive of some younger participants had drawn to some extent on the experiences of older people with dementia but were primarily derived from the accounts of family carers. As noted earlier this was a major conceptual and methodological limitation of prior work. Despite these limitations the extant literature proved useful in identifying the following sensitising concepts which exerted an early influence on the study:

* firstly, prior work had suggest that the dementia experience can best be understood from a temporal perspective, comprising of sequential but often overlapping and iterative phases
* secondly, that if a more complete picture was to be obtained then it was necessary to engage as fully as possible with both the (Y)PWD and their family carer in order to explore the dynamics of their relationship as this unfolded over time. It was hoped that this would go some way towards addressing the conceptual and methodological limitations of much of the prior work.
* thirdly, that as dementia developed over time and relationships changed both the (Y)PWD and their carer engage in varying types of ‘work’, some of which was overt and shared, whilst other forms of work were hidden and covert. The earlier literature, especially the work of Keady (1999), suggested that the nature of such ‘work’ could exert considerable influence on the type and dynamics of relationships between (Y)PWD and those close to them.

Whilst a range of literature was initially considered, the model and processes originally suggested by Keady (1999) and later work on ‘couplehood’ by Hellstrom (2005b & 2007a), exerted the most influence. The former in particular was central in identifying the sensitising concepts outlined above. As data collection and analysis were undertaken it became clear that there was considerable resonance between a number of processes described in this earlier work and those emerging from the existing study. However rather than explicitly incorporate such processes at an early stage of analysis it was decided to follow Morse et al’s (2001) advice and to recognise the overlaps but not to allow data collection and analysis to be ‘led’ by existing work. Therefore any processes emerging from the present study had to ‘earn’ their way into the theory and would later be compared to existing work. That is the purpose of this section.

Keady’s (1999) initial theory comprising a temporal model and a number of processes and forms of work was developed from a range of sources including carers of people with dementia and people with dementia themselves (a very small number of whom were YPWD) and sometimes both parties together. Keady, together with colleagues, initially developed two models of the dementia experience, one capturing the experiences of family carers and the other people with dementia. This reflected the fact that at the time interviews with these groups were often conducted separately, if indeed, the person with dementia was involved at all. In an synthesis of a number of studies Keady and Nolan (2003) explicitly sought to identify points of overlap between the experiences of people with dementia and their carers, in order to try and determine where trajectories crossed and what common and distinct processes were evident. Later, Hellstrom (2007b), in a methodological advance, explicitly built on some of this work in order to further explore the ‘dynamics’ of dementia, but unlike Keady involved ‘couples’ from the outset and conducted a series of longitudinal interviews over five years. In contrast Keady’s (1999) interviews had been cross-sectional purposively sampling participants at various stages of dementia.

As with Keady’s seminal work my study developed a temporal model but one that is relatively more focussed and does not, for instance, consider fully the role of prior relationships (although these are clearly important and acknowledged) nor extend to the end of the dementia experience and/or caregiving. However the resonance of my theory with Keady’s work is fully acknowledged here, especially the process of ‘noticing’ and the subsequent efforts made by people with dementia to keep some behaviours hidden (identified as ‘not sharing’ in the model proposed in this thesis) and carers efforts to discover what was happening by ‘increasing vigilance’. Such tactics clearly emerged in the present work.

Moreover central to Keady’s arguments was that one of the carer’s primary goals, often in collaboration with the person with dementia, was to ‘maintain’ the involvement of the person with dementia. He described this as follows:

*“(the data) suggested that the primary aim of both caregiver and PWD was to try and maintain the involvement of the PWD as an active agent in the world”* (Keady 1999).

Hellstrom’s (2005a & 2007b) work deliberately incorporated the idea of maintaining involvement but because of the longitudinal nature of her study and the more explicit engagement of the person with dementia, she was able to provide a much fuller and more nuanced account of maintaining involvement and the much more active role played by the person with dementia. She describes how later in the progression of their dementia the person with dementia actively either ‘handed over’ aspects of their role to their partner or more passively ‘let it go’. The similarities between the above and the processes of maintaining, modifying and abandoning described in this study are clearly apparent but these were developed with knowledge of, but separately from, Hellstrom’s work.

In contrast to both the above studies my own work explored the experience of dementia with an explicitly different group, that is, YPWD and those close to them. The fact that similar processes emerged, albeit in the context of differing background factors such as employment and child rearing responsibilities, both ‘validates’ and extends the above work. This demonstrates one of the determining characteristics of a good grounded theory, its modifiability (Charmaz 2006).

As important as the above synergies are it is when we consider to the notion of ‘work’ that the present study not only mirrors, but extends, existing understandings. In exploring the dynamics of dementia as they unfold over time, Keady and Nolan (2003) argued that four types of work and consequent relationships emerge. They describe these as follows:

‘We would suggest that, depending on the extent to which carers and PWD experience a shared early trajectory, then four main types of ‘working’ can emerge. These are:

* ‘Working together’ – describes the ‘best’ case scenario when there is shared and early recognition of the symptoms and help is sought jointly. Fears and concerns are recognized by the GP, and appropriate specialist advice is taken.
* ‘Working alone’ – occurs even when there is no shared and early recognition of the difficulties that the PWD has, as he/she is likely to have kept their initial concerns secret for some time and will have been ‘working alone’ to hide them. Furthermore, both carers and PWD are often left to feel that they ‘work alone’ when their efforts to seek professional help do not get the appropriate response.
* ‘Working separately’ – describes the instances where the PWD is working alone to ‘keep things hidden’, and the carer is also actively ‘increasing vigilance’ so that a situation occurs where both parties are investing considerable effort but are ‘working separately’, each trying to make sense of and respond to their circumstances. When the PWD is very adept at ‘keeping it hidden’ and carers accept this behaviour as normal, then this period of ‘working separately’ can be prolonged.
* ‘Working apart’ – usually occurred when prior relationships between the carer and the PWD had not been good, or when difficulties in the ‘working separately’ period lead to strained interactions. Consequently the carer and the PWD can ‘work apart’ so that their relationship deteriorates and the carer feels increasingly trapped in their role’ (Keady and Nolan 2003, p29-30)

Once again there are clear parallels between these types of ‘working’ and the various scenarios described by participants in the present study. However in addition to demonstrating the existence of these types of working in a new group of people, (YPWD and those close to them), an important and new addition to understanding provided by this study is the identification of ‘sharing’ as the core category and basic social process that helps to explain how and why these differing patterns of working unfold. In the absence of sharing (in its various guises and at differing stages) working together is not possible and one of the above, less desirable outcomes, is highly likely. Moreover ‘sharing’ not only facilitates working together but can be seen as the ‘oil’ that shapes the ways in which maintaining, modifying and abandoning are experienced. On this basis ‘sharing’ perhaps represents the most important ‘work’ of all and its implications for supporting and working with YPWD and those close to them will be considered later.

On this basis it is possible to add a further continuum to the two described earlier linking the extent to which sharing occurs andthe degree to which YPWD play an active role in decision making. This is captured in the figure below to which Keady’s dimensions of working have been added. Here it is suggested that when full sharing takes place and YPWD and those close to them play a joint role in decisions about whether to maintain, modify or abandon aspects of their lives then these provide clear and explicit examples of them working together. As will become clear when some of the more recent literature is considered shortly, there is now emerging evidence to support Keady’s assertion of the benefits of working together. Conversely when there is limited or no sharing and decisions are often made without the involvement of the YPWD then the conditions for ‘working apart’ are sown. In between these ends of the continuum partial sharing and the absence of full involvement in decision making (of either the YPWD or the carer) is likely to result in either ‘working separately’ or ‘working alone’. When the implications of the study for policy and practice are considered in the light of the current socio-political context of dementia, the concept of sharing and working together will be extended beyond the largely dyadic relationships considered here to include wider relationships and interactions between YPWD, those close to them and the communities of which they are part.

Sharing Continuum Figure 2

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Whilst many of the relations considered in this study explored couples a further addition to existing work is the extent to which the study more explicitly considered the influence of wider family, social and work relationships. Within the current study with YPWD, the context within which couples experienced dementia, was often significantly affected by the wider range of familial, and other, relationships. For YPWD the dynamics of their wider relationships, (such as with a living older parent, or with school age or young adult children), meant that there were additional layers of complexity in close personal relationships that interweaved with and influenced the relationship dynamic between younger couples where one person has dementia. One example of this as previously described was for David, who had provided care and support to his own elderly mother, through assistance with shopping, gardening and maintenance of her home. As his dementia had progressed he was no longer able to provide this, but this was not openly discussed between; him or his partner, him or his mother, or between his partner and his mother. If we consider the ways in which ‘sharing’ or ‘not sharing’ was occurring for David and those connected to him, these complex social processes and relationship dynamics can be made more visible and better understood.

Identifying ‘sharing’ as the basic social process and possibly the most important form of ‘work’ as conceptualized by Keady and Nolan (1999), enables a greater understanding of the nuanced and complex factors that interact to shape the experience of dementia for younger people and those close to them. The varying combinations of both active ‘sharing’ and ‘non-sharing’ of actions, perceptions, thoughts and feelings, between the YPWD and both a range of people close to them and also between many other ‘connected’ people, allows new types of understanding to emerge. In this way aspects of how these relationship dynamics occur at any one time, may be better understood by utilising ‘sharing’ as central to relationship ‘work’ when living with dementia.

For example, David was at one stage sharing in going for walks with his wife Rebecca and therefore ‘maintaining’ aspects of their relationship, shared interests and social activity, while simultaneously he was ‘abandoning’ (not through choice), his previous caring responsibilities for his elderly mother and Rebecca was not openly sharing or discussing with David how other family members were now supporting the mother. This was not openly discussed by Rebecca with David’s mother and David’s own perception was that he still undertook this role.

For the same couple, as previously described, the nature of David’s relationship with his young adult children and young grandchildren added further layers of complexity which significantly affect the processes of ‘maintaining’, ‘modifying’ or ‘abandoning.

Such complexity is also exemplified by Jane, (who was in her early 40’s), who described multiple roles as a wife, mother and carer. Until a few months before the initial interview, she had been the main carer for her disabled eighteen year old daughter, who was living in the family home and she had also been supporting her older daughter Sharon who lived nearby, by caring for her young child while she was at work. These relationships and responsibilities were identified as being at least as important and significant in Jane’s life, as her relationship with her partner Mick. In this example, as with David before, elements of Keady’ & Nolan’s ‘dynamics’ are evident in shifts over time in the nature of her ‘working’ with her husband, while other powerful immediate day to day relationships add additional layers of complexity in terms of the shifting nature of interpersonal relationships between Jane and her family. The complexity of this can again be more fully understood by additionally considering how processes of ‘sharing’ ‘work’ constituted ‘maintaining’ or ‘modifying’ (of roles and relationships), for Jane and her family, while at *the same time* for the same YPWD, other ‘not sharing’ forms of ‘work’ constituted the ‘abandoning’ of previous roles, relationships and activities.

Within the current study it can be seen that even from a relatively small number of younger people with dementia, there was considerable variation in who lived, or was in close contact, with them. A number of the YPWD interviewed were living alone, with varying degrees of contact with ex marital partners, while others had young adult or teenage children living at home. For others key relationships were with siblings, friends or adult children and grandchildren living nearby. This created a broad and diverse range of identified significant relationships that formed an individual context for each younger person with dementia and where considering ‘sharing’ as a social process and additional form of ‘work’ can enable these complex aspects of their relationship dynamics to be described and understood.

Whilst the degree to which the present study confirms and to a degree extends Keady’s work is readily apparent above, there are also important points of contact with some of Hellstrom’s (2007b) conclusions, especially relating to ‘making the best of things’. It is suggested here that ‘sharing’ is essential if all parties are to ‘make the best of things’ when living with dementia.

‘Making the best of things’.

Hellstrom’s (2007b) work on couplehood explicitly built on Keady’s (1999) notion of maintaining involvement and over time she described how both partners employ a range of strategies to help them ‘making the best of things’, in an effort to make the quality of their lives and relationship’s as good as possible. These were described as:

* Life’s little pleasures
* Searching for the positives
* Living for today

Despite the differences in the sample between Hellstrom’s work and this study there are, once again, obvious points of contact, with sharing providing the conceptual link that helps to unite the two studies.

‘Life’s little pleasures’, as described by Hellstrom, is achieved primarily by couples attributing far greater significance to day to day activities that were previously taken for granted. In her sample this often revolved around food and related rituals. For example Hellstrom described how one couple enjoyed a glass of wine each evening with their food ,

*”We think we can afford that and it can’t damage”. (Hellstrom 2007b p2)*

Such tactics were also evident from the accounts given by the younger couples interviewed for the current study. There were many examples of the YPWD taking pleasure from day to day activities, such as; going for short walks independently, walking the dog or listening to music. Even though these were not usually shared activities they were nevertheless appreciated by the carer as they brought pleasure to the YPWD, and demonstrated their continued engagement with the world.

On the other hand Dominic and his partner had, since the diagnosis of dementia, taken on a range of new activities that they explicitly shared which had involved moving house, taking up gardening and altering holiday arrangements. Conversely other participants had continued with their retirement plans, whilst others had to be abandoned. Whatever the course of action it was achieved most successfully when sharing had occurred. Once again this highlights the additional layers of complexity that confront YPWD and those close to them. For younger couples the focus was very much on ‘maintaining’ or ‘modifying’ activities and interests that they would have expected to still be undertaking and enjoying at their age. Many people plan financially and psychologically for retirement as a couple, but for YPWD and their partners in the current study, the unexpected impact of dementia while still relatively young had led to the ‘modifying’ or ‘abandoning’ of shared plans and some of their expectations of a shared future as a couple.

Hellstrom also described ‘seeking the positives’, with the PWD’s partner helping them to ‘look on the bright side’, by making comparisons with others who had ‘got it worse’. There were occasional examples of this in the current study as in the quote from Pete below, but this did not emerge as a significant theme in the analysis.

*“Compared to people I’ve seen at the centre she’s good, so I’m glad they caught it before it got worse”.*

The third way in which people ‘made the best of things’, in Hellstrom’s (2007b) study was by ‘living for today’, but this was far less apparent in the current data, as for younger people and especially for partners, ‘living’ for today’ was not a workable reality in view of both their age and commitment to younger family members, often children. However dementia at a younger age could bring people closer together (at least for part of the temporal journey of dementia), as was the case for David & Rebecca who over the first of their repeat interviews described how they were making the most of time together, with a sense that their time was now precious and should not be wasted.

It is clear from the above that there are considerable elements of complementarity between the idea of the temporal model and the processes that shape the experiences and dynamics of dementia from existing work in this field and the present study. However there are also differences that are attributable to the often more complex context within which YPWD and those close to them live with the condition. This study has, in addition to supporting early work, added potentially important new insights into the importance of sharing as a key process central to the impact of dementia in younger age.

As explained earlier at the start of the study a deliberate decision was taken to consider work that existed at that point as this could therefore have in some way shaped the conduct of the study at its outset. The key influences of this work and how the current study may have added to this literature have been described above. However since the study commenced other work has emerged and it is essential to consider the present findings in the light of this. That is the purpose of the following section.

**7.7 Recent literature and the present study**

Since the initial literature for this study was considered and during the process of data collection and analysis, there have been a number of further published reports relating both to research specifically involving YPWD and their partners or carers and also to the experiences of older people with dementia and those close to them. Whilst there are, as might be expected, differences between these studies there are also several shared and common themes, both methodologically and conceptually. By considering these studies as they emerged chronologically in the years since my work commenced it is possible to trace these methodological and conceptual developments and to relate the ‘sharing’ theory to them.

In synthesising this recent literature it is possible to discern a number of themes which are similar to those identified at the outset of the study but which have been extended and expanded upon since. In addition it is possible to identify some more recent trends in thinking about the experience of living with dementia that resonate with many of the findings emerging from my study.

In common with much of the prior work some studies continued to focus primarily on the experiences of family carers and to use these as a proxy for those of (Y)PWD (van Vliet et al 2010, Ducharme et al 2013), something noted by Svanberg et al (2010) in their review of the literature. However, at about the same time Hughes (2013) began to discern a ‘philosophical’ shift in how the experience of dementia was being portrayed, one in which relationships began to take centre stage. Similarly, Morhardt and Spera (2013) described the continued move over time from a person-centred approach towards a more inclusive relationship-centred model. Whilst Hellstrom’s work (2005, 2007) had been implicitly relationship-centred, later studies have made this emphasis more explicit. Many of these, in keeping with Hellstrom’s focus, concentrated on dyadic relationships between spousal couples (Ericsson et al 2013, Davis et al 2011, Daly et al 2013, Molyneaux et al 2012, Balfour 2014), and most also heeded the call to actively include the views of PWD, as had been promoted by a number of authors at the time (Braun et al 2009, Ablitt et al 2009).

These, and similar studies, began to identify the importance of maintaining closeness in relationships so that trust between the (Y)PWD and those close to them could be maintained and couples were able to remain close despite changes in their relationship dynamic (Gillies et al 2012, Hellstrom & Torres 2014). The importance of maintaining closeness in relationships, or the potentially deleterious effects of not doing do, also began to emerge. For example some studies suggested that there was more rapid cognitive decline in the (Y)PWD when relationships were not good (Norton et al 2009, Pointon 2011), whereas others noted less burden and a positive impact on the psychological health of carers when relationships remained close (Williams 2011, Fauth et al 2012). As a consequence some authors have begun to call for ‘relationship work’ to be a recognised from of intervention for couples living with dementia (Molyneaux et al 2012, Balfour 2014), especially the quality of their relationship dynamics and interactions (Sanders and Power 2009, Wawrznczny et al 2014) in order that, if necessary, couples can ‘re-validate’ their relationship (O’Shaughnessy et al 2010). I would suggest here that work around helping couples focus on their ‘sharing’ behaviours could form an important part of such relationship work. Moreover, reflecting the more recent trend towards a family– centred approach (see below), such a focus on sharing could extend beyond dyadic relationships to peoples’ wider social and relational network.

Extending the focus beyond dyadic relationships and calls for a wider family-centred approach to understanding and supporting those living with dementia have also gained momentum, especially over the last few years (Roach et al 2012, 2014, Barca et al 2015, Toms et al 2015).

In calling for a broader approach, especially in relation to YPWD and their families, Roach et al (2008) report that there are significantly different subjective experiences of symptoms by YPWD and those close to them and that these differences have personal and societal implications for the whole family. More recently Roach & Drummond (2014) have argued that there remains;

“ a particular lack of research focused on younger people (under the age of 65 years) with dementia and virtually none focuses on the experience of the family unit. The literature suggests that periods of transition place significant stressors on families living with dementia”

(Roach & Drummond 2014, p 1)

The notion of phases or transitions in living with dementia, and the challenges they face at such times, is one that has been recognised for some time and led to the emergence of temporal models, such as that developed by Keady (1999), the influence of which on the present study has already been acknowledged. Some of these are considered below.

Consistent with my study several recent pieces of work have highlighted the difficulties surrounding diagnosis, especially for YPWD and their families (Svanberg et al 2010, Johannesson and Moller 2013, Ducharme et al 2012, Ducharme et al 2013). Again reflecting my own findings Bakker et al (2010) highlight the very lengthy period of time it takes to receive a diagnosis and others stress the particular challenges surrounding the disclosure of the diagnosis (Hellstrom and Torres 2013) and the problems (Y)PWD face when initiating a conversation with others around sharing their diagnosis (Weaks et al 2015). Whilst such problems are not confined to YPWD and their families, they are nevertheless exacerbated for these groups due to a number of reasons, especially the reluctance of health practitioners to consider a diagnosis of dementia in younger people. This figured prominently in my work.

Other difficult transitions are either unique to, or are at least experienced more frequently, by YPWD and their families. Foremost amongst these is the transition out of work and gainful employment (Roach and Drummond 2014). The challenges this posed for many of own participants was all too clear and such challenges are not confined to the loss of income, as important as this might be when YPWD still have numerous financial responsibilities. As well as its financial impact the need to give up work often strips a (Y)PWD not only of their sense of engagement and purpose (Bakker et al 2010, Ataie 2014) but also threatens their identity and sense of self (Page and Keady 2010, Caddell and Clare 2011, Frazer et al 2012). This again has implications for the type of support that is needed, with recent studies for example highlighting the benefits of supervised volunteer work both for YPWD and their partners (Kinney et al 2011). Such studies reinforce the need to provide YPWD with a meaningful form of purposeful activity (Roach and Drummond 2014), in order to help them and those close to them to maintain a role in society.

From the above a number of conclusions can be distilled, all of which in some way resonate with, or are expanded upon by, the sharing theory that emerged from my study. These might be summarised as follows:

* Methodologically, in many recent studies, there has been a marked shift towards a more inclusive approach that actively seeks to capture the voices of (Y)PWD and those close to them, although as Roach and Drummond (2014) note there is still a long way to go;
* Conceptually, the importance of adopting a relational approach to understanding how people live with dementia has gained considerable momentum, with a focus on dyadic relationships and more recently the wider family. Whilst my study did not adopt an explicitly family oriented approach it extended its gaze beyond opposite sex couple relationships to include not only same sex couples but also those who were separated and those for whom much wider multi-generational family relationships played a major part;
* Recent work has further reinforced the importance of helping (Y)PWD and those close to them to understand major transition points and to enable them to respond to them. This seems especially important before, during and immediately after diagnosis. Moreover, for YPWD and their families help in making the transition from work to, hopefully, other forms of meaningful engagement and activity both within and beyond their close set of personal relationships, is an area where much more support is needed. Once again my findings reinforce these transition points and the need for better support;
* The above all have implications for the type of support that is most useful for (Y)PWD and those close to them at differing points in time and also highlight the importance of developing new and more appropriate forms of help, especially around managing transitions, relational work and maintaining meaningful engagement and activity.

The points of contact between the above and my own study are clearly apparent but it is the identification of ‘sharing’ as the main type of ‘work’ that largely shapes, not only the nature of relationships when living with dementia, but also the extent to which all parties are able to play an active role that marks the main contribution to emerge from my study. The implications of adopting the ‘sharing’ theory for better understanding and supporting (Y)PWD and those close to them are now considered below with reference to the current socio-political context of dementia care. In doing so attention will be paid not only to ‘sharing’ within close interpersonal relationships, but also to a wider notion of ‘sharing’ that might be seen as relevant throughout society as a whole.

**7.8 Implications of the ‘sharing’ theory for Policy and Practice in light of current socio-political developments**

In order to more fully consider the potential implications of the ‘sharing’ theory and the benefits of adopting the relational approach to responding to the challenges dementia poses that is implicit within the notion of ‘sharing’, it is important to highlight the socio-political context within which current debates are located. This section begins by presenting an overview of this.

Dementia continues to be identified as the disease people fear more than any other with 35% of people over the age of 55 fearing Alzheimer’s compared to 25% fearing cancer (DoH 2013). This in part can be seen as due to the stigma, negative stereotypes and associations that the term Dementia or Alzheimer’s conjures in peoples’ minds. The ‘Dementia Friendly Communities’ initiative (Alzheimer’s society 2013 & DoH 2013), has identified that increasing public awareness and understanding is key to challenging such images. The importance of countering negative attitudes to dementia that prevent people leading full rewarding lives, is central to this approach:

“A dementia friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them” (Alzheimer’s society 2013)

The dementia friendly communities programme was started by the Alzheimer’s society in September 2013 and draws together local community groups, leaders and organisations, with businesses, the voluntary and statutory agencies to achieve ‘dementia friendly’ status through increasing awareness, involving people with dementia and setting clear local goals. These initiatives are fully inclusive of younger people with dementia, with no age specific components or exclusions.

A parallel initiative was the Prime Minister’s Dementia Challenge which was launched in the UK in March 2012 and a progress report was published in May 2013 (Gov.UK 2013). The challenge comprises three key aims:

1. Driving up improvements in health and care
2. Creating dementia friendly communities
3. Improving dementia research

As with other policy directives and drivers, the Prime Minister’s challenge does not significantly distinguish between older or younger people with dementia. The 2013 progress report for the ‘Challenge’, identified that overall dementia diagnosis rates in the UK had increased by 6 per cent over the preceding two years and that 50 communities across England had signed up to the ‘Dementia Friendly Communities’ initiative. As is clear from the above there have been several recent policy initiatives in respect of dementia in general, and to a lesser extent, younger onset dementia that serve to highlight the present socio-political context within which debates are taking place. However based on the findings of this study and recent other research in the field I would argue that if such aspirations are to be achieved then ‘sharing’ has to occur at all levels, from the interpersonal to the societal, this is especially so for YPWD and those close to them. Moreover, as I will go on to suggest, there needs to be far more explicit recognition and acknowledgement of the potential benefits of adopting a collective and relational approach to responding to dementia as opposed to the largely individualistic one that still predominates. To place these arguments into further context, attention is turned below to recent epidemiological work on dementia at a younger age.

Dementia at a younger age is now known to be much more prevalent in the UK than previously thought. In 2014 it was estimated that there were at least 42,000 YPWD in the UK, but this figure could be much higher due to the complexities of diagnosis (Young Dementia 2014) Since the commencement of this study diagnostic rates of dementia in the UK at a younger and older age, have increased and the proportion of people with dementia under the age of 65 years as a percentage of this total has grown. What was often thought of as a comparatively small and diverse group of people is now known to account for at least 1 in 20 people with a diagnosis of dementia (Alzheimer’s society 2014). While the percentage of people with dementia who have received a diagnosis has clearly increased, it is also recognised within UK health policy that this still needs to substantially increase much further, in order that everyone can receive an appropriate and timely diagnosis and access to the education, information, support and potential treatment that this brings. As has been presented in the current study and previous reports over recent years, YPWD in particular often face a difficult journey towards diagnosis, with delay in receiving an accurate diagnosis and the potential negative impact that this can have on both them and their family. To date it remains unclear if this situation has significantly improved for people ‘noticing something unusual’ at a younger age, in terms of access to specialist diagnostic teams or services in the UK (Alzheimer’s Society 2014a). My own study, albeit on a small scale, would suggest that much remains to be done at all stages before, during and after receiving a diagnosis.

The findings from the current study (and others described above) demonstrate the importance of a wide range of people, from YPWD themselves and those close to them, to health and social care professionals and beyond that to employers, being more attuned to issues around access to assessment and diagnosis at an early stage, and on-going support thereafter. There remains a patchy network of specialist diagnostic provision and specialist service provision for YPWD around the UK (Young Dementia 2014). There is clearly a need for increasing awareness of the importance of early diagnosis, combined with more accurate epidemiological modelling of prevalence that can inform service commissioning in areas where access to specialist services is absent. As people become more aware of the possibility of dementia at a younger age it is likely that greater numbers of younger people will seek assessment while any cognitive symptoms are relatively mild and this in turn will demand more specialist diagnosis to meet that need effectively in a timely way (Young Dementia 2014). It is here that a form of ‘sharing could play a central role. Knowledge of the existence and prevalence of younger onset dementia is currently limited, not only amongst health professionals but also the wider population. This would suggest the need to ‘share’ the information we have far more widely and to raise awareness across society if negative stereotypes about dementia are to be challenged. This, as noted above, is central to current socio-political aims.

Despite some increased awareness, negative stereotypes continue to persist and hide the complexity and variety of individual experience of what ‘dementia’ actually means. It remains the case that Alzheimer’s disease prevails in many people’s minds as inextricably linked with the term dementia and from personal experience as someone working each week in a diagnostic memory clinic, it is rare that a week passes by, without someone asking me, *‘What is the difference between Alzheimer’s and dementia?’*. Within the current study there were examples of participants experiencing; Lewy Body dementia, vascular dementia and Alzheimer’s disease, amongst a relatively small sample of YPWD. There is a need for greater public awareness of the specific forms of dementia people can experience (and at what range of ages), in order to increase a truly societal inclusion and to reduce stigma as part of understanding the diversity of experience within having ‘dementia’. It is not until we have a ‘shared’ understanding of dementia that prevailing stereotypes will be challenged. In relation to older people with dementia much was done to raise awareness of its prevalence and impact when high profile public figures, such as the late president of the USA, Ronald Regan, ‘shared’ his diagnosis publically. In the UK this was taken much further by the author Terry Prachett who bravely ‘shared’ his journey from diagnosis to death in the public media. Such public ‘sharing’ by prominent YPWD would seem to have much to commend it as reducing fear and uncertainty might promote more early contact with health services. Providing that practitioners are appropriately trained the diagnostic journey and the difficulties it currently poses could be significantly improved. Moreover, greater openness at this time could do much to encourage the ‘sharing’ of the diagnosis, or at least conscious and carefully thought through decisions not to share it, within the YPWD’s family and wider social network. Such sharing would enable potential problems to be identified at an early stage, meaning that transitions could be planned for much more carefully and managed accordingly.

Notwithstanding the obvious difficulties YPWD face, ‘sharing’ positive accounts of those who continue to lead fulfilling lives, with examples of people staying in paid work, maintaining leisure activities, or developing new ones, is vital to give hope and direction to YPWD, those close to them and to the wider community, in line with current ‘dementia friendly communities’ work. There are clear positive examples of this within the current study alongside more negative experiences and accounts

As well as considering the negative impact on relationships and social functioning for YPWD and those around them when diagnosis is protracted, delayed or inaccurate, there has also been shown to be a negative effect on the person’s employment. When a diagnosis of dementia had been shared within the current study there were examples of employers successfully adapting work roles and thereby improving the YPWD’s potential to maintain positive psychological well-being as well as minimising the financial impact. Such examples could be shared more widely with employers and actively promoted as representing good working practices that all employers should seek to emulate. Conversely there were also instances where awareness of a diagnosis of dementia led to the YPWD experiencing stigma and of their employment being severed with the transition out of work being very poorly managed. This happened even when one might expect a more informed approach to be adopted, for example in the education sector. It is also important to raise awareness of such practices by sharing examples, albeit anonymously if appropriate.

In large part the nature of the employer’s reaction to participants in the current study ‘sharing’ their diagnosis of dementia, may be seen to reflect societal attitudes as a whole. Where the label dementia was seen to have purely negative or frightening connotations, the employer appeared to make a blanket decision, whereas in the more positive examples time was taken for the employer to understand the specific impact of the YPWD’s symptoms on their work role and whether adaptations or adjustments could be made to incorporate this, enabling them to continue working.

Current policy statements in England indicate that earlier diagnosis of dementia is beneficial (DoH 2013). This is strongly reflected in the findings of the current study with younger people in line with other more recent accounts and reports, both from the UK and elsewhere as highlighted earlier in this chapter.

The current study and the ‘sharing’ model also have implications for the provision of more appropriate support for YPWD and those close to them. Recent investigations of service provision by statutory bodies in the UK indicates that there has been a slight increase in specific provision for YPWD in some parts of the United Kingdom but;

“..generally this has been slow and access to good-quality care and support varies across the country (SCIE 2013, Page 1).

This clearly suggests the need to provide more and better services. However, the current study would suggest that simply delivering ‘more of the same’ will not suffice and that there is also a need to reconceptualise the type of support that is provided. Whilst services such as respite care will remain important the growing awareness of the central role played by relationships argues for the evolution of more innovative forms of shared support. Whilst not denigrating the need to provide services that target either YPWD or their carers in their own right, a relationship-centred model, with ‘sharing’ at its heart, would suggest the need to promote services that focus on the nature and quality of relationships and that target both dyadic relationships and those in the wider family. The nature of such ‘relational work’ is as yet not fully clear but support aimed at maximizing sharing and involvement so that YPWD and those close to them can work more actively together from an early stage would appear to provide a way forward. Also central to such services would be efforts to ensure that YPWD can have access to a range of personally meaningful purposeful activity to help them maintain an active role in society.

Such ambitions are implicit in a recent comprehensive dementia report for England from the Department of Health (2013), that identified a number of developments that are needed to improve the future experience of people with dementia of any age, these are captured below;

“We want a society where people with dementia can honestly say:

* I was diagnosed in a timely way.
* I know what I can do to help myself and who else can help me.
* Those around me and looking after me are well supported.
* I get the treatment and support, best for my dementia, and for my life.
* I feel included and part of society.
* I understand so I am able to make decisions.
* I am treated with dignity and respect.
* I am confident my end of life wishes will be respected. I can expect a good death.
* I know how to participate in research.”

(Dementia: A state of the nation report on dementia care and support in England, DoH, 2013, p 5)

Clearly for many of the participants in my study these aspirations had not been met and therefore addressing them appears well founded. However, as laudable as these aims might appear the frequent use of the term **‘I’** betrays an approach that is still, implicitly at least, underpinned by an individualistic understanding of the needs of people with dementia. If a relational model is to emerge there needs to be a cognitive shift away from ‘I’ and towards ‘We’. However, the challenges this poses should not be underestimated as the dominance of an individualistic approach to dementia is reinforced in the aims below, produced by the Dementia Action Alliance, another key national initiative to improve the lives of people with dementia of any age. Hosted by the Alzheimer’s society this initiative brings together organisations across England to create a; ‘society wide response to dementia’ (Alzheimer’s society 2014). Members were required to submit an action plan to deliver the Declaration’s required outcomes to Government. This is reproduced below:

* I have personal choice and control or influence over decisions about me
* I know that services are designed around me and my needs
* I have support that helps me live my life
* I have the knowledge and know-how to get what I need
* I have a sense of belonging and of being a valued part of family, community and civic life
* I live in an enabling and supportive environment where I feel valued and understood
* I know there is research going on which delivers a better life for me now and hope for the future (Dementia Action Alliance 2011).

Once again whilst appearing laudable these aims are cast entirely within an individualistic model of understanding and responding to individual needs. Whilst it would of course make no sense to suggest that YPWD do not have individual needs to cast the entire debate and related policy aspiration within an individualistic model provides a very narrow socio-political context. The adoption of a more relational approach, as advocated for in recent literature and reinforced by the current study provides a more holistic and inclusive approach, wider dissemination of the ‘sharing’ theory might help to add to, and advance, current debates.

The three continua outlined earlier, and reproduced again below, could be used as a heuristic to stimulate debate and as a means of illustrating how sharing, involvement in decision-making and working together can be promoted to advance a more informed approach to shaping both individual and societal responses, not only to dementia at a younger age but to dementia at any age.

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From the previous broader literature review and discussion of the ‘sharing model’ in the context of dementia at any age, it is clear that regardless of chronological age there can be sharing or absence of sharing at a range of levels for someone experiencing dementia and those close to them. The ‘Prime Minister’s Challenge’, the ‘Dementia Friendly Communities’ initiative (2013) and the DoH report ‘Dementia’ (2013), all promote societal inclusion for someone with dementia. In part this relates to tackling stigma to promote inclusion, by increasing awareness and working organisationally such as with employers to support PWD in continuing to positively contribute to and engage with their communities. In this way where exactly the (Y)PWD is on the ‘sharing continuum’, may well relate to broader societal and politically motivated controls and mechanisms, such as employment law, equalities law and the benefits system. These broader social mechanisms of potential control may then be experienced in conjunction with the extent to which the symptoms of the person’s dementia impact on their ability to share in activities such as work. The context of the PWD’s close relationships will also relate to how openly ‘sharing’ takes place with those closest to the person and whether there is fully shared decision making, or alternatively where others make a decision on their behalf. Of course there will be times when the latter is necessary but the goal should be to maintain active involvement for as long as possible. The ‘Sharing Continuum’ suggests how specific forms of decisions are made by, with, or for a (Y)PWD within the overall ‘Sharing Theory’ and as such may provide a useful tool to promote and stimulate debate about enhancing possibilities for sharing.

Having discussed the sharing theory within the current socio-political context and argued that debates should be broadened, attention is briefly turned to implications for education and training and further research.

Education and training implications from the current study

In recent years there has been an emphasis on the need to train health and care staff in dementia awareness (NHS Health Education England 2013). It is increasingly recognised that hospital staff and home care staff amongst many other care providers will necessarily have regular contact with people experiencing dementia and need to be responsive to their needs. Within this approach there remains a need to now recognise that dementia at a younger age is much more prevalent than previously thought and likely to be encountered across a wide range of health and social care settings and situations.

As has been highlighted in this chapter, there are similarities but also significant differences in the experience of dementia at either a younger or older age. It is hoped that the sharing theory can add to a slowly growing body of theory and knowledge of how to recognise and understand the complex impact of dementia at a younger age on the YPWD and those close to them in terms of their relationships and societal roles. The potential benefit of the sharing model specifically for education and training may be in representing the complex ways in which maintaining, adapting or abandoning can occur simultaneously and that there is not a neat linear pathway from mild symptoms to dementia progression that equates with an easily predicted range of needs. If training and education packages and curricula for health and social care staff and students can take account of this complexity, the sharing model may provide a way to conceptualise and understand what the YPWD and those close to them are experiencing and tailor appropriate forms of support when and where they are needed and wanted.

This is of course will require a shift on the part of practitioners too and they will need to be provided with the skills and resources to expand their repertoire of interevntions to reflect a more relational approach.

Implications for further research

While there has been clear investment in finding a better understanding of the causes of specific dementia diseases and treatments for YPWD (Alzheimer’s Research UK 2014), there is also a clear need for more evidence, information and understanding of how YPWD and those around them can understand and positively adapt to what they are experiencing. A broader deeper understanding of the psychological, social and relationship processes involved can inform choice and self-determination for those directly affected and influence societies’ response to those needs. As can be seen from the initial literature review for this study and published research during the course of the current study, there is recognition that the experience of dementia at a younger age can be different from the experience in older age for many people. More people are affected by dementia at a younger age in the UK than was previously thought (Dementia UK 2014) and therefore the need for appropriate responses from supportive health and social care agencies is significant and will need to be based in the reality of what YPWD need and want to live over often many years with this condition. As diagnosis rates improve and hopefully increased awareness leads to earlier more accurate diagnosis for YPWD in the UK, so the demand for an understanding of what factors promote and support positive living and adaptation is likely to grow.

At present there is a relatively limited range of small-scale qualitative studies that have explored the experience of dementia at a younger age based in the experience of those directly affected themselves. The sharing theory highlights the complex relational and societal factors involved in how YPWD maintain, modify and abandon aspects of their lives over the temporal journey from ‘Noticing something’ to ‘Getting on with it, where do we go from here?’. More research is needed grounded in the experiences of YPWD and those close to them, connecting with previous studies to more systematically explore how YPWD and those close to them can truly ‘live well with dementia’. There is an evident need for more information on how and why families respond in certain ways to younger dementia and how social inclusion can be promoted and maintained through employment, recreation and participation for YPWD themselves.

As this study has sought to be as inclusive as possible and to engage YPWD and those close to them in ‘co-constructing’ the sharing theory it seems appropriate to turn attention to how their voices can better be heard by considering some developments emerging from the current study.

YPWD sharing their stories

YPWD need to become more visible and share their stories. One of the participants in this study has since gone on to recently appear on a national morning television programme and their story is prominent on national support group information for YPWD and their families (Young Dementia 2014). This person has gone on from initially sharing their story with friends, neighbours and family, to becoming the lead for a local self-help group for YPWD and then moving on further to highlight at a more national level exactly how difficult achieving an accurate diagnosis can be for a YPWD. Her message is also a very positive one, describing how it is possible to positively adapt to the presence of dementia in someone’s life at a younger age.

It was clear throughout the interview processes for the current study that both YPWD and those close to them had a strong need to tell their story and describe how dementia had affected them, whether positively or negatively. As these stories are shared more widely and public and professional awareness of dementia at a younger age grows, so access to an appropriately speedy diagnosis is likely to improve. It will then be important to ensure that health and social care provision is able to respond to the often complex needs of these individuals as they negotiate a difficult journey with relationships and societal involvement key to ‘living well’ with dementia at a younger age.

The importance of how a diagnosis is shared and the ways in which this appears to shape people’s self-perceptions and psychological and emotional responses to their dementia have been highlighted by many of the participants. This impact needs to be recognised and planned for by existing services designed to meet the needs of YPWD.

Examples of difficulty in maintaining employment or coping with sudden stigmatising severance of employment can be addressed, such as through dementia friendly communities work. The goal would be for employers and employees to come together to adapt the workplace and respond positively to this form of illness, rather than being frightened or making inappropriate reactions out of fear, stigma or misunderstanding of health and safety issues for example.

It is clear that while there is a temporal journey for most YPWD over time characterised by symptom progression, the ways in which they are maintaining, adapting or abandoning aspects of their lives does not follow any standard linear model. Understanding the key importance of the multifaceted aspects of how ‘sharing’ mediates in these processes can enable services for YPWD across the span of their journey with dementia to tailor information, education and support in ways which promote informed choice for YPWD and those close to them in how they wish to deal with the practical, emotional, social and psychological impact of this progressive disease process. This indicates that YPWD require individually tailored support over time that is responsive to their shifting needs and how and with whom they want to share information at any one time. From the individuals in the current study it can be seen that YPWD are not a homogenous group. This term includes a number of specific neurological conditions, each with a different variety of core symptoms. Layered over this is the unique pre-existing biography, social and relationship context for any one YPWD. These factors, together with the individual variation in disease severity or progression over time create a unique set of circumstances for each individual. It is because of this very significant diversity over time, that it is so difficult to cluster YPWD in a way that fits with models of service provision. Any model of support therefore needs to take account of this diversity and to employ a more flexible theoretical model of understanding where a concept such as ‘sharing’ can assist in highlighting these complex shifting and nuanced processes.

Services therefore need to be flexible and responsive, with the capability to tailor individual support to YPWD and those close to them, utilising examples of positive maintaining and adaptation with the person, families, friends and employers so that ‘dementia friendly communities’ becomes a reality and an expectation for YPWD, based on shared expectations of positively living with dementia drawn from the accounts of others.

For individual practitioners working to support and empower YPWD and those close to them, it is hoped that the sharing theory can foster a deeper understanding of the forms of positive adaptation and maintaining that can be achieved and recognition of how and when abandoning occurs of any aspect of the YPWD’s life and how can they can be supported through this process. The sharing theory seeks to simplify and make visible a broad range of potential complex interactive processes experienced by YPWD and those close to them. Making this complexity more visible and understanding this may also be potentially beneficial to YPWD utilising self-help materials or attending self-help groups or education sessions, as well as for those around them

**Final thoughts**

At the outset of this study one of my main areas of focus was on developing a deeper understanding of what it is to live with dementia at a younger age. I had experienced in clinical practice many times the complex dynamics between couples or families in the presence of dementia, but had often struggled to see beyond their concrete issues and to consider these within a broader conceptual framework. Through the systematic analysis and theory generation of the current study, a clearer view and understanding of the shifting complex relationship dynamics and the role played by sharing or not sharing in this process became apparent. Even more surprising (at least to myself) was the emergence sharing as the key social process that shaped the dementia experience.

In many ways it was relatively straightforward to identify the key temporal stages experienced by YPWD over time and they were often able to openly articulate the periods or points of transition in their journey with dementia. It was the nature of the more complex and shifting relationships between the temporal stages of: ‘Noticing something unusual’, ‘What’s happening?’: ‘Seeking a diagnosis’, ‘Receiving & sharing a diagnosis’, ‘Where do we go from here?’: ‘Getting on with it’ and how these related to maintaining, adapting or abandoning aspects of their lives and the lives of those close to them that was much more difficult to conceptualise. Eventually through repeated systematic analysis ‘sharing’ emerged as the constant mediating social process that enabled a description and understanding of how someone could at any one point in the temporal journey of dementia at a younger age, be simultaneously abandoning some roles or relationships, while adapting or maintaining other significant elements in their lives.

It was not surprising that many of the YPWD and those close to them had been deeply affected by issues such as prolonged periods struggling to get a diagnosis or abandonment (through choice or otherwise), of societal roles or personal relationships. However equally there were many positive and inspiring examples of adaptation in the face of dementia at a younger age and it is a testament to the willingness and openness of the participants that they were so willing to share these sometimes painful, sometimes positive, but always powerful and often emotive experiences.

As it becomes apparent that the prevalence of dementia at a younger age in the UK is significantly more than recently thought (Dementia UK 2014), there is a clear need for theories and models that YPWD themselves and those close to them, as well as policy makers, educationalists and health and social care practitioners can utilise. It is hoped that the sharing theory can add to a growing body of knowledge and developing theoretical understanding of the complex interplay of factors within which YPWD have to find a path on their journey to living with dementia.

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