

Doctoral Thesis

Perspectives of People with Dementia: Experiencing Shame.
An Interpretative Phenomenological Analysis

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Abstract

Background

People with dementia who have participated in research have reported experiencing shame (Cheston, in press; Mitchell, McCollum & Monaghan, 2013), and other uncomfortable self-conscious experiences, such as self-criticism (Langdon, Eagle & Warner, 2006), embarrassment (Imhof, Wallhagen, Mahrer-Imhof & Monsch, 2006), and fears of stigma (Harman & Clare, 2006). Public Health guidance has emphasised the importance of addressing the stigma and marginalisation of people with dementia (Department of Health, 2009; World Health Organisation & Alzheimer's Disease International, 2012).

Methodology

This study uses Interpretative Phenomenological Analysis to explore experiences of shame for six people in the early stages of dementia, living independently in the community. Data was collected through the use of individual, semi-structured interviews conducted within participants' homes. The interviews were transcribed by the primary researcher and analysed through an in-depth, interpretive examination.

Results

Four superordinate themes emerged from the data. Firstly, Avoidance reveals how the participants made several levels of attempts to hide and distance themselves from shaming experiences. Secondly, the participants' accounts highlight Negative Self-Perceptions, including a weakening sense of self, a loss of value, and meaninglessness. Thirdly, Relationship Matters involve issues around trust, feeling a burden, and the impact of past relationships on current levels of shame. Fourthly, Uncertainty and loss of control highlights the participants' search for an understanding of their experiences, and fears about an unknown future and losing control.

Conclusion

The study contributes ideas for developing both public and professional awareness for promoting non-shaming experiences for people with dementia. In particular, suggestions are provided for improving communication during the assessment and diagnosis process, as well as options for responding to shame through psychological therapies.

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1. Introduction

1.1 Overview

This chapter begins with an introduction to dementia, some of the key concerns surrounding dementia, as well as the changing contexts in which dementia is understood. Then, a review of research is presented that explores lived experiences for individuals with dementia, relevant to this study, followed by a critique. The following section is focussed around shame, beginning with a description of existing psychological models of shame, which are then applied to experiences of dementia. Further, some of the specific processes that have been implicated in experiences of shame for people with dementia are discussed. A summary of the chapter is then given, followed by a rationale for the current research. The chapter closes with a statement of the research questions. At the end of each chapter, a reflection from the researcher is provided, offering her personal experience of engaging with the study at each of its main stages. This in line with an Interpretive Phenomenological approach, of which more details are provided in section 2, Methodology.

1.2 Dementia

Dementia is an umbrella term used to describe a set of cognitive, emotional, behavioural and physical symptoms, caused by structural changes in the brain as a result of progressive diseases or injuries, for which there is no current cure (WHO, 2012). The main cognitive symptoms include decreased memory function, reduction in concentration, problems with planning and organisation, reduced language and visuospatial skills, and increased disorientation. Emotional changes include increased anxiety, irritability and low mood. As dementia progresses, behavioural changes such as repetitive questioning, wandering, and increased aggression are reported, as well as physical changes in appetite, sleeping patterns, and decreased mobility (Alzheimer's Society, 2013). Dementia is described as a major cause of disability among the older generations, and can have an extremely stressful social and emotional impact upon sufferers, caregivers, and families (WHO, 2012).

Dementia is significantly more common in people over the age of 65 (Alzheimer's Society, 2014). The prevalence of dementia increases with age, from 2% in men and 1% in women aged 65-69, 12% for men and 14% for women aged 80-84, to 32% in men and 36% in women aged 95-99 (Alzheimer's Research UK, 2014). There are approximately 800,000 people in the UK living with dementia (Alzheimer's Society, 2014), and worldwide, at least 35.6 million people have a diagnosis (World Alzheimer Report, 2011). With the ageing of the

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge world's population (WHO, 2012), particularly among the "oldest old", those above age 80, numbers of people with a diagnosed dementia are expected to double every 20 years (WHO, 2012). This is particularly relevant for the next few decades as people born in the post-world-war II "boom", (the "baby-boomers") become our older generations.

1.2.1 The challenges to living well with dementia. It can be enormously difficult for people to make the adjustment to living with a diagnosed dementia, due to the social difficulties in talking about dementia, the emotional shock of a diagnosis, and the impact of the neurological impairment (Cheston, in press). It is estimated that 20 to 32 per cent of people with a diagnosed dementia experience clinical depression (Shub & Kunik, 2009). Estimated prevalence rates of anxiety disorders in dementia vary from 38 to 72 per cent (Badrakalimuthu & Tarbuck, 2012; Shub & Kunik, 2009). Furthermore, symptoms of depression and anxiety can make the severity of cognitive difficulties appear worse (Badrakalimuthu & Tarbuck, 2012). The assessment of depression and anxiety disorders in people with dementia is challenging, because of the overlap in symptoms across diagnoses, such as decreased energy, and poor concentration (Alexopoulos, 2014).

1.2.1.1 Stigma. Brooker (e.g. 2010; 2011; 2012) contributed an abundance of research and education aimed towards improving the lives of people with dementia, and highlights the risk of stigma and discrimination that people with dementia face. However there is little research that directly asks people with dementia about their experiences of stigma. Werner & Heinik (2008) conducted telephone interviews with 61 caregivers of people with dementia, finding that a high percentage of caregivers reported awareness of stigma directed towards their relative (61%). The participants frequently reported that there were not enough services for people with dementia (60%) or caregivers (78%). It was commonly reported that since their diagnosis, the person with dementia had been treated differently by family members (34%), and health professionals (29%). A much larger survey, "The World Alzheimer Report" (World Health Organisation (WHO) & Alzheimer's Disease International (ADI), 2012), details that 24% of people diagnosed with dementia reported hiding their diagnosis due to fears about stigma, 40% of people with dementia reported feeling excluded, and many others reported feeling marginalised by society. Despite including over 2,500 participants world-wide, including mainly carers, only 157 were people with dementia.

The WHO and ADI developed ideas for targeting stigma around dementia and enabling dementia friendly communities. These include fostering the participation of older people within society, and creating more inclusive and accepting societal attitudes towards

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge people with dementia. Similarly, the “National Dementia Strategy: Living well with Dementia” (Department of Health (DoH), 2009) provides objectives for improving public and professional education in relation to dementia in order to reduce stigma. Also emphasised is the importance of early diagnosis so that people with dementia are able to take better control over their illness, be actively involved in planning their care, and be supported to live well with dementia. However, it is estimated that the rate of non-disclosure of a diagnosis of dementia to the individual is 40%, due to fears about the emotional impact on the person (Bamford, 2010, in Mitchell, McCollum & Monaghan, 2013). This illustrates how professionals can unintentionally add to the experience of exclusion that people with dementia report. Mitchell et al. (2013) conclude that the person with dementia should be of central presence throughout their care, particularly at diagnosis.

1.2.2 The changing context of dementia.

1.2.2.1 The medical model. Dr Alois Alzheimer wrote up the first identified case of dementia, following 51 year old Frau Auguste D’s admission to a German asylum in 1901. Alzheimer wrote that she presented with “reduced comprehension and memory, as well as aphasia, disorientation, unpredictable behaviour, paranoia, auditory hallucinations and pronounced psychosocial impairment”, (Maurer, Volk & Gerbaldo, 1997, p1546-2547). Alzheimer hypothesised that these behaviours were due to plaques and fibrils found in Frau Auguste D’s brain, without recording any of her social context or psychosocial history to help understand her case (Cheston & Bender, 1999; Kitwood, 1997a). This approach to understanding mental health was common at that time, thus dementia was solely attributed to neurological changes, ignoring any psychosocial factors involved. This set the context for dementia over the following century (Cheston & Bender, 1999). Today, in western societies, the medical model contributes much of what is understood about assessing, diagnosing and treating dementia.

1.2.2.2 The psychiatric categories of dementia. The Diagnostic and Statistical Manual of Mental Disorders 5th edition (*DSM-5*; American Psychiatric Association, 2013) introduces the term Neurocognitive Disorder (NCD) to label what the DSM-IV previously, and what the International Classification of Diseases 10 (ICD-10, WHO, 1992) currently classifies as the Dementias. Major and Mild NCD are categorised to represent the different levels of severity of cognitive impairment, including those who have modest cognitive deficits in comparison to previous performance but can function independently, otherwise known as Mild Cognitive

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Impairment. The change in label of Dementia to Neurocognitive Disorder is a focus of debate
(Ballenger, 2010; Siberski, 2012). The rationale for renaming dementia in the DSM-5 includes
concerns that the term dementia is stigmatising and pejorative (Ganguli et al., 2011).
However, critics argue that the change in terms causes confusion (Siberski, 2012), and that the
stigmatising power of the label *dementia* comes from a cultural marginalisation of aging and
cognitive impairment rather than the label itself (Ballenger, 2010).

The ICD-10 and DSM-5 offer slightly varied definitions for dementias and NCD. Nevertheless, both classification systems use similar sub-categories to separate the most prevalent types of dementia/NCD. Dementia/NCD of the Alzheimer type accounts for 60-80% of cases of dementia, and is marked by a gradual decline of general cognitive functioning (Alzheimer's Society, 2013). This is described as resulting from a loss of neurons and synaptic connections, an overall shrinkage of the brain, and degeneration in cell structure (Alzheimer's Association, 2014). Early symptoms include difficulty remembering recent events and conversations. Depression, apathy, anxiety, and behavioural changes are noted as symptoms of the disease. Later difficulties include impaired communication, disorientation, and finally difficulties with mobility and swallowing (Alzheimer's Association, 2014). Vascular dementia/NCD accounts for about 10% of dementia cases, and is associated with problems with the cardiovascular system that lead to a lowered blood supply to the brain. Vascular dementia has a more stepwise pattern of progression (Alzheimer's Association, 2014). Initial symptoms include difficulties in making decisions, planning and organisation, before symptoms of the Alzheimer's type follow (Alzheimer's Association, 2014). Less common types include Dementia/NCD with Lewy Bodies, which involves sleep disturbance, visual hallucinations, and impaired motor-control; Frontotemporal dementia/NCD, which involves increased disinhibition, personality changes, and language difficulties; and Parkinson's disease, Huntington's disease and Wernicke-Korsakoff syndrome. Despite the proposed marked differences between the categorised types of dementia, in reality there is a substantial degree of commonality between cases. People often show a combination of characteristics across dementia subcategories simultaneously, and therefore not fitting into a single category, are diagnosed with a mixed dementia. Around half of dementia cases of the Alzheimer's type also involve other dementias, usually vascular dementia (Agüero-Torres, Kivipelto, & von Strauss, 2006; Alzheimer's Association, 2014).

1.2.2.3 The person-centred approach. Kitwood's (1997a) person-centred approach influenced a marked shift in the way that dementia was understood. Kitwood (1997a)

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge emphasised the importance of personhood, that each person should be recognised and respected as a unique individual, within the context of their family and wider social environment. Kitwood (1997a, 1997b) was most concerned with understanding the subjective world of the person with dementia, their emotional experiences and perceptions of what is happening to them. Kitwood (1997a) criticised the medical model for neglecting the subjective experiences of people with dementia and undermining personhood. He argued that this exacerbates a dehumanising cultural attitude towards dementia that informs damaging social interactions, which he termed “Malignant Social Psychology” (Kitwood, 1990). Kitwood (1990) observed care settings for people with dementia, noting interactions in which they were undermined. He developed a list of 17 “personal detractions” (p.40), including ignoring, mocking, blaming, disparaging, and invalidating. Kitwood (1997a) concluded that these interactions disempower and disable the person with dementia further than their neurological changes. Kitwood’s (1997a) ideas were shared by others, who felt that the behavioural and emotional responses in dementia are best understood as changes in the person’s emotional security, self-view and identity (Cheston & Bender, 1999; McCormack, 2004). Supporting the concept of “Malignant Social Psychology” with a series of case studies, Sabat (2002) argued that even in the advanced stages of dementia people retain a self, but that this is threatened by harmful interpersonal responses through the caring relationship.

1.2.2.4 Positive person work. Kitwood (1997a) developed a framework for “positive person work”, consisting of 12 categories of interactions that caregivers could practise to promote well-being and personhood for people with dementia. The categories include recognition, negotiation, validation, play, and holding, with examples for promoting choice, empathy, and opportunities for creativity to people with dementia within caregiving activities. Davis (2004) criticised Kitwood (1997b) for being idealistic and implying that experiences of dementia can be transformed, without providing empirical evidence for how this can be realistically applied. Davis (2004) argued that Kitwood (1997b) does not appreciate the challenges involved in caring for a person with a dementia, and that this is likely to promote feelings of guilt and despair in carers who found difficulty in maintaining personhood for dementia sufferers.

Kitwood’s ideas for person-centred care were taken forward with suggestions for applying them within care services. McCormack (2004) emphasised the need for choice and partnership in care decision making, and a focus upon the individual’s remaining elements of the self. Brooker (2003) made suggestions for creating a positive social environment around

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge the person with dementia, promoting their well-being, and valuing their perspectives. National guidance policies, based upon an evidence base for how to facilitate person centred care, emphasise that older adult acute and community care settings should aim to enhance the experience of health care, support shared decision making, improve training for professionals, and improve information giving (DoH, 2001; National Institute for Clinical Excellence, (NICE) 2006).

1.2.2.5 Psychological perspectives of dementia. A number of psychological approaches for understanding dementia became more familiar over the last 20 years. These draw mainly upon psychodynamic, behavioural, and cognitive-behavioural approaches, and can be used in combination with the medical model to provide a more adequate biopsychosocial understanding of dementia presentations.

Psychodynamic theories describe emotional and behavioural changes in dementia in terms of psychological defence mechanisms. A loss of skills and independence is said to trigger anxiety and shame, which is then managed through denial, projection and withdrawal (Evans, 2008; Soloman & Szwabo, 1992). These protective functions cause the appearance of more severe cognitive abilities (Evans, 2008). A person's earlier experiences are believed to influence their sense of self-worth, as memories from the past merge with the present (Sadavoy, 1991). As the person feels increasingly vulnerable, early attachment behaviours can be observed, such as seeking reassurance, and searching for caregivers (Evans, 2008). Psychodynamic therapies emphasise the value of safe, accepting therapeutic relationships to help people feel supported and understood (O'Connor, 1993), facilitate the resolution of earlier conflicts, support acceptance (Brierley, Guthrie, Busby, Marino-Francis, Byrne & Burns, 2003), help integrate changes in their experiences, and improve coping responses (Soloman & Szwabo, 1992). The majority of evidence for psychodynamic psychotherapies for people with dementia comes from case vignettes (Kasl-Godley & Gatz, 2000). Cheston and Jones (2009) compared exploratory group psychotherapy with a psychoeducative intervention for 16 dementia patients. This is one of the few studies of its kind that blinded participants and the data collector to different conditions, thus reducing expectancy bias. They found a significant statistical interaction between mode of therapy and level of depression (Cornell Scale of Depression in Dementia (CSDD), Alexopoulos, Arams, Young, & Shamoian, 1988), and a borderline significant interaction between mode of therapy and level of anxiety (Ratings of Anxiety in Dementia, Shankar, Walker, Frost, & Orrell, 1999); with decreased scores following the psychotherapy group, and increased scores following the psychoeducative

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge group. Although the psychotherapy group is said to have involved the analysis of the group dynamic, making interpretations, and drawing together themes, it is not clear what therapeutic model the intervention was based upon. A randomised controlled trial (Burns et al., 2005) compared 6 sessions of psychodynamic interpersonal therapy and treatment as usual for 40 participants. Other than a trend towards reduced CSDD scores, no significant improvements were found on a range of outcomes for the dementia participants. The use of attachment theory for formulating and caring for people with dementia is evidenced in a review of 18 studies exploring attachment behaviours in people with dementia and their carers (Nelis, Clare & Whitaker, 2013), concluding that attachment behaviours are observable at various stages of dementia, and that attachment security had implications for both the person with dementia and their carer's psychological health. However, the review contained inconsistent measurements of attachment styles, which are not validated for dementia populations.

Behavioural approaches explain how, when a person is unable to rely upon adaptive communication and problem-solving skills, they will engage in problematic behaviours such as wandering and aggression as a means of communicating their needs (Cohen-Mansfield, 2008; James, 2011; Moniz-Cook, Stokes & Agar, 2003; Stokes, 2000). Challenging behaviours can increase carer strain, and elicit negative responses, which in turn worsen distress in the person with dementia (James, 2011). Behavioural approaches thus inform the use of Functional Analyses, to assess the function of challenging behaviours, and design tailored interventions that aim to support the wellbeing of dementia patients through improving the system and environment around them (Gallagher-Thompson, Gray, Dupart, Jimenez, Thompson, 2008; Haupt, Karger & Janner, 2000). Behavioural interventions are evidence-based by a review (Moniz-Cook, Swift, James, Malouf, De Vugt, Verhey, 2012), although this contained a wide range of other interventions, making it difficult to assess the true contribution of behavioural interventions. Nonetheless, behavioural interventions are recommended as a first line treatment of behavioural and psychological symptoms of dementia (NICE, 2006, Banerjee, 2009).

Cognitive-behavioural approaches explain how, when the person first notices a loss in skills and abilities, self-perceptions of incompetence may influence psychological distress, as well as coping responses (Laidlaw, 2015). They may over-attend to cognitive mistakes, develop negative expectations for future events, and withdraw from their social activities for fear of embarrassment (Laidlaw, 2015). People around the person with dementia may attempt to reduce their distress by relieving them of responsibility, which can reinforce feelings of

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge worthlessness (Laidlaw 2015). Cognitive Behavioural Therapy (CBT) for people with dementia aims to help people with dementia function at more optimal levels for longer. It focuses on problem-solving and coping around memory problems, cognitive restructuring around negative memory-related thoughts, and increasing positive activities (Scholey & Woods, 2003). It emphasises understanding the support systems around the person, particularly close relationships across generations, as well as understanding the internalisation of negative cultural beliefs about aging and dementia (Laidlaw, 2015). CBT was shown to be efficacious in reducing negative affect in people with dementia (Kraus et al., 2008; Orgeta, Spector, Orrell, 2014; Scholey & Woods, 2003). Furthermore, CBT-based psychoeducational groups for caregivers of people with dementia (Gallagher-Thompson et al., 2008) can be effective at alleviating caregiver distress (Laidlaw, 2015).

The assimilation of problematic voices (APV) model is a conceptualisation of therapeutic change (Stiles, 1991; 2001), which draws upon a social-constructionist perspective to describe the self as a series of voices that adapt to a changing social context (Gergen & Kaye, 1992). The APV model was used to describe the idiosyncratic process of adaptation to dementia experiences (Cheston, 2013; Cheston 2014; Lishman, Smithson & Cheston, in press). At the onset of dementia, a “Dominant Voice” represents a resistance to change and pushes difficulties out of conscious awareness, to protect the person’s identity. As the person begins to acknowledge their difficulties, the “Problematic Voice” represents a recognition of a need for change. With this conflict, emotional distress increases; However, with successful assimilation, the problem will be integrated with the person’s life, and they will learn to cope with their experiences. The APV model has been supported by a series of qualitative analyses of the Dementia Voice Group Psychotherapy Project (DVGP), which involved six, 10 week psychotherapy groups, with a completing total of 19 people with dementia (Cheston, 2004, 2013, 2014; Cheston, Jones & Gillard, 2004; Watkins, Cheston, Jones, & Gillard, 2006). The analyses provide interpretations of individual experiences of the groups (e.g. Cheston et al., 2004; Watkins et al., 2006), illustrating how participants were able to process and assimilate their experiences over time, and shift from a stage of shame and denial, to stages of acknowledgement, insight, and finding solutions. Cheston (2013) suggests that shame presents an emotional obstacle to the person’s ability to admit to what is happening and adapt to the changes. These analyses of the DVGP raise questions about the use of measures of symptomatic distress as a measurement of therapeutic change for people with dementia: If the aim of interventions is to assist patients to process their experiences, such measures may not

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge reflect effectiveness, particularly for short term therapies which are less likely to see people through to a final stage of assimilation. The acceptability of the therapy groups to patients is questionable as, with an initial uptake of 42 participants, a large percentage of them dropped out. Furthermore, Cheston and colleagues produced a number of research articles from the data of the DVGP (Cheston, 2004, 2013, 2014; Cheston et al., 2004; Watkins et al., 2006), meaning that a number of interpretations were collected from an arguably limited amount of data.

1.2.3 Summary. Dementia is a complex and increasingly relevant concern. Stigma, anxiety and depression appear to be significant contributing challenges, with many people with a diagnosed dementia feeling stigmatised (WHO & ADI, 2012). Kitwood's (1997a) ideology signifies a paradigm-shift in the dementia field, which prompted the integration of psychological perspectives to dementia into the predominantly medical model. Today there is an increased consideration of the person with dementia's internal experiences, including those of stigma and marginalisation. Psychological approaches have developed to explain more comprehensively how the person's emotional experiences are influenced by their past experiences (Evans, 2008; Solomon & Szwabo, 1992), their present social environment, relationships and interactions (Cheston & Bender, 1999; Kitwood, 1997a), and the responses they utilise to cope with the experience (Cohen-Mansfield, 2008; James, 2011; Moniz-Cook et al., 2003). The next section reviews research that attempts to provide deeper insights into the quality of psychological experiences in dementia.

1.3 Experiences in dementia

The greater focus on the perspective of the person with dementia involved an increase in research designed to gain insight into their subjective worlds. Many studies use Interpretative Phenomenological Analysis (IPA, Smith, Flowers & Larkin, 2009), a qualitative approach dedicated to understanding how significant life experiences are made sense of by those who live them. IPA uses an interview method for collecting information from a small number of participants. It employs an intensive interpretative method of analysis to consider the deeper meaning of participants' accounts. A comprehensive description of IPA is given in section 2.

1.3.1 Emotional reactions. A number of qualitative studies with people in the early stages of dementia concluded that painful emotions such as sorrow (Holst & Hallberg, 2003), uncertainty, perplexity, uselessness (Svanstrom & Dahlberg, 2004), embarrassment (Cheston, in press; Imhof, Wallhagen, Mahrer-Imhof & Monsch, 2006) and shame (Cheston, 2005;

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge Cheston, in press; Holst & Hallberg, 2003; Imhof et al., 2006) are key every-day struggles. Lishman, Smithson, & Cheston (in press) conducted a narrative review of 38 qualitative studies exploring subjective experiences of receiving a diagnosis of dementia. They concluded that as well as negative responses there are also expressions of hope, humour and growth. They discuss how the emotional experiences of people with dementia are not inevitable consequences of the disease, but the product of psychosocial processes. Their review explores general experiences in dementia and this limits what it says about what the experiences mean to individuals. Despite the flexibility that a narrative review offers for linking studies of different topics together, there is no specific search strategy so it cannot be easily replicated.

In Mitchell, McCollum & Monaghan's (2013) systematic review of 12 studies exploring the impact of a diagnosis of dementia, four studies clearly identified shame as a central experience (Aminzadeh et al., 2007; Frank et al., 2006; Langdon, Eagle & Warner, 2007; Moniz-Cook, Manthorpe, Carr, Gibson, & Vernooij-Dassen et al., 2006) and anxiety about stigma was consistently identified in all 12 of the studies. Stigma was related to loss of the self, loss of self-esteem, loss of control, and loss of activities. Alzheimer's disease was more likely to be associated with negative emotions than dementia or vascular dementia across 7 studies, and this was thought to be due to a greater degree of stigma linked with the term "Alzheimer's" (Mitchell et al., 2013).

Other studies have explored experiences for people in later stages of dementia. Clare, Rowlands, Bruce, Surr & Downs's (2008a) IPA study analysed unstructured individual interviews with 80 people living within residential care. Results revealed a range of distressing emotions relating to loss, isolation, uncertainty, and perceptions of being worthless, unwanted and useless. Some participants expressed intense fear and terror of being alone or lost, and some expressed anger and frustration. Experiencing social acceptance and friendliness was vital for coping, as well as a sense of pride in one's background, positive memories, and appreciating remaining abilities. With such a large amount of data and heterogeneous sample, recruited across 10 care homes, it is questionable how well the analysis of this study subscribes to the idiographic principles of IPA (see Smith's (2011) guidelines for acceptable standards of quality and validity in IPA research, p47).

1.3.2 Risks to social support and identity. Dementia involves a loss of social networks and supportive relationships (Bender & Cheston, 1997), which can impact on identity and self-esteem. Sabat & Harre (1992) suggest that the perception of people with dementia as confused and burdensome makes it difficult for them to maintain a positive self-

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge identity (Sabat & Harre, 1995; Sabat, Napolitano & Fath, 2004).

These ideas are supported by IPA studies. Langdon, Eagle & Warner's (2006) investigation into social experiences in early-stage dementia found that people were aware of their changing social roles, commonly feeling "left out of the loop". This could impact negatively upon their self-esteem, seeing themselves as "poor" and "daft". Participants reported feeling that others were inauthentic and withholding towards them, and that it was unsafe to disclose their diagnosis to people, due to fears that they would be stereotyped. The researchers interpreted that this felt excluding and marginalising, and that authenticity was important due to an increasing need to trust others. Harman & Clare's (2006) exploration of illness representations in early stage dementia reported similar findings that participants struggled to maintain a positive identity due to a sense of stigmatisation and exclusion from others. Focusing on identity in early stage dementia, Caddell & Clare (2013) found that the majority of participants maintained some aspects of their identities, such as attitudes and values. However, changes in their social abilities, such as word finding difficulties during conversations, could lead to embarrassment, self-directed anger, and worry about upsetting others. Loneliness was commonly reported. Thus, these studies suggest that despite the continuity of identity in dementia, social difficulties create a tension in the maintenance of a positive identity, leading to feelings of exclusion, loneliness, and negativity towards the self.

1.3.3 Coping and awareness. Several IPA studies focussed on how people cope with the challenges of living with early-stage dementia. Wolverson et al. (2010) explored how people with early-stage dementia maintain hope. They found that participants talked about how maintaining their relationships were important for being hopeful, for example in hoping for their families' futures. Hope was also expressed in terms of maintaining some level of ability and activity. However, descriptions of dependency, loss of respect, and being ignored by others narrated how participants had adjusted their expectations. The authors conclude that stigma presents a barrier to maintaining hope in dementia. Van Dijkhuizen et al.'s (2006) study explored coping with early-stage dementia for a female sample. Feelings of connectedness presented a major theme within the findings; disconnectedness from the past, social support and social roles was experienced as distressing by the participants. The women reported feelings of humiliation, embarrassment and anxiety about stigma, which they managed through protective strategies of minimising or avoiding the problem, often using humour to deflect and cover up difficult feelings. Adjustment strategies involved acceptance of the difficulties, and problem solving to find a way around them.

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Preston et al. (2007) found that a major challenge for people in the early stages of dementia was that decreased abilities evoked perceptions of being substandard in relation to others or their former selves. Participants used self-critical and self-blaming descriptions of themselves, such as “weak”, “daft” and “stupid”. Some participants coped by talking about and sharing their difficulties, explaining that educating others was important for overcoming stereotypes. However, other participants admitted to covering up and hiding their problems. Clare (2003) suggests that, because such efforts to mask problems become more difficult as dementia progresses, the most adaptive way to cope with dementia is through “self-adjusting coping”, the development of an adjusted identity that integrates the changes of dementia with a person’s valued attributes. In her model of the construction of awareness, Clare (2003) argues that a person’s social context, personality type, and coping style, influences whether they will use adaptive mechanisms of adjusting or less adaptive methods of suppressing what is happening. In her IPA study, Clare (2003) found that higher levels of awareness are linked to self-adjusting styles of coping, whereas lower levels of awareness are linked to suppression. Her follow up study of the same sample found that they displayed similar, and more polarised coping responses a year later (Clare, Roth & Pratt, 2005). Participants who were aware that their dementia was getting worse engaged in more adaptive self-adjusting coping, and used strategies for coping with memory problems. Other participants, who demonstrated a lack of acceptance and normalised their memory difficulties, sometimes acknowledged their diagnoses of dementia, but kept this secret due to feelings of shame.

1.3.4 Summary and critique of the existing qualitative research. Bringing together all of the research discussed so far, dementia appears to involve a complex set of emotional experiences, including fears of stigma, embarrassment, and shame (Cheston, 2005; Holst & Hallberg, 2003; Mitchell et al., 2013). Dementia involves negative shifts in the way people see themselves, as well as an awareness of negative perceptions from others, exclusion, and disconnection (Caddell & Clare, 2013; Clare et al., 2008a; Langdon et al., 2006). Relationships can provide coping mechanisms for these challenges, but can be a source of concern about stigma, provoking avoidance of or covering up the problem instead (Preston et al., 2007; Van Dijkhuizen et al., 2006). The impact of stigma and shame on identity provides an obstacle for hope (Wolverson et al., 2010) and adaptive coping with dementia (Clare, 2003, Clare et al., 2005).

However, the research described is of varying quality and there are a number of limitations that should be acknowledged. First, many of the studies refer to “mild” and

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge “moderate” stages of dementia (Caddell & Clare, 2013; Preston et al., 2007; Wolverson et al., 2010). Often this is measured using memory assessment tools such as the Mini Mental State Examination (Folstein, Folstein & McHugh, 1975) which is not an accurate measure of dementia stage, and this would hopefully be recognised by studies that draw upon the principles of phenomenology and hermeneutics that are fundamental to IPA (see Smith’s (2011) guidelines for acceptable standards of quality and validity in IPA research, p47). Secondly, some of the studies discussed (Moniz-Cook et al., 2006; Clare et al., 2008a) include samples which are arguably too large for IPA (n=48 and 80 respectively), and thus do not subscribe to the IPA principle of ideography (Smith, 2011). Thirdly, in some of the papers (Langdon et al., 2006), there was insufficient detail regarding the process of interpretation within the analysis, leaving a seemingly descriptive account. Therefore, such studies do not subscribe to quality standards for transparency in IPA research (Smith, 2011). Fourthly, although IPA requires the use of samples that are willing to discuss their experiences of dementia, the samples may be biased towards people who were happy and confident enough to take part. Presumably, people who are having a more difficult time adjusting to their diagnosis might be less likely to take part. Therefore these studies may portray views of people who were generally coping better, and feeling relatively accepting of their experiences of dementia. Perhaps experiences of shame, and avoidance and concealment of difficulties, may be more of a concern for people who choose not to participate in research. Finally, participants in Wolverson et al.’s (2010) study had received a stigma-neutralizing intervention and psychological support, and this may have impacted on their experiences.

1.4 Shame

Shame is a label given to an emotional experience that is widely believed to be shared amongst humans, and linked to other particular experiences. Shame is described as a painful, self-focussed emotion that comes with the consciousness of personal faults, and a fear of being judged by others as inferior, worthless, or defective (Isenberg, 1940). Shame is placed within a family of “self-conscious emotions” along with embarrassment, guilt, empathy, and pride (Lewis, 2000; Tangney, Stuewig & Mashek, 2007). Shame is also classed as a “moral emotion”, concerned with evaluation of the self in relation to moral standards (Tangney et al., 2007). Shame theorists are generally cognitive-affect theorists, perceiving shame as an emotional experience that is attached to appraisals (Gilbert & Andrews, 1998). Cognitions that are associated with shame include beliefs about worthlessness, thoughts of being negatively evaluated by others, thoughts about failing to meet standards, self-blame, and social

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge comparison (Gilbert & Andrews, 1998). Other feelings, such as anger and disgust often occur simultaneously with shame, and anxiety is said to be a central part of shame (Gilbert & Andrews, 1998). Particular behaviours, such as hiding and secrecy, are associated with shame (Gilbert & Andrews, 1998). This section further presents psychological models of shame, and the next relates these models to experiences of dementia.

1.4.1 The development of shame-vulnerability. Kohut (1984) discusses how shame proneness develops when an infant is deprived of experiences that offer them a sense of belongingness, leaving them with an underdeveloped internalised secure base, and a poorly differentiated sense of self. This leaves people vulnerable to feeling socially disconnected, anxious, overwhelmed by interpersonal conflicts, and less efficacious (Kohut, 1984). A questionnaire study (Williamson, Sandage & Lee, 2007) found that the relationship between social-connectedness (Social Connectedness Scale revised, Lee & Robbins, 1998) and shame (Test of Self-Conscious Affect, Tangney, 1989) was mediated by differentiation of the self (The Differentiation of the Self Inventory, Skowron & Friedlander, 1998). Thus, a socially disconnected individual is likely to experience a poorly differentiated sense of self, which in turn leaves them prone to feelings of shame. This study was limited by a sample of mainly white, middle class students, and the use of hypothetical scenario-based measures, thus hindering generalisability to other populations and real-life shame experiences.

Gilbert (2009) uses an evolutionary-based approach for explaining shame as having evolved as a protective emotion. He agrees that shame-vulnerability develops within the primary attachment relationship, but emphasises how early experiences shape neurological patterns and the development of the nervous system. Compassionate behaviour from the caregiver is hypothesised to protect the infant from shame-proneness, whereas blaming behaviour leads to increased susceptibility to shame. He emphasises that being accepted by a group is a survival need across species, and that shame is triggered for people when they are at threat of being rejected. He therefore describes shame as a combination of feelings of inferiority, anxiety about social disapproval, aloneness, and anger, and suggests that developing capacities for self-compassion can help individuals to manage shame.

1.4.2 Self-awareness and social-acceptability. Ellis (1977) describes how childhood experiences influence individuals towards conditions of self-acceptance, which lead to feelings of inadequacy when these conditions are not met. Ellis (1977) uses a cognitive-behavioural model to describe how shame involves moral judgement and rejection towards the self, which then lead to feelings of worthlessness and further cognitions of self-blame. The

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge person becomes focussed upon their inferiorities, or makes attempts to deny their imperfections, both of which prevent them from making positive behavioural changes. Similarly, Tracy and Robins' (2004) model of self-conscious emotions sees shame as based upon internalised social norms. The ashamed person is said to experience a sense of failing to live up to an idealised self-representation, and reflects upon the discrepancy between their self-representations, and the external evaluation of their behaviour. Tracy & Robins (2004) suggest that shame also distinctively depends upon the individual's internal, stable and global attributions of their behaviour.

Martens' (2005) multi-model of shame combines many of the ideas described above, describing the interplay of moral, cultural, and neurobiological influences of shame. Martens (2005) considers shame as primarily an unconscious and physiological response to threat of social rejection, involving neurobiological responses. An individual therefore attempts to maintain the respect of others using their awareness of moral and cultural acceptability. Conscious cognitive processes such as self-representations and problem solving are then secondary reactions concerned with preserving self-identity and preventing negative consequences. Intrapsychically, shame therefore involves a conflict between our internal drives and desires and our self-conscious, social, cognitive and moral capacities, resulting in both self-directed and other-directed anger.

1.4.3 Shame consequences. The models described above contrast in their explanations of the different consequences that shame can have for individuals. In agreement with ideas from Ellis (1977) and Kohut (1984) that shame interferes with interpersonal relationships and adaptive behaviours, Martens (2005) suggests that shame impacts upon relationships through a lack of assertiveness, feelings of inferiority, and a dependent attitude on a partner. Tangney & Dearing (2002) consider shame to be an unhelpful emotion, as it triggers global negative evaluation of the self and hostile defensiveness. They compare this to guilt, which is linked with an evaluation of one's behaviour, feelings of empathy, and seeking forgiveness (Tangney & Dearing, 2002). In contrast, Tracy & Robins (2004) argue that shame motivates behavioural responses towards appeasement, acceptance, and forgiveness from others. A number of different unhelpful responses to shame are outlined in Nathanson's (1992) compass of shame. These include "attack self", through self-directed anger and blame; "withdrawal", through a tendency to hide; "avoidance", using emotional distancing or minimisation, and "attack other", through outward-directed anger and blame. Elison, Pulos & Lennon (2006) added a fifth method of coping to the compass, "adaptive", where the person acknowledges their shame and

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1.4.4 Shame and internalised stigma. The relationship between shame and stigma is discussed by Goffman (1963). Firstly, he describes stigma as a relationship between an “attribute and a stereotype” (Goffman, 1963, p.4 in Jones, Farina, Hastorf, Markus, Miller & Scott, 1984), where the person is perceived as possessing an attribute that is linked to undesirable characteristics. This reduces the bearer “from a whole and usual person to a tainted, discounted one” (Goffman 1963, p. 3). Stigma is said to negatively affect the self-image of those to whom the negative attribute is ascribed, and causes them challenges for interacting with those who are deemed as “normal”. Goffman (1963) suggested that shame arises for an individual when they hold stigma towards one of their own attributes.

Link & Phelan (2001) conceptualise stigma as involving the convergence of several processes. Firstly, a difference between people is considered substantial enough to legitimise an official label. The label is then linked to negative attributes, thus separating groups of people in an “us” and “them” dynamic. This involves a loss of status for the stigmatised group, which provides a rationale for their devaluation and exclusion. Link & Phelan (2001) write that stigma is dependent upon power, whereby a group will only become stigmatised when they occupy a lower position of power in comparison to those judging them. However, this condition is overlooked because power differences are frequently taken for granted. Link & Phelan (2001) suggest that people who are stigmatised expect rejection, and may act less confidently, more defensively, or simply avoid threatening contact. This results in uncomfortable social interactions, reduced social networks (Link, Cullen, Struening, ShROUT, & Dohrenwend, 1989), a compromised quality of life, and negative feelings towards themselves. Finally, stigma has a negative impact upon coping resources such as self-esteem and self-efficacy (Link et al., 2001), thus influencing negative social and psychological outcomes of a condition through stress.

Support for these ideas is provided by Hasson-Ohayon, Or, Vahab, Amiaz, Weiser, and Roe’s (2012) review of the literature on stigma and shame in mental health problems. They found that the internalization of societal stigma towards a mental health problem leads to self-stigma. This was associated with poorer social and psychological outcomes such as lower self-esteem, and poorer interpersonal relationships. Hasson-Ohayon et al. (2012) suggest that, some people with mental health problems are likely to experience shame, whilst others are more likely to respond with guilt, depending upon whether the person accepts or rejects the social stigma. Hasson-Ohayon, Roe and Kravetz (2007) tested the relationships between

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge shame-proneness, guilt-proneness and self-stigma for 60 participants with diagnoses of mental health problems. Shame-proneness, but not guilt-proneness (Test of Self-Conscious Affect, Tangney, 1989) was correlated with self-stigma (Internalised Stigma of Mental Illness Scale, Ritscher, Otilingam & Grajales, 2003). The authors' conclusions thus provide support for the concepts that people who are susceptible to shame are likely to accept social stigma on the basis of internal attributions of their behaviour (Tracy & Robins; Tangney & Dearing, 2002), thus engaging in self-stigma, and compounding their experience of shame. A study by Van der Beek, Bos, Middel & Wynia (2013) suggest that susceptibility to shame and fears of rejection are greater risks for people than actual experiences of discrimination. In a sample of 235 people with neuromuscular diseases, they found that reported rates of self-stigma (the Stigma Scale for Chronic Illness, Rao et al., 2009) were higher (86%) than reported rates of social stigma (64%). Both self-stigma and social stigma were strongly negatively correlated with quality of life (the WHO Quality of Life - BREF, WHOQOL Group, 1998), and regression analysis revealed that self-stigma was a stronger predictor than experienced social stigma of quality of life.

Stigma researchers are criticised for studying stigma from the point of their theories rather than from the lived experience of the people they study, resulting in continued misunderstandings of the experience of stigma, based upon unfounded assumptions (Schneider 1988). The stigma literature is criticised for placing emphasis and responsibility on the individual, rather than the acts of discrimination from those who exclude and reject the person (Sayce 1998). However, rather than shifting responsibility from one group of people to the next, an increased focus upon the sources and consequences of social and economic exclusion may be most helpful (Oliver, 1992).

1.4.5 Applying models of shame to dementia. The discussed understandings of shame and stigma appear relevant to some of the key findings of dementia experiences. Findings that dementia can involve fears about judgement, stigma, withholding and exclusion from others (Harman & Clare, 2006; Van Dijkhuizen et al., 2006), fit with the idea that shame occurs through a threat of social disapproval (Gilbert, 2009; Martens, 2005). Findings that a changing self-image in dementia can cause shame related experiences (Caddell & Clare, 2013), fit with concepts of shame as being triggered when an individual feels dissatisfied with themselves, and unable to meet their self-expectations (Ellis, 1977; Gilbert, 2009; Tracy & Robins; 2004). Findings that people with dementia can experience increased self-criticism (Preston et al., 2007), self-directed anger (Caddell & Clare, 2013) reduced self-acceptance

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge (Clare et al., 2005), and thoughts of worthlessness (Clare et al., 2008a) link with ideas that self-judgement and self-blame are involved in the maintenance of shame (Ellis, 1977; Gilbert, 2009). Findings that shame can lead to less adaptive coping with dementia (Van Dijkhuizen et al., 2006), and evokes avoidance, denial, and a desire to conceal difficulties (Clare, 2003; Clare et al., 2005) fit with theories that shame has negative social consequences (Martens, 2005; Tangney & Dearing, 2002). Some studies (Hasson-Ohayon et al., 2007; 2012; Van der Beek et al., 2013) support the idea that people who are more vulnerable to shame (Ellis, 1977; Gilbert, 2009) are more likely to engage in self-stigma, and it is this internalisation and acceptance of stigma that impacts upon quality of life. This suggests that although shame is concerned with social experiences, it occurs primarily through internal processes.

1.5 Shame in Dementia

This section addresses concepts and studies that have further highlighted the opportunities that dementia provides for individuals to experience and respond to shame (Cheston, in press; Clare, Rowlands & Quin, 2008b; Genoe & Dupuis, 2012; Lishman et al., 2014).

1.5.1 Shame and avoidance. As dementia involves the loss of valued competencies and independence (Cheston, in press), a person who is experiencing dementia understandably avoids exposing their dementia. There are various ways in which avoidance contributes to the development of “shame inducing spirals” (Gilbert, 1998) around people with dementia (Cheston, 2005). Firstly, it is argued that due to the social stigma of a diagnosis of dementia, individuals are likely to avoid situations or cover up behaviours that will reveal symptoms. Secondly, individuals may avoid articulating the extent of their difficulties, for example by using neutral terms such as *memory loss* rather than *dementia* (Cheston, in press). Thirdly, people with dementia might create accounts that position themselves as competent people (Cheston, 2005). Fourth, denial about memory problems is best understood as an attempt to avoid shaming interactions, but medical professionals often label this as lack of insight, which compounds shame (Cheston, in press). Finally, those people closest to the person with dementia may attempt to protect the person from potentially shaming interactions, by taking control of matters to prevent them from making mistakes, out of concern about causing the person distress or indeed shame. Shame therefore alienates people, preventing them from being open with others and encouraging separation. Cheston (2005) argues that psychotherapy groups that enable people to openly share their experiences can help people with dementia to overcome shame, through reducing feelings of alienation and abnormality. Extracts from the

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge DVGP (Watkins et al., 2006), are used to illustrate how one particular member, Robert, was helped to accept his experiences of dementia through the group's shared expression of shame and embarrassment about having Alzheimer's disease. Towards the end of the sessions, Robert says, "it frightened me, because I thought, well, I'm going mad, I'm going crazy, what am I going to be like in another 5 years? But now I realise that everybody is getting this problem" (Cheston, in press, page 13). Cheston (2005) concludes that shame must be acknowledged in order to help people with dementia adjust to their difficulties.

1.5.2 Loss of control. Cheston (in press) further suggests that a fear of losing control is central to the experience of shame in dementia, such as a fear of losing one's self or going mad. Robert's statements above demonstrate how for him, the reluctance to confront his difficulties were associated with fears of madness. Another participant, Judith, expresses fears about becoming "useless" and "not having all my faculties", illustrating fears about losing who she is (Cheston, in press, page 12). Similarly, in Snow, Cheston & Smart (2015) another woman voices concerns that "your body could go on longer than your brain, and then you just cease to be, you, you're just a function" (Cheston, in press, page 13). As previously mentioned, Mitchell et al.'s (2013) review found that fears about stigma in dementia were related to a loss of the self and loss of control, however their report says little more about this experience.

1.5.3 Forgetting and embarrassment. Lishman et al. (2014) provide extracts from their data illustrating how struggling to find words can lead to feelings of embarrassment: "I forget something silly, that I should have known, it's embarrassing..." (Lishman et al., 2014, page 55). They demonstrate how this leads to shame and poor self-worth, and influences withdrawal: "That's quite upsetting when you're trying to think of something and it's not there anymore... because you can't think of the words to say so you withdraw" (Lishman et al., 2014, page 64). The researchers interpret that these experiences make people feel different to others and unable to fit in. They add that the fear of being judged is central to this experience, and so other people's acceptance is crucial for overcoming shame.

Genoe & Dupuis's (2012) phenomenological study of the meaning of leisure for people with early-stage dementia involved a comprehensive method; individual interviews, observation, and photo diary data were collected over several months, to help gain insight into participants' everyday lives. Photographs that participants took were discussed during second individual interviews. The findings highlighted that participants' experiences of muddled thinking, forgetting, and lost skills led to feelings of embarrassment, guilt and shame. This led

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge them to discontinue their hobbies and activities. The participants felt pride when they were able to overcome this, and so the study concludes that it is important for people with dementia to be supported in maintaining their participation in meaningful activities. One issue with this study is the enormous volume of data that they collected, which may have hindered the depth of their analysis.

1.5.4 Value and purpose. Clare et al.'s (2008b) IPA study explored people with dementia's use of an internet based support group. Participants talked about dementia as a place of isolation and loneliness, involving a loss of identity and self-worth. Participants said that the support network provided collective strength, with feelings of belonging and understanding, and the sharing of coping skills and emotional support. Participants reported feeling a sense of pride in being a group member, regaining a sense of self-respect, value and purpose at contributing to potential social change and making a difference to others. Some members brought up controversial issues that challenged the support of the network, such as voicing a desire to die, and as a result could be criticised and shamed. The participants of this study were younger in comparison to most dementia sufferers, with a mean age of 62, and might have been less burdened by negative age stereotypes and age-related stigma (Levy, 2009) than older adults with dementia. The participants of this study had been diagnosed an average of 6.5 years previous to the study, and may also have had time to adjust to the challenges of diagnosis.

1.6 Summary of the Chapter

Dementia is a growing problem (WHO, 2012), and living with a diagnosis of dementia involves challenges of social exclusion, stigmatisation and marginalisation (Brooker, 2004; Kitwood, 1997; WHO & Alzheimer's Disease International, 2012). Qualitative studies provide people with dementia a platform to discuss their experiences. In the early stages of dementia, some of the key challenges involve shifting self-perceptions (Harman & Clare, 2006), feelings of exclusion (Caddell & Clare, 2013), and changing social roles (Van Dijkhuizen et al., 2006; Langdon et al., 2006). These experiences can evoke negative feelings towards the self, such as feelings of inadequacy (Clare, 2003) embarrassment (Van Dijkhuizen et al., 2006), self-criticism (Preston et al., 2007), and self-directed anger (Caddell & Clare, 2013). Shame is specifically linked to fears about being judged in social situations for difficulties with speaking and thinking coherently (Cheston, 2005; Genoe & Dupuis, 2012; Lishman et al., 2014). In addition, people with dementia have demonstrated shame in relation to fears about losing control or becoming mad (Cheston, in press).

Shame fundamentally concerns the experience of potential social judgement. The person who experiences shame considers himself to possess a characteristic which is perceived by others to be outside of moral or social norms. Thus, the person fears that the reveal of this characteristic will mark them out as being deviant, and potentially lead to them becoming a social outcast. Therefore, behaviour associated with shame is motivated by a wish to hide the possession of this characteristic from public view in order to avoid the risk of being judged as morally deficient.

There is some conflict between theories and findings around shame and the discussed interpretations of dementia experiences, with regards to the extent to which experiences of stigma and shame occur through internal processes, or social discrimination. Some researchers suggest that individuals who are more shame-prone are more likely to stigmatise themselves (Hasson-Ohayon et al., 2007; Van der Beek, et al., 2013). This may downplay the roles of others in contributing towards a person's perceptions of stigma (Sayce 1998), such as a person with dementia's reported experiences of being withheld from (Langdon et al., 2006), excluded (Harman & Clare, 2006), and ignored (Wolverson et al., 2010).

Both theoretical models and empirical research suggest that shame interferes with adaptive social coping and creates further problems for relationships (Cheston, 2005; Clare, 2003; Clare et al., 2005; Genoe & Dupuis, 2012; Gilbert, 2009; Lishman et al., 2014; Martens, 2005; Tangney & Dearing, 2002), thus exacerbating negative feelings. Some studies highlight how, when people with dementia overcome these challenges, improvements can be observed in their self-worth (Claire et al., 2008b), self-acceptance (Watkins et al., 2004), and pride (Genoe & Dupuis, 2012).

1.7 Rationale for the Current Research

Many of these ideas are still within their infancy, and there is still much to be learned about what experiences of shame involve for people with dementia. As of yet, no published research has specifically aimed to explore experiences of shame for people with dementia, by asking them about their experiences. Therefore, an in-depth understanding of what shame involves for people with dementia remains absent. A study that explores how shame is experienced and made sense of by people with dementia, and places the findings within the context of the existing literature, may be helpful for improving our understanding of this. This developed understanding may then enable us to develop more effective ways of providing support to people with dementia in a number of ways. Dissemination of the findings may provide training to health professionals, as well as education to the general public about the

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge relevance of shame to specific experiences in dementia. Health professionals can be made more aware of how people with dementia might be feeling when they are seen within services, and how to promote non-shaming experiences. Health professionals and carers can be assisted in learning to respond to difficulties with shame for people with dementia. Psychological interventions that specifically target shame for people with dementia may be developed. In line with the World Health Organisation's (2012) plans for enabling more dementia friendly communities, these advances would enable a society with a more accepting attitude towards people with dementia.

1.7.1 Rationale for a qualitative approach. Qualitative research attempts to investigate the quality and content of experiences for specific groups of people (Willig, 2013). It aims to explore and understand rather than quantify or generalise phenomena. While studying individuals with dementia, it is important to avoid over-defining their experiences or applying generalisations, as these assumptions undermine the personal experiences of individuals with a dementia. Elliott, Fischer and Rennie (1999) suggest that:

“The aim of qualitative research is to understand and represent the experiences and actions of people as they encounter, engage, and live through situations . . . the researcher attempts to develop understandings of the phenomena under study, based as much as possible on the perspective of those being studied,” (p.216).

A qualitative research approach is therefore well suited to the current study aims: to represent the voices of people with dementia, and allow their descriptions and interpretations to develop our understanding of what experiences of shame mean for them.

1.8 Research Questions

The current study aims to explore shame-related experiences for people with dementia, with the following research questions:

1. How do people with a diagnosis of dementia experience shame related feelings?
2. How do people with a diagnosis of dementia make sense of shame related experiences?
3. How do people with a diagnosis of dementia respond to experiences of shame?

Reflection 1. Starting position

As a researcher, it is important that I maintain an awareness of how my own experiences and assumptions influence this project. At the time that I begin this research, my Grandmother is in the later stages of a dementia. My interactions with her throughout her progression of dementia shaped the way I perceive the experience of dementia. I also worked with people with dementia; firstly within a hospital ward specifically for people with dementia, and later within an older adult community mental health team. I developed assumptions that in the early stages, dementia can make social interactions awkward and embarrassing. I imagine that reactions from others, such as amusement, irritation, and helplessness, despite being natural, can cause the person shame and a wish to hide or minimise their symptoms. I may have a negative perception of dementia, as I witnessed people with dementia exhibiting high levels of distress, as well as the stress it can cause for families. Particularly disturbing memories stayed with me, for example, of a woman brought to the dementia ward after being found unconscious in her car with her husband, who had already died from gas inhalation. Despite my assumptions about how distressing and shaming living with a dementia can be, I never openly talked to anyone I knew about their experiences. I am therefore looking forward to inviting people to talk about their experiences of dementia with me and explore, as accurately as I can, how they experience shame.

2. Methodology

2.1 Overview

The study's design is determined by the research questions stated at the end of the previous chapter, alongside the epistemological position of the research. This chapter begins by presenting a rationale for using Interpretative Phenomenological Analysis (IPA), and offering a description of the epistemological position of IPA. Information about the methodology is then presented, starting with a description of the participants, and followed by the development of the interview schedule and the study procedure. A discussion of ethical considerations is then presented, followed by an outline of the stages of analysis. Finally, the questions of validity, accountability and transparency in qualitative research are considered.

2.2 Design

2.2.1 Choosing Interpretative Phenomenological Analysis. In considering the distinctive nature of shame in early-stage dementia, it is important to adopt an exploratory approach and a method of enquiry based on a flexible stance. Interpretative Phenomenological Analysis (IPA) is a meaning-focussed approach which aims to assist the understanding of how individuals make sense of their personal experiences, and specifically their social emotions and cognitions. It is concerned with exploring people's accounts of their phenomenology, which is their significant life experiences, and their interpretations, that is the meaning they attach to them. IPA is used in studies exploring subjective experiences in dementia, due to the significant and personal nature of experiencing a dementia, and the subjectivity of the different meanings that it might hold for people. IPA also allows individuals with dementia to voice their unique experiences. IPA is suited to the exploration of shame, due to shame being a complex emotional experience attached to social cognitions. The nature of shame, being uncomfortable to experience and associated with an urge to hide, means that it can be difficult to verbalise for the individual, and difficult to directly perceive by the observer. The hermeneutic quality of IPA is therefore useful in getting closer to the experience of shame, as it allows the researcher to look beyond surface level communication by the participant, and interpret paralinguistic cues (see section 2.5.2.1 for more detail on the interpretation of shame). IPA was therefore selected as the qualitative methodology for this study, due to its ability to explore the significance of dementia as a life experience, the subjective nature of shame, and how these are internalised by each individual.

2.2.2 Epistemology. IPA is founded upon theories of phenomenology, interpretation, and ideography. IPA adopts a position between realism and social constructionism. It suggests that there is an objective reality, but that it only becomes meaningful through our engagement with the world, and therefore life always takes place through a subjective and personal perspective. IPA assumes that although individuals can describe their cognitive and emotional states, the meanings of their experiences are best accessed through a careful and thorough interpretation which is carried out by the researcher. The researcher provides an interpretation of the participants' first-person accounts, using their own perspective, and knowledge of previous research and theory. Thus, it draws on a descriptive tradition, as it provides the participant's descriptive account, combined with a hermeneutic phenomenology tradition, bringing in the researcher's interpretive account (Smith, Flowers, & Larkin 2009). In order to understand how these theories come together, each will be addressed here in turn.

2.2.2.1 Phenomenology. Phenomenology is a philosophical approach to the study of experience, where phenomenologists attempt to understand what a particular experience is like. An experience can be understood as parts of a life which are reflected upon and connected by a common meaning (Dilthey, 1976). When people are engaged with an experience of something major in their lives they reflect on the significance of what is happening to them. For this study, the experience would be "feeling shame about having a dementia".

A major principle of phenomenology is to focus on the experiential content of experiences, rather than to fit experiences into predetermined categories; Husserl, the founder of phenomenology, (1927) said we should "go back to things themselves" (In Smith, Flowers, & Larkin, 2009, p12). For this study, the essential features of *feeling shame in relation to dementia* are therefore examined in depth, exploring each quality of those experiences in their own right. This is in contrast to the way that experiences in dementia are understood, when they are imposed into categories of medicalised symptoms. Husserl (1927) suggested that in order to return to the raw qualities of experiential phenomena, we need to "bracket off" and separate it from the rest of conscious experience, so that we are able to both view the phenomena in its simplest form, and use the separated experiences to provide different perceptions upon it. Where *shame in dementia* is our bracketed subject phenomena, we can use outside concepts to explore this phenomena through different perspectives, such as in relation to relationships or self-perceptions.

Subsequently, phenomenology developed a more interpretative stance, as Heidegger

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge (1962) built upon Husserl's (1927) work. Heidegger (1962) emphasised that people make sense of the world through social, historical and cultural contexts, of which we cannot detach ourselves. Heidegger's suggestions mean that for IPA, we need to be aware of the contextual perspectives that shape interpretations. For the current research, participants' experiences of shame in dementia were understood within their contextual worlds of activities and relationships. It was important to consider how their experiences were interpreted according to their previous experiences, as well as being coloured by societal and cultural influences, such as certain occupational values.

For Merleau-Ponty (1962), a major focus of phenomenology was about our embodied interaction with the world, where our physical body provides our separation from the world around us and the perspective from where we interact with it. Embodied in the world, we engage in a physical and sensory relationship with the world and others. Sartre (1953) focussed upon the interpersonal context of our experiences, suggesting that as our experiences are largely shaped by the presence or absence of others, the rest of the world takes its place around other people. For example, our self-consciousness is only dependent upon the awareness of the perception of another. Applying these ideas to our study of experiences of shame in dementia, it is important to consider how experiences of shame for people with dementia might be shaped by their sensory interpretations, as well as their interactions with other people.

2.2.2.2 Hermeneutics. Hermeneutics is the theory of interpretation, concerned with the methods and purposes of interpretation. Schleiermacher (In Schleiermacher & Bowie, 1998) explains how a participant will use language to provide their interpretation of a particular experience, and that the analyst can take this interpretation further by understanding the participant themselves and their context. Therefore, IPA adopts a double-hermeneutic method of enquiry. In this way, the researcher moves between the participants' interpretations and their own, trying to get as close to the participants' worlds as possible, whilst understanding that they cannot do this completely (Smith, 2008). For this study, the participants describe their interpretations about their experiences of shame in relation to dementia. The researcher has then used her personal and professional experience, understanding of previous research, and her psychological understandings, to provide an interpretation of the participants' descriptions.

Heidegger (1962) connected his theory of phenomenology to hermeneutics, by suggesting that our access to experience is always through our interpretation. He emphasised

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge how interpretation is always founded upon pre-existing assumptions according to our own prior experience. Concurrently, Heidegger said that an analyst always brings their own preconceptions to an interpretation, although he highlighted that we can bracket off our preconceptions to prevent them from blocking our interpretation of the subject under study. For this study, as Gadamer (1960) suggested is important, the researcher reflected upon her own preconceptions about people with dementia and how they might feel shame, prior to, during, and following her interpretations, and did this openly and explicitly through the reflective accounts. An important idea in hermeneutic theory is that of the hermeneutic circle. This relates to the dynamic, non-linear style of analysis. This concept operates at a number of levels, such as where the interpretation of a single word, extract, or interview is dependent upon the understanding of the context of the whole sentence, transcript, or project. Simultaneously, the analysis of a complete sentence, transcript, or project depends upon the meanings of individual words, extracts, or interviews.

2.2.2.3 Ideography. Ideography is concerned with detail and the particular. IPA is ideographic in two main ways. Firstly, IPA is committed to understanding particular experiential phenomena in detail and depth, and therefore the analysis is thorough and has an identified focus. Secondly, IPA is interested in understanding how particular experiences are made sense of by particular people within a specific context. IPA therefore uses small, carefully selected samples, and only cautiously makes generalisations within those particular contexts. An ideographic approach is important for the current study, as the aim is to discover a meaningful way of understanding the particular experience of feeling shame in the context of dementia, and to focus in detail on the unique interpretations of the participants themselves. The advantage of investigating particular cases in research is that it can reveal flaws in existing claims, disconfirm our expectations, and provide a way of testing our assumptions. We can then move away from the broad generalisations about people with dementia, whose own interpretations are rarely heard. In return, we need to think carefully about how the findings of this study can be applied to other people with dementia who experience shame.

2.2.3 IPA methodology. IPA employs purposive sampling, where, as described in the previous section, participants are carefully selected and recruited according to them having shared a particular experience within a particular context. This fits with the current research question which aims to explore the specific experience of shame within the context of dementia. IPA uses individual, semi-structured interviews which allow each participant to tell their story in their own words, and allows the researcher to prompt and explore particular

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Due to the focus of IPA being the analysis of participants' attempts to make sense of their experience, there is no definitive method for data analysis. However, there are a set of common processes and principles which are meant to be applied flexibly. These involve the close analysis of the words of each participant, the identification of patterns within and across transcripts, the researcher's interpretation of the meaning of participants' experiences, the development of a structure illustrating the relationships between themes, the use of supervision in developing the plausibility of the interpretation, and reflection upon how the researcher's own perceptions impact upon the findings.

2.3 Research Procedures

2.3.1 Sampling. The study aimed to recruit between 6 and 8 older adults with a diagnosis of dementia, from National Health Service (NHS) older adult mental health teams across East Anglia. The sample was purposefully selected based upon the participants' shared experience of being an older adult diagnosed with a dementia. The inclusion and exclusion criteria were selected in order to include the most common types of dementia, ensure a relatively homogeneous sample, and ensure that participants would be practically able to take part in the interviews, and minimise the risk of distress to participants. All participants met the following inclusion criteria:

- Received a diagnosis of Alzheimer's disease, vascular dementia, or mixed dementia.
- Over the age of 60.
- Diagnosis had been shared with them at least 1 month prior to recruitment.
- Judged by service professionals as having insight into their memory difficulties and able to reflect upon their experiences.
- Assessed as having capacity to give informed consent recently prior to the study.
- Living at home.
- Fluent in English.

Participants who met the following criteria were excluded, due to the likelihood that

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these would significantly impact upon usual experiences of dementia:

- Diagnosed with a frontotemporal, or early-onset dementia.
- Experiencing another current, major, physical or mental health problem or life event.
- Anxiety or depressed mood that was significantly impacting upon their functioning.
- Significant communication or behavioural problems.
- Current alcohol or drug misuse.

2.3.2 Meeting with services. The researcher attended the team meetings of 5 older adult mental health services of Cambridgeshire and Peterborough NHS Trust (CPFT) and Norwich and Suffolk NHS Trust (NSFT), to present the research to clinicians and ask them for help with recruitment. Meetings took place in June-November 2014. At the meetings with services, clinicians were asked to identify potential participants, briefly inform them about the research during their next appointment, and offer them information packs, making it clear that it is their choice to participate. Contact between the researcher and clinicians was maintained so that interviews were scheduled in accordance with clinicians' availability in case follow up support was required, as well as letting them know reasons why people were excluded.

2.3.3 Information provided to services and participants. Information sheets about the study were provided to clinicians (Appendix A). Five information packs were provided to each team, which contained participant information sheets (Appendix B), consent forms (Appendix C), and consent to contact forms (Appendix D). Potential participants were provided with two options for facilitating contact with the researcher: they could contact the researcher directly on the telephone number provided on the information sheet, or alternatively they could give their clinician the signed consent to contact form which allowed the researcher to contact them, or a relative/friend on their behalf.

2.3.4 Contact with participants. All potential participants that expressed an interest in taking part in the study provided their clinician with a signed consent to contact form. The researcher maintained contact with services on a fortnightly basis to follow up on the progress of collecting consent to contact forms. Clinicians were also encouraged to contact the researcher as soon as they collected consent to contact forms, so that the researcher could collect forms and contact potential participants to offer them an interview as soon as possible, within the following 2 weeks. The maximum time between the participant's initial introduction to the study and the interview was therefore 4 weeks.

When initially telephoning potential participants, the researcher checked that they had read the information sheet and understood what the study involved. The potential participant was asked if they were interested in taking part, and if they were, the researcher checked that they met the inclusion criteria, through some screening questions. A time for interview was then arranged, at the participant's home address. The participant was asked to have their consent form with them for the interview. Participants were encouraged to have a friend or relative with them at home after the interview in case they wanted support.

The researcher was sent 9 consent to contact forms collected from potential participants interested in taking part in the study. Of these, 6 people were interviewed and included in the analysis. Of the 3 who were not interviewed, 1 person no longer met criteria by the date of their interview, as they reported that their diagnosis changed, 1 person was admitted to hospital the evening prior to their scheduled interview, and 1 person initially agreed to an interview but changed their mind following a conversation with their relative.

2.3.5 Interview schedule. An interview schedule (Appendix E) was designed in accordance with the stages provided by Smith et al. (2013). The purpose of the schedule was to provide a loose agenda of the main topics, allowing the researcher to anticipate her phrasing of questions, and prepare for sensitive points within the interview. Open questions were prepared to encourage the participants to talk, help the participants to feel comfortable talking and ease into the interview. Descriptive and narrative questions were combined with more analytic and evaluative questions; so that participants could describe stories about their experiences, and the researcher could then explore the participants' interpretations. Five main questions with two closing questions provided an approximate plan for 1 hour of interviewing.

2.3.6 The interview process. The researcher conducted the interviews independently. Interviews lasted between 50 and 75 minutes each. On arriving at each participant's address for interview, the researcher introduced herself, reminded the participant of what the interview would involve, and asked them if they had any questions. The researcher and the participant then signed the consent form in each other's presence. The researcher used active listening skills and a flexible response to help the participant to feel as comfortable as possible. Engaging in the IPA approach, the researcher allowed the interview, to as large an extent as possible, be led by the participant. The participant could then describe in depth the matters that were important to them, utilising the potential of the interview for finding out unexpected things. As normally happens with IPA interviews, the questions deviated, greatly at times, from the interview schedule. The researcher prompted participants to explore points that were

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge relevant to the research question, and therefore interviews addressed the research questions, at an individualised level. Interviews were audio-recorded using a Dictaphone, and the researcher noted any observations that felt important (e.g. body language, vocal intonation) using a notepad. Following the interview, participants were given time to talk through any issues or questions that arose. Finally, the researcher thanked them for their involvement in the study and offered them a written summary of the study on completion.

2.4 Ethics

2.4.1 Ethical approval and permissions. Ethical approval was obtained from the Research Ethics Committee of the National Health Service (NHS) Research Authority. Approval was obtained from the Research and Development committees of both CPFT and NSFT. See Appendix F for approval documents.

2.4.2 Informed consent. Following the Mental Capacity Act Code of Practice (Department for Constitutional Affairs, 2005), participants were included in the study if they demonstrated their capacity to consent. Capacity to consent was demonstrated if they were able to understand the participant information sheet, retain the information for long enough to make their decision and then communicate their decision to participate. Once the patient demonstrated that they understood, they were asked if they wished to participate. If they agreed, they were asked to sign the consent form. It was made clear to participants that they were under no pressure to take part in the study and that they could withdraw from the study at any time. This was stated on the information sheets and consent forms, as well as verbally before the interview.

2.4.3 Participant well-being. Given the nature of this study, there was a possibility that some questions within the interviews may evoke feelings of distress for participants. Participants were made aware of the sensitive nature of some questions, and were reminded at the start of interviews that they were free to refuse to answer particular questions or terminate the interview. The interview was conducted in a sensitive manner and therapeutic communication skills were used to contain any distress that arose. Although some difficult thoughts and feelings were expressed during interviews, the researcher was able to contain and respond to this appropriately. The researcher had adequate training and experience in assessing and responding to emotional distress and risk issues, such as potential thoughts of suicide. Time was provided at the end of interviews for the participants to reflect upon how they were feeling. None of the participants were observed to be in significant levels of distress at the end of the interview, and all reported having found the interview a positive process. In

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certain cases, with the participant's consent, it was felt appropriate for the researcher to share with a clinician specific issues that the participant brought up, so that they could access further support.

2.4.4 Researcher well-being. The researcher considered her own safety and well-being during the study. The lone working policies of CPFT, NSFT and the University of East Anglia were followed when conducting interviews. These included the researcher conducting interviews between 9am-6pm, and keeping a colleague informed about her whereabouts. The researcher was mindful of her own emotional limitations, and managed her own emotional response to the interview data through keeping a written reflective log, and the use of supervision.

2.4.5 Confidentiality and anonymity. Participant confidentiality was protected at all times, within the limits of managing risk and distress. It was a requirement of this study that participants gave consent for their General Practitioners to be informed of their involvement in the study via letter. Interviews were recorded using a password protected Dictaphone, and all recorded data was transcribed by the researcher. During transcribing, in accordance with the NHS Code of Confidentiality (Department of Health, 2003), all data was made anonymous, using pseudonyms, in order to protect participants' identities. The researcher and supervisors were the only individuals to have access to the data. Individual responses are described in the analyses, however all possible precautions were taken to disguise individuals' identities so that readers of the report are unable to recognise individuals.

2.5 Data Analysis

Analysis of interviews was based upon the IPA procedure outlined by Smith et al. (2009). This process involved firstly working with each individual interview in turn: Transcribing, reading and initial noting, coding, searching for emergent themes, and developing a list of main themes for each individual case. Secondly, a cross-case analysis involved taking the 6 sets of main themes together, finding connections across cases, and producing a final hierarchy of themes that captured the shared experiences of the sample. The analysis process continued during the writing up of results, with further consideration of how the themes complement each other to provide a clearer, logical narrative to the findings (Smith et al., 2009).

2.5.1 Transcribing. Interviews were transcribed as soon as possible after the interview was completed. Through the transcription of interviews, the researcher was able to immerse herself in the data. Whilst reading each transcript, the researcher simultaneously listened to the

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge audio recordings, slowing down the process of reading, and engaging with the participants' words. During this stage, the researcher recorded any initial impressions of the transcripts and put these ideas aside until she was familiar with the content of participants' points of view.

2.5.2 Individual case analysis.

2.5.2.1 Developing codes and emergent themes. The researcher created a document with a 3 column table for each transcript. The transcript was copied into the first column of the table, on the left hand side of the page. Working with each transcript separately, the researcher began to engage in the coding process, noting anything of interest within the transcript within the centre column. Coding involved 3 discrete focuses. Firstly, descriptive comments highlighted the key words and phrases within the content of the participant's words. Secondly, linguistic comments explored the use of language. Thirdly, conceptual comments moved away from the explicit meanings of the participants' words, towards an understanding of the concepts brought up. The researcher used different colours of text when coding from each of these focuses, (see Appendix G for an example). In the third column of the table, the researcher developed emergent themes. This involved the researcher looking at each small section of the transcript, alongside the corresponding sections of coding, and summarising the key experiences. This involved the researcher engaging in a deeper, interrogative and questioning process, thus adding her interpretations to the participant's key experiences, making sense of what these experiences meant for the participant. Within the table, each emergent theme was paired with a quote from the transcript, with line numbers, so that the theme could be easily traced back to the transcript through the next stages of the analysis. The process of coding and developing emergent themes was intensive and took between 6-10 hours per transcript, generating between 50-100 emergent themes for each participant.

2.5.2.1.1 Interpretation during the coding process. The coding process involved a substantial level of interpretation. Thus, within the emergent themes, new terms appear that, to the reader, may not be obviously reflective of the transcript. An example of this can be seen within the first page of Joe's transcript, where Joe's references to embarrassment, irritability and frustration (lines 5-13) are together transformed into a theme of shame. The researcher, with the benefit of having actively engaged with the participants' experiences within the interview, was able to notice a range of verbal, paralinguistic, and visual markers that indicate the presence of the experience of shame (Retzinger, 1995). For example, within the first page of Joe's transcript, many of Retzinger's (1991) verbal cues to shame can be found, such as Joe's use of the words "embarrassing", "embarrassment" and "embarrassed" (lines 5, 7 and 11

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge respectively). Additionally, Joe describes being unsure and confused, and of disagreeing with his wife only to be proved wrong. Other verbal cues to shame used by Joe in the same section of transcript include mitigation, an attempt to appear less affected, through Joe's repeated use of the phrase "a bit". In addition, a range of Retzinger's (1991) paralinguistic markers to shame can be observed to be used by Joe, including a substantial degree of presented hesitation, pauses, stammer, repetition, and laughter. These markers are also common across other participants' transcripts, particularly the use of humour and laughter, as discussed in the results section. Across the sample's transcripts, a variety of verbal cues to shame listed by Retzinger (1991) are present, including terms describing a sense of being unwanted, e.g. "outcasts" (Betty, line 75); terms depicting a sense of being confused, e.g. "gormless" (Gwen, line 997); descriptions of feeling foolish, e.g. "stupid" (Betty, line 198), and of experiencing "hurt" (Betty, line 305). Many descriptions of feeling inadequate, e.g. "weak" (Thomas, 322), and examples of participants' censoring themselves, e.g. "I've refrained from saying things" (Brian, line 664), are provided by participants across transcripts. Furthermore, examples of where some participants appear to maintain an attitude of indifference through the emotionally arousing context of the interview, e.g. "it doesn't affect me no" (Thomas, line 91), which is another verbal marker of shame described by Retzinger (1991), are discussed within the results.

2.5.2.2 Clustering emergent themes under main themes. Once each transcript had a completed table of coding notes and emergent themes, the column of emergent themes was copied into a spreadsheet. Continuing to work with each individual list of themes, the researcher mapped connections between the emergent themes, grouping them together and creating "clusters" of emergent themes under main themes. Similarities and opposites between emergent themes were considered, in terms of how themes represented challenges, meanings, and how they positioned the participant. Sometimes, particular emergent themes took the position of a main theme. At other times, clusters of themes were grouped under a new main theme. Throughout this process, the researcher aimed to capture the key experiences of participants, build an understanding of how they made sense of their experiences, and produce a structure that told the important aspects of participants' accounts.

A new document was then produced for each individual case, listing all of the main themes. The meaning of each main theme was described, with several corresponding quotes taken from the original transcript to illustrate the cluster of experiences and meanings that the main theme captures. This process generated between 8 and 10 main themes for each

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge participant. The process of clustering emergent themes under main themes, and then describing and illustrating them in this way, took approximately 4-6 hours per case. An example of a finalised list of main themes with illustrative quotes can be found in Appendix H.

2.5.3 Cross case analysis. Once a list of main themes was produced for each case independently, the cross case analysis began. The main themes for all participants were entered into a new spreadsheet, with a label indicating which participant they belonged to. This resulted in a table containing 54 main themes. The main themes for all participants were grouped together, according to similarities in their shared meanings. Many of the main themes clearly overlapped, whereas the connections between others required further levels of interpretation. The main themes were initially grouped into 13 master themes. These master themes were then further condensed into clusters, under 4 superordinate themes. Some master themes took the position of a superordinate theme, particularly where the same master theme was present for the majority of the sample. However new names were developed for other superordinate themes. These 4 final superordinate themes aim to capture the key shared experiences of shame in relation to dementia, for the sample as a whole. All master themes and superordinate themes are illustrated within table 1 in Analysis section.

2.6 Quality Issues in Qualitative Research

2.6.1 Validity. As in all qualitative research, the validity and quality of the analysis needs consideration. A number of guidelines for assessing quality and validity in qualitative research have been produced. Smith et al. (2009) recommend using Yardley's (2008) guidelines which are appropriate for assessing the validity and quality of IPA research. However, Smith (2011) developed a guide specifically for assessing the quality and trustworthiness of IPA studies. Smith (2011) suggests that an acceptable paper firstly subscribes to the theoretical principles of IPA, and is phenomenological, hermeneutic, and ideographic. Secondly, the researcher is transparent in what they did. Thirdly, the analysis is interesting, coherent and plausible to the reader. Fourthly, there is sufficient evidence for each theme from extracts across participants. Smith (2011) writes that for an IPA paper to be assessed as of a good standard the study must be well focused and offer an in-depth analysis of a specific topic, the data and interpretation should be strong, and the reader will be engaged and find the analysis enlightening. The following sections address each of Yardley's (2008) criteria for assessing validity and quality in qualitative research: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

2.6.2 Sensitivity to context. Yardley (2008) argues that it is important to demonstrate sensitivity to context, such as appreciation of the socio-cultural context in which the study is set, the interactional nature of data collection, and the relevant literature available. It is made explicit who the participants are and where they were recruited from. The researcher attempts to show sensitivity to the interview data throughout her analysis, and provides a substantial number of verbatim extracts from the interviews, giving the participants a voice and allowing the reader to check the interpretations being made. The relevant literature and theoretical background has been described and will be related back to within the discussion of findings.

2.6.3 Commitment and rigour. The researcher demonstrated her commitment to the study in a number of ways. Firstly, she developed an ethical and purposeful study design, with a careful selection of a homogenous sample. The researcher took time to develop a full understanding of the epistemological stance of IPA and its assumptions. The interviews required the researcher to engage in an ongoing process of reflection in an attempt to build upon her interview skills, including the use of supervision in gaining feedback on the transcripts. Consistency in the researcher's style within interviews, and the full degree of attentiveness towards the participants, demonstrates the researcher's commitment to, and rigour of the study. The transcription of each interview was undertaken with care in order to accurately record the full interactions during the interview. The analysis of each case was also conducted intensively and systematically, and extensive lists of quotes from the accounts of each participant were collected to illustrate each theme. The researcher aimed to provide a substantial enough level of interpretation of the data, and made use of her supervisor's feedback in developing her interpretative skills. A commitment to providing equal accounts from each participant was made, in order to fairly represent each person that took part within the research, and make their experiences known. Finally, the researcher aimed to provide a clear and meaningful narrative of the study and its findings, through this write up.

2.6.4 Transparency and coherence. Transparency of the research is available through the clear description of the selection of participants, the provision of the interview schedule, and the description of each stage of analysis. The appendices include copies of all of the materials used, as well as a step by step illustration of how the analysis was conducted. The researcher demonstrates transparency through providing her own stance on the research topic (see Reflection 1, p33). Further reflections were recorded by the researcher as and when they came up during the research process. The researcher aimed to provide a coherent argument within this write up, providing a logical narrative of themes. The researcher had discussions

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge about the emerging themes with her supervisors, to ensure that the story being told about the data made sense and that she could justify her position in relation to the data.

2.6.5 Impact and importance. Yardley (2008) explains that a decisive test of a piece of research's validity is its degree of usefulness and interest to real-world applications. It is hoped that the rich analysis undertaken will provide a fuller understanding of what experiences of shame are like for people with dementia. It is hoped that this understanding can be passed on to relevant health professionals and services, so that the experiences of people with dementia can be improved. It is also hoped that this piece of research will prompt further research in this area, which may more specifically investigate particular experiences of shame for people with dementia.

Reflection 2. Personal impact upon the methodology

Conducting the interviews involved several challenges. Asking the participants directly about experiences of shame was less straightforward than expected. Some of the participants presented with a powerfully positive exterior, and overcoming the pressure to mirror their presentation and not 'upset the light mood' was challenging. When the participants expressed negative emotions and perspectives, it was tempting to fall into my 'comfort-zone', and rely upon therapist habits, such as empathising with the emotional content of a person's account, and challenging their self-critical statements. This will have impacted upon the interview process, depending upon how comfortable the participant felt with my style. Both my interview style and the openness of the participant impacted upon the extent to which the interview achieved a phenomenological focus. It took time to develop skills in prompting participants to describe their experiences in depth and detail. Some of the interviews were very much easier in this respect, and in contrast, other participants appeared less comfortable in discussing their experiences. It was important to strike a balance between being assertive and persistent in my line of questioning, and responding to participants' resistance in a sensitive and ethical way.

3. Analysis

3.1 Overview of Findings

The analysis revealed four superordinate themes: Avoidance, Negative Self-Perceptions, Relationship Matters, and Uncertainty and Loss of Control. In line with Smith's (2011) guidelines for quality in IPA, each of the superordinate themes are present across all participants' transcripts (see Appendix I). The organisation of themes is structured within a four level hierarchy. The highest order themes include the four superordinate themes, which are each divided between three master themes of their own. Twelve master themes then contain the main themes across participants (of which there are eight to ten for each participant), and each one of these main themes represents a group of many more emergent themes (of which there are fifty to one-hundred per participant), which were pulled from the initial-level coding. The hierarchy of themes is illustrated in table 1. Each superordinate theme will be discussed in turn of each master theme, with a thorough account of how master themes are relevant within individual participant transcripts. Short quotes and longer extracts from transcripts are presented to illustrate the analysis. Longer extracts are numbered and presented within block text, with specific words or phrases underlined, to highlight key points of the analysis.

Table 1. *Organisation of Themes Across the Sample.*

Superordinate themes			
Avoidance	Negative Self-Perceptions	Relationship Matters	Uncertainty and Loss of Control
Master Themes (in bold), grouping Main Themes across participants			
Pushing Away	A Weakening Self	Self-Blame for Burden	Losing Self-Control
Acceptance vs. denial (George)	Certainty of inferiority (Joe)	Self-blame for impact on others (Joe)	Loss of control (Betty)
Fighting vs. accepting dementia (Joe)	Shame in increasing vulnerability (Gwen)	Shame of her impact on others (Betty)	Fight against weakness (Thomas)
Rejection vs. acceptance (Thomas)	Inferiority and disease (Thomas)	The burden of dependency (Gwen)	Lack of control (Joe)
Emotional Distancing	Shame in illness and vulnerability (George)	Impact on relationships (Brian)	Loss of control over life
Shame and avoidance of emotions (George)	Meaninglessness	Shame of breaking social boundaries (Brian)	Lack of knowledge/ preparation (Brian)
Emotional avoidance (Joe)	Missing out on life (George)	Self-blame (Gwen)	Battling for control (Brian)
Avoidance of emotion (Betty)	Emptiness (Gwen)	Trusting Support	Control (George)
Avoidance of emotion (Gwen)	Meaninglessness (Thomas)	Sharing and trust (Thomas)	Wanting the Answer
Avoiding the threat of shame and fear (Thomas)	Not being present (Brian)	Accepting support vs. rejecting dependency (Brian)	Shame in incoherence and lostness (George)
Avoidance of emotion (Brian)	Devaluation	Importance of trust (Joe)	Shame in not knowing (Joe)
Secrecy	Accepted inferiority and devaluation (Betty)	The increasing importance of trust (Betty)	Shame in uncertainty (Thomas)
Avoiding shame through secrecy and isolation (Betty)	Humiliation of being exposed as stupid (Betty)	Losing trust and battling for control (Gwen)	Fear of the Unknown Future
Secrecy and shame (Thomas)	Losing value (Gwen)	Past Rejection and Shame	It's getting worse (Betty)
Hiding/concealment from others (Gwen)	Loss of a normal life (Brian)	Significance of the past (George)	Fear of the unknown (Gwen)
Build confidence (Betty)	Losing value (Brian)	Impact of the past (Betty)	Staying positive (George)
Feeling alone (George)			
Disconnection (Gwen)			
Maintaining worth (Joe)			

3.2 The Participants

Table 2 provides an overview of the participants’ demographics. All participants were of White British ethnicity. Participants’ diagnoses were received by them between two to six months prior to their interview. Apart from Thomas and George, who had no offspring, all participants had at least one son or daughter whom they received support from.

Table 2. *Key Demographics of Participants*

Participant	Age	Dementia Diagnosis	Previous Occupation	Situation
Brian	81	Mixed Alzheimer's and Vascular	College lecturer	Living with spouse
Joe	83	Mixed Alzheimer's and Vascular	Clergyman	Living with spouse
Gwen	83	Alzheimer's	Office worker	Living with spouse
Betty	74	Alzheimer's	Charity worker	Living alone
George	90	Alzheimer's	School caretaker	Living alone
Thomas	85	Vascular	Engineer	Living alone

3.3 Avoidance: Pushing Away, Emotional Distancing, and Secrecy

All participants can be seen as engaging in an attempt to avoid their internal experience of dementia, through pushing away the experience of dementia, distancing themselves emotionally, and/or keeping their difficulties a secret. Participants who push away the experience of dementia appear to do so to protect themselves from feelings of weakness and vulnerability, and hold onto identities of being “normal” or strong. The participants use strategies such as humour, in attempt to emotionally distance themselves from shame. This appears related to painful experiences, such as feeling that they are letting others down, revealing incompetence, and breaking social boundaries. Secrecy was demonstrated via participants’ reports of having withdrawn socially, hidden away, and concealed their difficulties. Participants’ accounts reflect that they engage in secrecy to appear “normal”, avoid others pitying them, and avoid causing discomfort to others. Thus, the experience of

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge avoidance appears to be a way of managing and preventing the shame associated with dementia. However, as described below, avoiding shame experiences is not an easy task for the participants. Avoidance involves a great deal of mental effort, and exacerbates shame when moments of acknowledgement or exposure override this effort. The participants also experience internal conflict between avoidance and competing motivations to draw upon support that require an element of letting go of avoidance strategies.

3.3.1 Pushing Away: “get away from me memory problems” - Thomas. The participants differ in how open they are about the impact of dementia on their lives. Of the six, Thomas demonstrates the most explicit attempts to push the experience of dementia away, claiming that dementia does not affect him because he fights it. Thomas uses “fight” metaphors throughout his interview: “*Well I think you’ve got to be a bit a bit strong in your constitution and more or less say get thee hence, get away from me memory problems, yeah. And face it, glaring eyes on*” (103-107). Thomas’ transcript reveals his desire to be brave and aggressive in relation to dementia.

1. Thomas: I think if you’re going to fight it you should fight it, and not give way.

Researcher: What would happen if someone was to give way to memory problems?

Thomas: I think it would affect their health. I think it would yes.

Researcher: Do you have any ideas how?

Thomas: Probably wanting to do certain things and turning them down and not doing certain things, and just giving way to it. Giving up, and I think if you give up in certain matters it is likely to affect your health, I think. (371-382)

Extract 1 highlights Thomas’ experience of battling against dementia in order to maintain his identity as strong and healthy. It suggests the shame he feels about allowing dementia to impact upon participation in activities, which he considers to mean losing the fight, giving up on life, and thus exposing a weakness. Where Thomas demonstrates some acceptance that he has dementia, he remains adamant that he must fight it. “*I’ve been trying to say as a matter of fact I’ve got this problem, and use that as a whipping block and attack it as best as I can*” (230-234). Thomas appears to oscillate between different perspectives. At times, he pushes away the experience of dementia, whereas at others, he shows some acknowledgement that dementia is affecting him. He suggests that some level of awareness of dementia is needed in order to prevent it from affecting him: “*I’m conscious of the fact that I’m fighting it*” (455-456). However, as extract 2 demonstrates, Thomas is unable to explain how dementia can be attacked or prevented, other than through a vague notion of “mind over matter”.

2. Thomas: “you just have to get on with it and just fight it, and think, psychologically speaking anyway, and just think that you’re winning.”

Researcher: And how do you fight it?

Thomas: Ah that’s the thing explaining it, that’s difficult to answer you know, that’s a good one on your part.

Researcher: I’m not trying to catch you out.

Thomas: No alright no.

Researcher: I’m just wondering how you, what can you do to fight dementia.

Thomas: I don’t think just like that you can. I just think you’ve got to go over a few things. I think you’ve really got to kid yourself on that you’re fighting it rather than knowing for sure that you are fighting it.” (267-293)

George at first appears to largely accept his memory difficulties: “Well, all I put it down to it’s inevitable anyway, that’s how I look at it, I don’t let it get any further than that” (384-386). However, there are apparent limitations to this acceptance. He pushes away ideas about dementia, asserting that his memory lapses are just a consequence of old age: “It’s not because of any illness or anything like that it’s, it’s the fact that it’s age, that’s what I put it down to. Yeah yeah” (278-295). George’s change in statement from “it’s the fact” to “what I put it down to” indicates that there is a degree of doubt in his assertion. In extract 3, George has difficulty acknowledging the chronicity of his memory problems, and when he refers to times that he was vulnerable, he attributes problems to other influences.

3. Researcher: What do you know about it [dementia]?

George: Well actually it’s happened to me, (soft tone) it’s happened to me. Yeah I went to town once and - (stammer) why why you know why have I come here? (Rapid speech) Why are you here? Why have you come into town why are you here for? And I stood there and I’ve had to go back home, because I didn’t know, and that’s happened to me.

Researcher: Do you remember what that experience was like?

George: Well, yeah I do because I think well this is a damn bloomin’ nuisance isn’t it? I mean (Sigh) Oh God all of a sudden it come on and it was so unexpected, yeah, it certainly wasn’t pleasant that’s for sure yeah (laugh) frustrated again wasn’t it?

Researcher: Ok, now this might sound like a silly question, but what was frustrating about it?

George: Well it it’s frustrating - it’s silly to say it’s frustrating but it is frustrating

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because I've got all these problem with the with trying to remember what I'm trying to remember, that's you know that's what it is that's so frustrating I, I just can't remember I just can't think what it is want what I'm here what I came into town for now. Yeah, I mean I what was it - a couple of nights ago, I can't go out in the dark anymore, I was 3 hours on my blimmin own, and I wandered around I walked about 10 miles I think before I, I really got back home, and in the end the taxi driver didn't know where to go he was a foreigner, that was worse I had to pay him just the same, anyway I'm sidetracking now.

Researcher: No actually that sounds really important.

George: Yeah it did happen yeah, 3 nights ago I think it was yeah in the dark yeah in the dark, so I I've realised now I must never go out in the dark again, never ever, no I can't work it out, because I can't see can't see where to go. (659-712)

Up until this point, George has been hesitant in telling his story of how dementia affects him. In extract 3, George's use of the words "once" and "happened to me" portrays dementia as a one off occurrence; despite his earlier acknowledgement that dementia means "*you always forget things at different times*" (287-288). The change of pronoun from "I" to "you" indicates George's discomfort in personally identifying with this experience of repeatedly and impatiently questioning his purpose for being in town. He expresses awareness that these experiences were unusual. However, George laughs at retelling how unpleasant he found the experience, and then invalidates his emotional reaction with "it's silly". Despite the strong image of disorientation and vulnerability described in the story, George does not mention feeling afraid. Instead his emotional experience is anger and blame. Rather than his memory, he attributes his getting lost on not being able to see. George's expression of frustration at not being able to remember, as well his phrases "damn bloomin' nuisance" and "on my blimmin' own" reflects potential self-directed anger. The presence of verbal markers of shame, such as the expression of confusion and lostness, and paralinguistic markers of shame, such as a soft tone, stammer, rapid speech, and laughter (Retzinger, 1991), suggests that George may feel ashamed about this episode of confusion and vulnerability.

Joe moves between states of being "*up against*" dementia (214), and accepting it "*to a degree*" (351). On one hand Joe wishes to find solutions to overcome dementia, and on the other he accepts that he may need to adopt a different way of being: "*In a way it [a practical nature] puts me up against it and said "right, ok we can't do that, but let's have a try at... plan B"* (214-216). Generally Joe he tells himself that he can accept life as it is, however, as

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge extract 4 illustrates, there are parts of the dementia that he finds more difficult.

4. Well the memory problems really (stutter) I I I I I've just come to (pause) to a degree, umm (laughs) when you have a (laughs) pocket full of loose change it's a bit embarrassing when you have to sort it out on the counter in the shop (laughs) 5 p at a time, and that I find extraordinarily difficult, and then I do feel an idiot. (350-356)

Joe's laughter when describing this situation, and the change of pronoun to "you", reveals his motivation to distance himself and minimise the emotional impact of dementia. His stutter, pause, and neglect to completing the first claim demonstrates that he is not able to say that he accepts his dementia, due to the embarrassment that it causes in such situations.

3.3.2 Emotional Distancing: "we laugh at it, to cover it up" - Betty. The participants demonstrate emotional distancing through many strategies, including the use of humour, idealising, minimising, intellectualising, and avoiding naming dementia. Across the participants, humour and laughter present common strategies for hiding or easing the emotional pain and shame attached to certain experiences.

5. Joe: I just know (laugh) that I can't rely on (laughs) - yes, I - just know that she's going to be right every time (laughing). In the way of it, she's got a whole brain, put it, and I've got half a brain (laughing)

Researcher: Is that how you think about it?

Joe: (Sounding serious, quieter) yes, really. Umm (pause) and uh we can laugh about it. (101-115)

In extract 5, Joe's comment about not being able to rely upon his own brain conveys a sense that he is incompetent and inferior in comparison to his wife. He laughs and makes a joke of it; however his quieter tone after the follow up question makes his humour less convincing. Another emotional avoidance strategy that Joe uses when discussing something painful, is immediately minimising the issue with laughter, then replacing it with positive and idealising statements about his wife and their history, as seen in extract 6.

6. Joe: I let her [his wife] down and say something really stupid and she's embarrassed. It doesn't happen very often (laughs).

Researcher: You feel like you let her down, by saying something, that wasn't right?

Joe: She uh, she's an absolute treasure... really, I wouldn't have thought it possible. (Pause) um, (laughs) we have um, had an interesting time. We we sailed on the boat up out of Plymouth... (491-501)

In extract 7, Betty describes the self-criticism she feels when she makes a conversational error, and how humour is used as a strategy by her son to help them both manage the impact of dementia on their emotions.

7. Betty: I can go and say something that I shouldn't have said which shouldn't have been in the conversation. I'll say "sorry I shouldn't have said that". But my son he just has to laugh, to make me laugh at times, he just says "yeah alright mum we know where you are, we know where you're going".

Researcher: What does he mean by that do you think?

Betty: (laughs) I'm having a senile moment. You know, and that's the way he handles it, he has to laugh it off.

Researcher: Ok, so he laughs it off, and what is that like when he does that, for you?

Betty: Well I usually turn around and give him an answer. He might not like the answer but... Essex girls call themselves silly cows... So when I do something like that I say "alright I know what I am I know I'm a silly cow" and we laugh at it, to cover it up so to speak.

Researcher: Ok, what do you think it means to call yourself a silly cow?

Betty: (laughs) stupid. (115-144)

Betty's conversational mistakes appear to leave her feeling that she has broken social boundaries, and that she needs to apologise. Her son may have his own emotional reaction to this, perhaps fear about what the future holds for them. Betty laughs off his comment, and puts herself down as a way of defending herself against her son's criticism. Although these comments are made with humour as a protective strategy, the meaning behind Betty's self-description as a "silly cow" can be seen as exacerbating her sense of shame.

Where Brian openly talks about painful emotions, such as shame, he does so with hesitation and minimisation, such as in extract 8.

8. Brian: Yeah... at times can't yeah, at times I just you know, (quietly) feel just absolutely fed up, and I get to the stage where "ah can I die?" you know, uh, but uh, it's uh comes and goes, that it's not continuous. You know I sometimes think, oh you know Jill might say something... "oh God uh, do I have to put up with this?", sort of thing and (laughs) you think oh, but I... she reads a hell of a lot. (356-365)

Brian's quiet voice in the extract above demonstrates how he wishes to keep his painful feelings hidden. He uses laughter when describing a shameful event, and then changes the subject.

George also demonstrates the use of humour, as well as a further avoidance strategy, using an alternative physical disability, his hearing, as a distraction away from the effects of dementia: *“I’ll say “I’m sorry I’m getting a bit Anno Domini you know can you just say that again for me?” And of course my hearing’s not as good as it used to be”* (392-398).

Thomas' interview demonstrates this theme through several processes. He manages to complete the interview without talking directly about how dementia affects him. He can be seen as refusing to engage with his experience of dementia, through avoiding naming dementia and talking about it, denying the impact on him, giving short answers to questions, intellectualising the experience of dementia, and addressing dementia as though it is something external to him. The interview therefore stays at a superficial level, and he remains distanced from his experiences of dementia, and protected from the potential shame it may bring. Although this makes it difficult to consider his experience in depth, the processes emphasise how determined he is to avoid his experience of dementia.

9. Researcher: Do you think dementia is something that’s troubling you?

Thomas: No I don’t think it’s troubling me very much at all. No, not bothering me too much at all.

Researcher: What are the things that dementia makes difficult for you?

Thomas: Not very much for me, no, no.

Researcher: Is there anything?

Thomas: Not very much no. I think it’s because I trained to have a strong mind. (423-439)

10. Researcher: And what about the memory problems? Can you tell me a bit about that?

*Thomas: Yes I think I’ve always been a thinker, always been a thinker (pause) *umm. I think the main thing about such goings on is, not to let it worry you too much. Or else the worry may get on top of you, and upset you, like in your day to day life, I think* (coughs).*

Researcher: Do memory problems ever worry you?

Thomas: I don’t think they do really because of my attitude towards them. Get thee hence you know get thee hence memory problems! (quieter) get thee hence (laughs). (57-74)

In extract 10, Thomas avoids questions about his memory, and avoids the use of negative words. When he talks about his experiences of memory difficulties, he metaphorically pushes

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them away and rejects them.

George and Thomas both suggest a fear and shame of experiencing negative emotions, explaining that such feelings can become unmanageable and reveal weakness. When questioned about the level of their acceptance and positivity in relation to dementia, In extract 11, George demonstrates an extreme belief that allowing anything other than positive experiences is life threatening. Thomas strongly states his opinion that worry is attacking, suggesting that he feels threatened by dementia related worries: *“Well I think worry, worry is a terrible thing to have, I think so, that’s why I think you should give, not give not give way (mutters) should not give way, you should stand up against it”* (394-398).

11. George: *No good being any other way is there? Not good at all, no good at all.*

Researcher: *What other way is there?*

George: *Well, well it’s uh CS commit suicide isn’t it? I’ve had enough of all this I’ll just you know get a bit of rope and hang it up there and that will be the end of it.* (791-802)

3.3.3 Secrecy: “I just keep quiet and pretend I understand” - Gwen. The participants demonstrate a need to hide their dementia to avoid shame. However, the interviews suggested how secrecy can breed shame. Betty discusses how she prefers to stay in her comfort zone at home, than go out and face the outside world. However this leads to her feeling increasingly alone: *“I mean sitting here I can be quite lonely on my own (pause) you know and (pause) people looking at you when you go out, and that (pause) I suppose the word is slightly ashamed again, going out”* (721-725). Betty therefore faces a dilemma of either protecting herself from shame but feeling lonely or going out but feeling ashamed. She chooses to suffer loneliness over shame, revealing the intensity of discomfort with shame as well as the motivation to avoid it: *“Oh yeah but I can amuse myself at home, you see, but if I’m outside and I’m on my own, I only go to the shops I’ve got to go to, get what I want and come back”* (729-732).

Gwen talks about wanting to hide and conceal her dementia from others, out of a fear of pity and a desire to appear normal. In extract 12, she talks about her experience of meeting someone else (the wife of her husband’s friend) with dementia.

12. Gwen: *He had his his wife with him, and she’d (whispering) lost it she just (stutter) s stood there and smiled, and um, and this man kept talking and talking, and he did sort include her in the conversation, and she just like, something hanging on his arm, I don’t want to be like that, I’d rather not go out.*

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Researcher: What did you think about that lady?

Gwen: Well she's since died. Umm, I just thought how sad, (voice cracking) terribly sad, and um, yeah, and we haven't seen him lately actually. But um, no it was awful, I wouldn't want my husband to take me out, if I got like that, that's what I think. I wouldn't want people to pity me so much. (500-515)

Gwen's whisper reveals the shame she attaches to "losing it", as well the secrecy she wishes to maintain in her perception of dementia as meaning having "lost" something, perhaps one's mind or personhood. She describes her husband's friend as "talking and talking", perhaps to fill in the space that his wife's emptiness left. Gwen's description of the woman with dementia as "something hanging on his arm" portrays her as a vacant object rather than a person with thoughts and feelings. Gwen then emphasises the shame she attaches to becoming "like that", and her motivation to conceal herself rather than have others think of her in the same pitying way that she feels for the friend's wife.

Gwen later talks about how she currently manages social situations: "*Just (pause) I I sometimes bluff my way through it, you know they they say, you know we sort of - I just keep quiet and pretend I understand what what they said*" (734-736). Gwen emphasises how she conceals her difficulties, in order to avoid embarrassment. She indicates that others behave in the same way, pretending everything is normal, protecting her from the shame that dementia can bring.

Both Betty's and Gwen's transcripts reveal how they choose to cut themselves off from the outside world and their social circles in order to avoid the shame of being exposed as suffering from the difficulties that dementia can bring. Brian demonstrates this same dilemma. Despite his wish to be present in his friends' and family's lives, he chooses not to involve himself out of the shame of being a burden: "*I know that I wouldn't be uh, very good company to the two of them*" (565-567).

Thomas discusses the difficulties that a person with a dementia faces in wanting to hide it from others.

13. Researcher: What do you think could be embarrassing about it?

Thomas: Probably fighting to keep it down to a small level, not sort of going around advertising the fact that in their mind and memory (coughs) it's with them, and their worried in case they make it apparent that it's with them.

Researcher: So do you think it would be embarrassing for other people to know that it's with them?

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Thomas: Oh I don't think so much with myself because I've geared myself up to the fact that it doesn't embarrass me.

Researcher: Ok, yeah, and how do you stop it from embarrassing you?

Thomas: (breath in sharply) I can't answer that, I don't really know, possibly the answer may well be don't keep it a secret, and you might say to me well you more or less said that you can't do that, well it is a job to do it. (579-604)

In extract 13, Thomas suggests that although keeping dementia hidden from others aims to prevent embarrassment, it actually makes the experience of shame worse. Perhaps Thomas experiences embarrassment in the “fighting”, to keep dementia at bay, particularly if he feels that he is losing the fight. Thomas highlights the dilemma between keeping dementia a secret from others or discussing it openly: either way it will cause embarrassment.

3.4 Negative Self-Perceptions

All participants refer to ideas that dementia impacts upon their self-perceptions. Perceptions of a weakening self and inferiority are strong across participants' transcripts, with different meanings for each individual. The participants indicate that they desperately want to be “normal” and like others, but feel something is wrong with them, that they are abnormal, inferior and less worthwhile than others. Some discuss how dementia presents risks that their life will be meaningless, empty, dull, and that they would miss out of pleasures. Gwen expresses a unique fear of becoming “gormless”, meaning unable to do anything for herself, being vacant, without a mind and awareness. They also talk about feeling less important to and valued by others, for example, feeling forgotten about, unwanted, disconnected, and mistrusted. The participants' feelings of meaninglessness and devaluation appear to occur through social interactions, or lack thereof. Some of the participants express feeling that their withdrawal means that they are not “playing a part” in life, however they feel unable to express themselves due to a fear of saying something wrong. Others describe being made fun of and humiliated, dismissed and invalidated. Often, participants describe experiences of being wrong, making mistakes and feeling stupid, useless, helpless, and unable to cope. This involves an identity struggle, as self-perceptions of uselessness, abnormality, and powerlessness are at odds with participants' existing identities. Many of these experiences appear to cause feelings of shame, and are often responded to with self-directed criticism and anger.

3.4.1 A Weakening Self: “I learning not so strong willed” - Joe. This theme covers two main experiences for the participants. In some cases, the participants appear to express

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge that having dementia means not being as good as others, not “normal”, and thus being weaker in some way. In other cases, the participants talk about a weakening of abilities and an increase in their vulnerability.

For some of the participants, there appears to be a conflict between the wish to be perceived as “normal”, and the realisation that there is a problem.

14. Thomas: I mean, one explanation explains it all, that there is a problem, there's a memory problem it means that, just as simple as that, it's not a complex thing as you might expect it to be. And as I said earlier one explanation does tend to explain it all. Just saying I have a memory problem explains it all.

Researcher: What do you think is the explanation for your memory problem?

Thomas: I don't personally think it is very serious but you might think I'm wrong. I would say I have a memory problem from growing older.

Researcher: And you say you've had it for a year.

Thomas: That people have noticed it, seems to be something that people have caught on to, memory problem because I've met several people who've said so have they, that I have memory problems, so have they, several people that I've met have said that, several people that I know have said that they have memory problems. (792-820)

In extract 14, although Thomas prefers to see his memory problem as something simple and typical, he expresses doubt that this perception is correct. The repetition of “several people” indicates how strong his desire is to be normal. This demonstrates how important the terms people use to describe their memory problems are, particularly when explaining it to other people.

Brian talks about how a diagnosis of dementia changed his self-perception and how he and his life seem unusual and inferior.

15. Knew very little about it yeah, yeah because I'd been, what shall we say [sighs] for want of a better word, a normal sort of guy, you know, I was getting on a bit like [laughs] but you know. I had five and a half years in the air force. (16-21)

Extract 15 reveals how Brian's perception of himself as “normal” and of having lived a worthwhile life jars with his experience of receiving a diagnosis of dementia, perhaps because his perception of dementia is that it makes a person different, and their life is less worthwhile. Brian then goes on to discuss a memory support group that he attends.

16. You know and then it develops and, uh this group that we go to on Thursday now, you know they're all, they are all, 15 of us who have got dementia, in various stages,

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you know [sighs], basically, they seem nothing wrong with them. (122-126)

In extract 16, when talking about the memory support group, Brian shows a recognition that dementia is degenerative and that “it develops” into different “stages”. His description of the people in the group as “seeming” like they have nothing wrong with them reveals his preconception of people with dementia as being “wrong” in some way.

Joe explicitly talks about a certainty of making mistakes. As a retired engineer, Joe is used to an identity as a practical and knowledgeable person, and therefore this acknowledged reduction in his competence imposes a shift in his identity, and at times this causes him to feel stupid.

17. Joe: And bought the wrong thing in a shop, oh yes (laughs) this happened, and (coughs) or if there's um if it's a birthday card, I got one out and she thinks another one would be very much more preferable (laughs). Um (pause) I'll tell you she's very strong willed, um, and (lower tone) fortunately I'm learning not so strong willed and um a little bit more flexible (laughs). She isn't flexible (laughs) she knows what she wants and goes for it (laughs). And so in a way this is good because we've got a solid benchmark.

Researcher: And what is that like for you?

Joe: (laughs) ah well I probably have to say “you win love”, um because generally if there is a - any difference in the present circumstances, um it's (lower voice) guaranteed that she's right.

Researcher: Ok so generally you have to accept that she's right...

Joe: Eat humble pie (laughs) yes yes (lower tone) yes. (50-72)

In extract 17, Joe talks about getting things “wrong”. He emphasises the experience of losing confidence in his own opinions, and having to trust that his wife will know better than himself. Although the use of the word “fortunately” suggests that he perceives his flexibility as a positive thing, his lowered tone of voice expresses sadness in learning to be less strong willed. Similarly, his admission that his wife's strong will provides a “solid benchmark” highlights that in comparison he feels unable to provide a reliable guide for them both. The phrase “eat humble pie” suggests adopting a lower status in comparison to his wife, and perhaps feeling humiliated when admitting to a mistake.

18. Joe: Yes, you you can you can feel an idiot then really, supposing (coughs) somebody asked me, umm, is such and such a shopping, and I would find myself completely at a loss, and (laughs) completely useless (laughing).

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Researcher: Ok, so when that happens, what does it mean for you?

Joe: (quietly) I have to apologise and eat humble pie (laughs). (169-173)

In extract 18, the repetition of and pronoun use of “you” reveals Joe’s motivation to distance himself from this experience of feeling idiotic at unable to help someone. The repetition of “completely” emphasises just how lost and useless Joe feels in such situations. Joe goes on to provide another example of a situation where he felt stupid, when counting coins to purchase something.

19. Joe: the shopkeeper (laughing) will just sort of... pull out the tiddlers and 50 ps and so on and he will just do it very quickly and scrape them up and and and.... and I've got to take them one at a time and very cautiously. And you do feel (laughing) a bit of an idiot.

Researcher: But why?

Joe: Because I can't do it. (358-371)

In extract 19, Joe describes feeling idiotic because he is less competent at rapidly counting money. Similarly, Joe’s comment “*I’ve got half a brain*” (106), suggests that he feels substandard, and implies that he is half as able as other people. In contrast with Joe’s perceptions of weakness and uselessness, his Christian faith offers him a way of perceiving his suffering as virtuous.

20. When you think about what the Lord went through, he had the most appalling humble pie with no complaint, and...(sigh) I hope that my life will show something in umm - a Christian learns to um make - draw the short stick now and again but put up with it, and he writes in the bible, we share what Jeremiah went through in our hearts, it was horrendous the way that he was treated, and and a large number of people in the bible are like that um (pause) and so, really I, I don't think it's right for me to complain. (313-324)

Gwen describes fears about losing independence, getting lost, and of others being unable to help her: “*Well if all of a sudden I can't think where I am, and I have to ask somebody, if they can tell me if I can't remember my road or something, I worry about, what might happen*” (172-175). Gwen’s statement conveys a fear of being vulnerable, dependent and helpless. She continues to talk about losing other competencies such as baking.

21. And then I'm making a cake, and I thought did I make did I put the baking powder in? I thought don't be daft just tick it off these days you know, your list, just just help yourself don't just, you know just you throw the flour in throw the fat in get on with it. (1032-1037)

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In extract 21, Gwen questions herself, and then critically responds to her self-doubt. She sounds angry and impatient with herself, repeating the word “just” to express how simple the task should be, and using the word “daft” to describe how incompetent she feels. Throughout her transcript, Gwen continues to express shame in the perception that she is unable to cope with dementia: *“I don’t really know how I could cope”* (275).

Like Gwen, George also describes feeling angry and frustrated with himself when he experiences memory problems during day-to-day activities, that make him feel less able and efficient: *“Well it’s alright getting old George but it’s a bloody nuisance isn’t it all the things you want to do, and uh, you can’t do them right away, it it holds you back a bit”* (585-588).

22. George: *Well it it it it’s irksome, and troublesome, and wearisome, cause you you use that energy going back and when you get to my age you haven’t got the energy you had when you was a lot younger have you? (laugh) The fires are burning lower all the time.*

Researcher: *so, it’s a bit wearisome?*

George: *Well, yeah that’s a description of it, yes. A literate description at least anyway.*

Researcher: *Ok, are there any other descriptions of it?*

George: *Urm, well, it gets me fed up to think well you know I didn’t have my slip here, and it’s a damn trouble going back again especially if it’s raining, it makes it worse than ever doesn’t it?* (241-258)

In extract 22, George’s metaphor of “the fires burning lower” indicates how forgetting is a reminder that his health is deteriorating, and that he feels he is losing the strength and energy to live his life. His more emotional language towards the end of the above extract reveals how difficult these memory problems make life.

3.4.2 Meaninglessness: “I feel like... a body” - Brian. Some of the participants talk explicitly about how dementia made them feel meaningless and empty. Brian talks at length about feeling that he is not present in his own and other’s lives, and this makes him feel like he is not living a meaningful life: *“Yeah... [quietly] I guess I don’t feel that I am... playing a part... in my life. Jill’s around”* (501-502). The quietness in Brian’s voice, as well as the pauses, indicates the shame that Brian feels about not being present. His mentioning of his wife Jill suggests that he feels guilty that he is not so present in her life. Brian continues to discuss the impact of his illness on Jill’s life, suggesting that Jill was not expecting her life to be this way.

23. *I'm not, uh... no. It's, I feel... that I am not... well enough, I haven't been well enough for a time... to live by, living really. I mean Jill's the same because she didn't even know when it first....uh, but I mean I always say to her I'm going to so and so's, because she goes on Tuesday, with a friend of hers. And I say No, you know, it's... I'm not putting any obstacles, getting a bit tongue tied, getting into obstacles in the way if she wants to do something, you know, this is part and parcel of her life, as well as mine. (522-533)*

Brian struggles in starting the first sentence in extract 23. He seems to feel guilty that his dementia has become a significant part of Jill's life and therefore makes a point of allowing Jill to continue her life as usual. Brian goes on to talk about how it is difficult for him to participate and express himself spontaneously in social situations, partly due to fear of saying something that upsets others and partly due to feeling slower, and so it is easier for him to withdraw.

24. *Umm, uh yeah I feel like... a body. You know, if we... it's uh, yeah it's one of those things, sometimes, I mean it's not permanently. Oh I get to the stage where I think, oh, I don't go out because I might say something that... upset other people. You know say there's a six of us. I might say something, or not say something, not take a part... (627-634)*

In extract 24, Brian's description of himself as "a body", portrays how empty and vacant he feels when he is unable to contribute his own thoughts and feelings. In contrast, Brian later talks about how the memory support group he attends allows him to contribute to social activities and feel more of a person again.

25. *Uh, I think, that, the dementia group that we go into this afternoon, I think that helps, yeah because we're all, we're all in a group where, we, we are, we all have our chance to say things, and we have to think them up on the spur of the moment, and the, and that goes deeper into life, really, uh not life, just something that you think, oh I'm good at that, or other I can't do that. I mean this chap that I was sat at the side of, yeah, he must be getting on for 90, but when you start talking about his experiences of motorbike driving (laugh), the trouble is when to stop (laugh). (813-821)*

During extract 25, Brian's repeated use of the word "we" implies the support he feels in being in this group. He talks about feeling more able to play a part in this group, because they pace slower and allow each other time to think and speak. Being able to express himself spontaneously, and contribute to the group allows him to feel meaningful and alive, and then

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he is no longer just a body but a whole person, like the gentleman talking about his motorbike experiences, expressing his opinions and feelings.

Gwen discusses her own perceptions of how having dementia leads to a meaningless, empty life.

26. Gwen: Well it it looks, I, I just keep thinking about my f- this fella and his wife it's, it's just like you're walking, and you don't got any - I don't want to look like that. You're just walking and not got any - how she sort of got herself dressed I don't know, I don't want to be, be like that.

Researcher: And what do you mean by like that, what is that like?

Gwen: I don't want to just be gormless, and I don't want to be so people have got to everything for you I don't want to be, so you don't do anything for yourself, I don't know how it develops this dementia what happens, what what do people do with dementia? (985-1000)

In extract 26, Gwen voices her fears about becoming an empty body, unable to do the necessary things, and dependent upon others. She refuses the idea of that happening to her, rejecting that part of herself that is becoming less independent and able, which reveals the shame she experiences with it. She ends the statement with a question, looking for an answer as to how she might stop herself from becoming “gormless”. Gwen goes on to explain what the words she uses to describe herself with dementia, such as “gormless” and “wimp” mean: *That you haven't got, any idea of things, you just shrug, sort of shrug your shoulders you don't know this and you don't know that, and you don't care really (laughs) (1008-1011)*. Therefore Gwen reveals her emotional struggle against becoming vacant of drive, motivation and understanding.

George expresses concerns that the memory problems may cause him to miss out on the remainder of his life. He discusses the importance of engaging in mental exercise to prevent this from happening.

*27. Yeah, well if I didn't I mean my brain would be inactive a lot sooner, and I'd miss out a lot on me, I'd miss my reading and the TV and everything you know, talking to people and all that, I'd miss out on life wouldn't I? Yeah I would do. (103-108)
*Like all the wonderful things there are in books and Shakespeare, yeah gonna miss all that you see, I won't get the pleasure from - I wouldn't get pleasure from life like I'm getting now. That's what it means to me. That's why I strive to you know derive, yeah yeah that is the thing to do yeah yeah. (547-553)**

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Extract 27 indicates how for George, the concept of losing his cognitive abilities causes him concerns about missing out on pleasures, becoming inactive, and not engaging with life.

3.4.3 Devaluation: “you’re not as good as you used to be” - Gwen. Several of the participants suggest that having dementia makes them feel less valued by others. Throughout her interview, Gwen conveys a sense that everyone is quickly aging: meaning that she is less supported, particularly by family, increasing a sense of vulnerability and of being unwanted.

28. We go half way, my son takes us half way and one my daughter meets us at the other other half, because it’s 160-odd miles, and uh, it’s too far for my husband to go, so um, and not only that they’ve got busy lives themselves so you know. (72-77)

In extract 28, Gwen talks about feeling disconnected from her family and that her children are too busy to drive the distance to visit her. She goes on to discuss her experience of taking her memory concerns to her GP, and initially having her concerns dismissed.

29. I went last year to the doctors and said uh - I keep forgetting things, and she said we all forget things, and um (pause) so I saw um, I must have seen another lady she asked me 30 questions, and she says uh oh 29 out of 30, you know go away don’t think about it, (102-106)

30. So I went back again I said well I know I come last year, but um I think it’s got worse and I saw the same lady and she asked me a total set of different questions and some extra ones, and she said well you’ve still scored high, but from what I gather from talking to you, I think you used to be really bright, and now you’ve gone down a level or two, and you’re not as good as you used to be, so I’m referring you, so that’s how it’s gone on from there... (109-199)

In extract 30, Gwen experiences being told that she is “not as good” as she used to be, thus reducing her as a person. Although there is a sense that the GP is referring to the memory test scores being “not as good”, rather than Gwen herself, this is experienced by Gwen as devaluing, perhaps due to her feelings of shame about this appointment. Additionally, the vagueness around the referral process and where this led to indicates towards how the medical system is experienced as mystifying.

Brian refers to a threat of being devalued by others, when talking about how his friend, who died after suffering dementia, is no longer mentioned by his friends.

31. It’s just we always say sometimes... he got that bad that the dementia did kill him, but that’s how much we’ll go out, it was only last Sunday or a week last Sunday, she had a lunch uh Sunday, it was Jill’s birthday, and she arranged a nice day, she

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arranged lunch for the 6 of us on the lawn, and her husband, ex-husband, was never mentioned. You know I mean umm, what shall I say... 5 or 6 years ago since he died, but she's got over it. (338-349)

In extract 31, Brian displays sadness about his friend being quickly forgotten by his wife. Brian seems sad for his forgotten friend, perhaps fearing that one day his friends will forget about him too.

Betty makes several references to feeling unwanted and mistrusted by others. Like Gwen, she feels disconnected from her family: *"I don't see much of them though admittedly. They've got a lot to do at home as well, and keeping the cars on the road"* (818-820). She can also feel undermined when reading people's facial expressions in response to her social mistakes: *"sometimes there's a little smirk come on their face. You know, or else you get a strange sort of, lopsided sort of look"* (679-681). Often though, her feeling of devaluation occurs through an internal process of undermining herself, and accepting a position of inferiority in relation to others.

32. Betty: So err, it's just going out and facing people, you know, so then if I go and say the wrong thing, I feel total stupid. Umm...

Researcher: Hmm. I'm just wondering what wrong thing might you say?

Betty: Well I could ask some single man "how's your wife?" not realising that I've said it, thinking automatically he's married. You know same as with a single woman, to me they're single, or I'll ask her if she's got a friend or anything, you know it's all, what can I say? I might ask how so-and-so is, and I've got the wrong person, when I've asked her, it wasn't her I should have asked, it's somebody else (laughs).

Researcher: When that happens, do you notice anything about how the other person responds?

Betty: (pause) Normally in a nice way, they don't get annoyed or anything. But I feel more of a wally if you know what I mean. So umm... my son does they always (coughs) excuse me they laugh at me. And they say "what are you?" and I say "I know what I am you don't have to tell me", you know and we laugh about it then, you know, but umm, and I'm getting it off my grandsons as well now. (196-224)

In extract 32, Betty engages in self-criticism at having said something "wrong". She describes feeling stupid despite the other person's reaction, and that although usually people don't get annoyed, her "son does", which he expresses through making fun of her. Betty's son may be attempting to keep the atmosphere light-hearted, however his comments are undermining.

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However, Betty has allowed this treatment, and she acknowledges that she is now receiving this devaluing attitude from her younger family members.

George's sense of self-value appears to be protected by a sense that he is healthy and resilient, as he discusses how others appreciated him for being well and reliable.

33. I've only had one day off sick in in my my whole life I think when I couldn't go to work, and that was when I had, when the Asian flu was around. That's the only day I've ever had off sick in my whole life, yeah, yeah, well, always working on a farm, you always had to be there 7 days a week anyway, you know had to go round to see the animals everyday to see if they whether they was in season or whether they'd injured themselves and they wanted feeding, so there you go so, I bet they liked me on the farm didn't they for always doing that. Yeah I bet they did. (776-789)

This might explain why George prefers to see his memory problems as a part of normal aging, so that they do not challenge his identity as 'well'. Perhaps he believes that if he is unwell with dementia, then he will be not be so well valued.

3.5 Relationship Matters

All the participants talk about issues within relationships, past and present, that impact upon their experiences of dementia, as well as how their dementia impacts upon these relationships. Some of the participants express self-blame for burdening others, through accidentally causing them emotional distress by saying the "wrong thing", or causing others strain through being dependent on their care. Sometimes, participants appear frightened that the strain they caused others will lead to being rejected or abandoned. Experiences of burdening others through saying or doing the wrong thing link with participants losing trust in themselves. Some of the participants describe feeling unworthy of another's trust due to their level of vulnerability. The participants' loss of self-trust means that their trust in others was more important. Most participants had a person or small group of people whom they felt more trusting of. The participants' lack of trust in their wider networks is expressed through fears that people might not have their needs in mind, reject them, or worsen their health. Participants also describe memories of past rejection from family members, employers or romantic partners, as well as the distress and shame this caused them, and how this impacted upon how they felt in the present.

3.5.1 Self-Blame for Burden: "I let her down" - Joe. Joe expresses shame and self-blame for the impact of his dementia on his wife Ellie, causing her embarrassment and distress: "*Really sad for Ellie really, because it probably makes it more difficult for her, and*

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she has to explain me” (202-203); “I let her down and say something really stupid and she’s embarrassed” (491-492).

Gwen describes the shame she feels at causing burden and strain to her children and her husband.

34. Gwen: they take it for granted don’t they - I don’t know. I don’t know - because of the way they say it “I’ve told you that”. And I thought, you know and then they’re going to lose patience with me or something.

Researcher: Ok so they might sound a bit irritated in their tone of voice, is that right?

Gwen: Yes.

Researcher: When does that happen?

Gwen: I mean I don’t know I don’t make a note about it, but it does happen. I don’t - we live a very quiet life, and we don’t go out to dinners like we used to or evenings, so and uh so I don’t I’m very dependent on my husband really, and he’s good but the poor man’s having physio himself, because he’s - that’s where he’s gone this morning because he’s got dread - he’s got dreadful chest - a dreadful cough - and apparently it’s - I don’t know what it is but it’s not, they’re not treating it as a chest problem he’s got exercises this morning and um, it’s suddenly crossed my mind he might die before me.

Researcher: Ok, that’s quite a thought...

Gwen: I don’t want to get upset (tearful) but he might mightn’t he? He’s eighty- eighty four? Going on eighty-five yeah. He’s good, he has - he is good, and he can do - he does a lot more than he used to, he does - I get tired, I know that’s one of the symptoms I get ever so tired. But then I wake up a lot in the night, and uh he goes round with the cleaner, I mean, my house is clean isn’t it, my house is ok, and uh, he doesn’t - he can peel potatoes, and he can do things like that, but he doesn’t actually cook anything, but I can, so I can do it. He’s getting old himself and the garden’s getting a bit much. And he’s got a greenhouse, and uh, and he drives, you know I trust him driving, and I’d be lost without him because nobody else would have the patience with me, I couldn’t live with my daughters, because it’s not fair on them. (224-253)

Extract 34 reveals the shame Gwen feels in being dependent upon her husband and the fear that he may leave her unable to cope, or under the care of her daughters. She feels that her children don’t have the patience to care for her. Depending upon others therefore comes with a risk of losing them and being abandoned. Gwen blames herself for this potential burden and

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge rejection, suggesting that she is being punished for lacking patience with others in the past: *and I think, possibly, I might have been a person like that myself, I might have said I told you that you know and so ooooh it's all coming back to me that's what you get for being mean (369-372)*. Gwen later expresses a dilemma between the shame of feeling a burden on her husband, and the fear of not being able to cope alone.

35. I just think I'm going to be, hard work, I just worry about the sort of burden I'm going to be on my husband, I think that's the thing and being an embarrassment, you know and people don't understand, that's what I think. No the main thing is being a burden on my husband, but I - looking at it that way I think he would cope better that way than me having to cope if he should die before me. (1130-1138)

In extract 35, Gwen attempts to manage the shame of feeling a burden on her husband by arguing that he is more capable than she is. However, this reminds her of the risk that he may die before her. Gwen is therefore struggling between the shame of feeling a burden and the fear and shame of being abandoned, without any solution.

Brian notices the impact of dementia on his close relationships, making him feel worried and ashamed of the restrictions and problems it might cause for his family. This becomes clear when Brian talks about his son, who travelled to care for Brian whilst his wife, Jill visited her dying mother in hospital.

36. Brian: He was so concerned... that she got to look after her mother, when she was dying. He made a point of coming down here. Three weeks in succession. You know... so... I wasn't worried about that. I was worried about his reaction... with his wife... with him coming up here.

Researcher: Oh I see. You were worried about how his wife would feel.

Brian: Yeah... yeah, yeah.

Researcher: What were you worried about?

Brian: What was I worried about? I was worried about them splitting up. You know as a result of him being here. And she was there in Leicester working. You know it seemed to me that, uh, he my son, was taking some priority, for me. Yeah, and that was his wife and his wife was... being left on her own.

Researcher: Hmm. And how did you feel about that?

Brian: Rotten. Yeah I didn't want him to... oh, uh I didn't want any way for them to split up. (441-466)

In extract 36, Brian describes feeling guilty that his son put Brian's care first. Brian suggests

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge that this is not how he thinks their father-son relationship should be. Brian expresses shame at his potential for upsetting others. He describes attempting to conform to social norms, by contributing to social activities in an appropriate way. However he cannot trust himself, and fears accidentally upsetting someone.

37. I could say something that upsets others. About, whatever they're talking about. You know... the group I've made friends with... we're all friends. We're always trying to join in the conversations, but because uh, what shall I say, because I've refrained from saying things... rather than upset them. You know it's... I've just left it and been... for want of another word, I don't want to say anything in case it upsets one of the others. (658-668)

Brian is therefore also trapped in a position where whatever he does, he is unable to live up to his perception of social expectations: He feels worried that he might upset someone through contributing to the group and thus withdraws, but he then feels ashamed for not participating.

Similar to Brian, Betty describes shame in how the loss of self-control that comes with dementia means that she may negatively impact on others, causing them pain, burden, fear, or upset.

38. Betty: Well it's embarrassment more than anything. Yeah, especially when you really know deep down you know, and you've come out and said something you know, how's fathers sisters brothers or whatever, and then realise they've already lost that one (laughs), you know, and I feel hurt then, myself because I've said it. So...

Researcher: What does that mean to you then?

Betty: I should have remembered I should have known. Yeah, yeah, yeah, and I feel awful then because I've opened up a wound probably for the other person, which is the last thing I'd want to do (tearful). (299-314)

Despite the concern that they might upset others through saying the wrong thing, both Brian and Betty's words, in extracts 37 and 38, highlight that the shame of saying something wrong occurs through an internal process of self-criticism, rather than through the social impact.

They may feel embarrassed and critical about what they said, however they noticed that their behaviour does not upset others, because they can tolerate it. In reality, Brian's group of friends seem to protect him from embarrassment by using humour.

39. Basically, it's... we're in a... group, who, we'll say what we think, and to hell what anybody else thinks [laughs], you know, because there's no question of response that they are affected, it's "oh you know, is that your attitude is it?" [laughs], end of story.

Similarly, Betty's friends don't appear to mind her mistakes: "*They don't get annoyed or anything. But I feel more of a wally if you know what I mean*" (213-218). Therefore for Betty and Brian, the shame of the impact of their dementia upon their relationships is caused by their thoughts and feelings about their behaviour.

3.5.2 Trusting Support: "I'd be lost without him" - Gwen. Most participants talk about having one person or small group whom they can trust and feel comfortable with, but lacking trust in a wider social circle. For example, Joe trusts his wife Ellie and this seems to protect him from shame.

40. She won't do anything that's going to, be a distress to me, I I I I (stutter) might find it a bit frustrating but, I know that our love for each other is absolutely rock solid, um there was never any um no no um no (stutter) comparison at all... (81-86)

Betty talks about losing trust in herself; "*Well some are really... well they don't - can't go out on their own or nothing, someone's with them all the time because you don't know what they're going to come out with or nothing else sometimes*" (435-439).

Trust in other people is a vital factor in how Betty feels in social situations and how she responds to the dementia, for example, how openly she talks to people about dementia. Betty has one person that she feels comfortable sharing her experiences of dementia with, her son.

41. Betty: At his reaction, yeah I can laugh at that one. Yeah, probably because I know what he's like. I'm alright with him, but if I was outside with someone I didn't know, I'd probably, have some sort of effect.

Researcher: So with him you feel more comfortable, but with other people it might affect you more?

Betty: Yeah embarrassment I think really. Yeah. (163-172)

The embarrassment and shame that Betty would feel with people she doesn't know so well is due to a lack of trust in them. In extract 42, she discusses how in order for people to know about her dementia, she needs to trust them to consider her feelings and not make it more painful for her by reminding her of her difficulties or questioning her.

42. I think if they do know they're not going to come up and say something to me. I think that's what you know, if I thought that, I probably wouldn't say nothing. If they were all going to come up and say I've heard you got um, a bit of a memory loss. I can laugh and joke about it with them. But I don't want them to keep coming up and saying things to me about it, because, I should find that hard I think. (388-396)

Gwen experiences a loss of trust in herself, a fear of losing the person she trusts, her husband, and having to trust others with her care.

43. Gwen: Well I I don't know if I can - I want to trust myself, like yesterday, we don't have a paper delivered - we you know pop out and get a paper, and I say to my husband "I'll just pop over the shops" and I thought what if I just, I don't have to drive, I mean I've got some little shops, and it's only across there, but I just think what if he suddenly starts thinking "I better not let her go on her own" you know, and uh I walk across and I think well I remember this road, and I remember this one, but I start to worry. I begin to worry. (157-167)

Gwen therefore feels that she is not worthy of being trusted, and this ties in strongly with her sense of vulnerability and feelings of dependency. As mentioned previously, one of the key problems with this is that she feels unable to trust anyone other than her husband to take care of her: "I trust him driving, and I'd be lost without him because nobody else would have the patience with me" (249-252). Gwen also describes a lack of trust in the medical care she received in relation to dementia. In extract 44, her use of vague language highlights her confusion and cynicism towards the medication she was prescribed and the doctors she saw.

44. So he said "you can go on blah blah blah", and uh, but I had such terrible nightmares. Well you know you can read these side effects and there's a whole list of them, and um demen- nightmares was one of them but I just woke up in terrible fear and worry, and I said to my husband "I've just had a dreadful dream and he's (high pitched) sound asleep and I don't wake him anymore because he - and uh so and the next night it happened again and I thought no I'm not taking them anymore. I'm not taking them anymore. (318-329)

Gwen's experiences of the medical staff and the medication left her feeling confused, afraid, and out of control, and she decides to take back control back by discontinuing the treatment. She does not trust the person who prescribed it to her, and questions his position in doing so: "Well I don't know who this gentleman is, I mean he's somebody who who to do with my doctor's surgery I suppose. So do people find medication to help?" (354-356)

Both Gwen and Betty express strong ideas about people within the family that they do not trust to support them emotionally.

45. Betty: And... if I could just be my quiet self and go in my own little... world so to speak, I'd be alright. But, the nearest one who could send me around the bend could be my sister, if she came down here to stay and help, that would certainly drive me

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straight up the wall, because she's - her name's (uses a posh accent) Mrs Bouquet, and she's her to a double. (439-446)

Betty's statement reveals her certainty that she does not want her sister involved in her care, because this would make her feel inferior, and worsen her mental health. Likewise, in extract 46, Gwen is sure that she would not want to live with her eldest daughter, because she feels that she would not understand her emotional needs.

46. My second daughter would be more sympathetic than the eldest daughter, because um like like like you know you want something or you don't want - you don't want to dither, which I am a bit of a ditherer you know and, and I don't know that that would be a good thing if she - to live with her and her husband no... (661-668)

Thomas talks about how he discusses dementia with his friend, Jess.

47. Thomas: Yes we discuss it, we discuss it, which is probably the best way really but she's got a lot of qualities in her in respect that she does remember things.

Researcher: How do you find discussing your memory problems with Jess?

Thomas: I don't have any trouble at all. No I don't.

Researcher: And do other people know?

Thomas: She doesn't keep it a secret, she will discuss the fact that she appears to have a memory problem.

Researcher: And what about you? Do you discuss your memory problems with anyone else?

Thomas: Ahh that's a good one that's a good one, do I discuss my memory problems with other people? I do think so yes, at least in a small way, perhaps not in a bold way. (784-809)

Thomas' hesitation in discussing dementia with people other than Jess highlights that he may not trust them as well as her to accept him in spite of dementia. Given his perceptions of dementia as a weakness, he may have concerns about putting himself at risk of rejection. In extract 48, Thomas discusses the difficulties in sharing experiences of dementia with others:

48. Some people may think it shows a weakness, I'm not sure that that's right either, I'm not sure that they think it is a weakness. There's always people bound to say ooh not with me it's not I can fight it off any time which probably is a load of rubbish (laughs) I just think that people may feel better by sharing it with someone. (654-661)

Thomas appears stuck in a dilemma here between hiding the dementia to avoid exposing a weakness, and considering sharing it to feel better.

As mentioned previously, Brian values the support of his memory support group.

Towards the end of his interview, in response to a general, ending question from the researcher, Brian begins to talk about his difficulties with planning and thinking ahead. He then tells a story about how he used a strap to manage sudden pain in his wrist, and then changes the subject to talk about how he finds that the dementia group he attends helps him to feel more alive.

49. Researcher: I wondered if there was anything else that you feel is important for me to understand about your experience of dementia?

Brian: You've asked an awkward question there, you see it's things that suddenly occur, you with me? And you, it it's things that, just happen, and you cannot uh, talk about things that, you don't know are coming up. Uh, let me give you an example, because yesterday morning I got up and I had a hell of a pain in this arm so she was going into town so yes so I get a strap, which helps, and that's, that is it, it's a pain in the wrist and we got a strap (pause). Uh, I think, that, the dementia group that we go into this afternoon, I think that helps. (798-816)

Brian's story about the wrist strap could be seen as a metaphor for explaining how the support he receives from others with dementia helps him to find solutions for managing emotional pain. For Brian, his emotional discomfort appears linked with a decreasing ability to foresee and prepare for challenges.

3.5.3 Past Rejection and Shame: "I'm ashamed of my past" - Betty. Two of the participants, Betty and George, explicitly discuss how their past experiences of rejection shaped the way they now manage their lives, including their experiences of dementia. George discusses the rejection and sadness he has suffered in the past, and how he wishes to make the most of the remainder of his life, due to having missed out on parts of his childhood.

50. I missed out on on a on a on an upbringing, I could have had at home. And I would have had a lot more confidence maybe to do more. I missed out all that you see. You know, in in the children's home the sisters who'd look after us, I mean they wouldn't put your hand on your shoulder put your hand - you'd get nothing of that, you were just a number. Yeah, yeah, but I mean in in my later years I mean I could understand it all but not not at the time you know I thought oh - as a matter of fact I did um I remember when I was about (pause) well I suppose I was about 8 or 9 years old and (pause) I was in bed one day about 10 o'clock in the morning I thought why am I in this home here and I I started to cry you know and I thought why why why am I not

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with my mother you know and all that came on you see. (475-493)

In extract 50, George remembers his previous experience of lacking recognition as a person, and being “just a number”. He experiences a clear and vivid memory of a moment when he felt grief at having been abandoned, repeating “why” which emphasises his confusion and distress.

Betty talks about a feeling of rejection from her family when growing up, which seems to have left her with an ongoing sense of inferiority. This feeling of inferiority developed in response to her sister being treated as superior to her. It now seems that through this earlier learning that she is inferior, Betty developed a pattern of undermining herself, comparing herself to others, and treating herself as inferior, allowing others to contribute to that pattern: “*and they never treated us outcasts... but we knew. My sister was the one and only one, not that they would admit it because they wouldn't... that's how we felt*” (75-78). Betty's past intrudes into the present moment, with regrets from her earlier life causing her current shame, self-blame and guilt.

51. (tearful) I'm ashamed of my past. What happened (pause) and (sigh) something that I would have loved, but I couldn't. I got (sigh) pregnant, he was a married chap, I can't think which one he was, but I gave her up for adoption, whereas deep down if it had been a different father I would have loved to have had her. (528-535)

Betty's sighs indicate how painful she finds remembering her regret, and her use of the word “loved” reveals how much she hates what happened. She then expresses shame attached to the perception that she did something terrible: “*I could never imagine myself ever doing it, but I did it, I did*” (562-563).

3.6 Uncertainty and Loss of Control

All of the participants demonstrate concerns about losing control over their cognition, such as losing a conversation due to word finding difficulties, or affecting someone in a way that they hadn't intended. Mostly, concerns about loss of control relate to internal experiences of cognitions and emotional equilibrium. However, at times they relate to external lifestyle, such as having choices taken away. Experiences of loss of control appear to relate to fears of exposure as being faulty or weak. Participants express concerns about not understanding their experiences, and this exacerbates feelings of being out of control. Participants also express fears about the future. These fears threaten the participant's existing identities of being knowledgeable, skilled, intelligent, and being prepared, leaving them feeling helpless. Some participants express a need to find reasons for their problems and behaviours. Participants

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge search for answers and certainty through questioning themselves at times of confusion and disorientation, and wondering what caused their dementia. The participants vary greatly in how they manage this loss of control over themselves; from accepting that they have no control, denying a loss of control, trying to maintain control by holding onto skills or staying in a predictable and safe environment, and trying to maintain hope, positivity and mental strength. Some of the participants experience a conflict between two or more of these positions.

3.6.1 Loss of Control over Self and Life: “nothing I can really do about it” - George. Betty demonstrates a fear and shame in “losing it”, not having control over her memory, cognitions, and actions, and not having the capacity for choice or decisions. Often the meaning of this is about negative social consequences, of being exposed as faulty through saying the wrong thing, or doing something against her values, which would then impact negatively on others.

52. I don't find it a problem in my own four walls. But when I go out and should I meet people, because not everyone knows. And... sometimes I have to end up telling them because I've said something I know is not right. (43-47)

Betty's experience of losing control links strongly with her experience of social avoidance, as avoiding others means that Betty can regain some control and avoid the potential exposure as being abnormal. Avoidance therefore means that she does not have to voice it, and does not have to accept it: “*But, it's (pause) voicing it I suppose, with this thing, it's voicing it, and in that way you're admitting it even more then, aren't you?*” (349-352)

Joe describes experiencing a lack of control over his memory and cognition, which leads to a lack of control over what happens in social situations. For Joe, the social consequence is that he can lose his way in conversation and have to terminate the interaction. He can also experience thoughts from the past intrusively taking over.

53. When you're looking for a word to describe what you want to say (pause) and you can't for the life of you find out what that word is um (pause) and so I I can I can be stopped end (laughs) um end of story because you don't know what to say um (pause, cough) and it's - the astonishing thing is that um all sorts of thoughts sort of pop up, um thoughts from, yes the quite far distant um past. (124-132)

However, Joe deals with this lack of control in a different way to Betty. Joe appears to adopt a more accepting attitude towards a lack of control, and acknowledging that he has limited control over his cognition appears to help him to accept the dementia: “*it's a thing that*

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up with which I will have to put. (Laughs) you can't get round it can you'' (426-428).

By contrast, Thomas suggests that he has control and choice in his experience of dementia, comparing it to his past decisions never to smoke. This relates to the narrative of strength and weakness throughout Thomas' transcript, as he suggests that not having control over dementia makes someone less strong-minded.

54. Thomas: As it's not a very desirable thing to have, the best thing to do is to fight it, I think.

Researcher: How do you fight it?

Thomas: Well, train yourself to have a strong mind. I think it's different for different people.

Researcher: And what about for you?

Thomas: Well I think I've tried to train my mind already, with that in mind - there's a joke there, train my mind with that in mind.

Researcher: How did you train your mind?

Thomas: Unconsciously I think. I think.

Researcher: So you feel like you have a strong mind.

Thomas: Yes that's why I'm a non-smoker, or I should say that's why I think I have never been a smoker, more important, never been a smoker, I would not give way to it (pause) well. I don't consider myself a strong person a particularly strong person but I do in that department, I'm a determined person.

Researcher: Do you think the dementia will ever impact on your determination?

Thomas: Yes I do think so, yes I do think so.

Researcher: How do you think might it affect you?

Thomas: Well that's not an easy one because I don't think in my state of mind that it will affect me, I don't think it will affect me, because I'm determined to make sure it doesn't get a grips at me (laughs). (703-756)

Thomas appears in conflict about the level of control that he feels he has over dementia. He seems to be saying that he thinks he is stronger than some people and therefore more able to control his experiences of dementia, but then he does agree that dementia will impact upon his own strength. In the later part of the interview, Thomas partly admits that he does not fully have control over dementia.

55. I'm sure I've got the upper hand most of the time. I think there are people who perhaps yourself would say, I don't think you've got the upper hand as much as you

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think, ok that's fair comment, and I'm quite prepared to accept the fact that I probably haven't got as much of the upper hand as I think that I have, but all the time I'm conscious of it and doing my best to keep it at bay. (463-472)

Thomas' point in extract 55 seems to be that although he may not have control over dementia, he is trying to prevent it from controlling him, and therefore, the shame would be in giving in without a fight.

Brian describes losing control over his daily activities, and having his choices taken away from him.

56. And my son... just couldn't realise there were certain things that I could do, and I wouldn't do. So, he goes let's go and have a meal, well you know, I didn't want a meal, oh come on let's have a meal... (165-170)

George mentions the lack of control he has experienced through memory problems, “*Oh god all of a sudden it come on and it was so unexpected*” (688-689). More often, he discusses the strategies he uses in order to maintain control over his cognitive skills:

57. It's keeping the brain active isn't it, is the main thing for me. Like I do the um, I do always do the the, not the crossword, but I always do the polywheel in the in the daily telegraph... (53-57)

This is at odds with his frequent claims that he does not worry about his memory as it is out of his control, “*there's nothing I can really do about it except try to stop it happening, you know as much as I can to to delay it as much as possible*” (96-98). These opposing views in relation to control over memory skills offer George different means of coping, either actively or passively, with the frustration and shame he experiences at feeling lost, vulnerable, and disabled.

3.6.2 Wanting to Find Answers: “why have I why I come over here?” - George.

Joe describes emotionally struggling with not knowing and understanding, not having explanations, and not finding answers. In extract 58, he talks about how having an explanation for his difficulties helps him to feel in control, and find solutions.

58. I've got a reason for it happening, but it having no control over something that I that I can't think of why or how, that I find, this is not - I've got no practical answer... (227-231)

Joe discusses looking for “the right answer” but not being able to access it, and also not knowing that he gave a “wrong answer”. There is therefore a sense of right and wrong in the way Joe describes his behaviour. This is reflected in the way that Joe oscillates between

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge sounding certain and sure in what he is saying at times and sounding vague and confused at others.

59. Embarrassing, (laughs) yes and uh (pause) uh a bit irritable really (pause) it's it it's difficult to describe really, umm embarrassment is is one, and uh the other is (pause) there's a bit frustration because I can't get get the right answer. Yes if I give the wrong answer, um Ellie gets embarrassed (laughs) and I probably don't realise that I (laughing) I've made a wrong answer. (5-13)

George expresses frustration at becoming disorientated and confused. He searches himself for answers, explanations and certainty. At times his lack of clarity leads to anger and blame, either towards himself or someone else. He has a series of strategies, list taking and checking, to prevent him from experiencing incoherence and feeling lost: “*I go there and say “why have I why I come over here?”, or when I go over there, or I'll make a and say “why have I - what have I come in here for?”* (5-8)

Gwen expresses a fear of what will happen to her in the future, Gwen seems sure that there must be a reason for her developing dementia. At times she blames herself for being uncaring to others in the past, “*I think it serves you right*” (382), and she later suggests that it was caused by a fall, “*I sometimes wonder if if when I fell over and bumped my head, and knocked my shoulder, if that's anything to do with it*” (1059-1061).

3.6.3 Fear of the Unknown: “I was one of these fools” - Brian. Betty knows her dementia will worsen, and is afraid of the things that may come. Part of her doesn't want to accept this, and instead wants to live a “normal” life for as long as she can. She is afraid that accepting the dementia means that she will lose control and become a burden on others: “*Knowing it's coming or on its way, and perhaps I'm praying that I won't get as bad as some people*” (427-429).

Staying in her comfort zone offers Betty predictability and certainty, away from the potential shame and threat of the outside world: “*It's your own little world, your own little cosiness. But out there you don't know who you're going to see and who's going to - if anyone speaks to you. That's the... lot of strangers, I don't know and uh*” (238-242).

In contrast, when Betty finds that, despite the temptation to stay in her comfort zone, she can encourage herself to do things that she finds difficult, and this can improve her confidence and pride.

60. When I'm grocery shopping I take my bag on wheels and waddle over there and come back, and then I'm quite satisfied with myself if I've got everything on my list.

Oh, I admit I have to write it all down, but as long as I get it all I don't mind. (742-747)

Gwen experiences fear and shame around uncertainty in her future awareness: *"I don't know how I how they how they feel (pause) I don't know if you realise that you're like that"* (828). Gwen, like Betty, favours routine and predictability: *"I don't want a lot of complications"* (11), perhaps as a way of coping with this uncertainty, and staying within a safe, protected environment.

Early on in his transcript, Brian discusses his previous life experience of being made redundant. Initially, Brian tells this story with a narrative of being in control.

61. He said I'm afraid we have from, some bad news for you, and I said yeah when do you want me to leave? You know, I'm, I'm all there [laughs] for certain things. He said, well he said I give you, let's say you get a week's notice, that will give you a chance to clear your desk out, so I said I don't have to, go and look at my desk... so he goes there's nothing in it. I said no, I clear it before I went on my honeymoon, I said because I knew what was going to happen ... oh you knew? Oh I knew. (47-59)

In extract 61, Brian's story of redundancy conveys a message that having foresight and being prepared protected him from being hurt by rejection. However, it later becomes apparent that Brian was not as in control of this situation as he would like to have been, and he then confuses the experience of redundancy with the experience of receiving the dementia diagnosis.

62. But uh... then... then it just seemed to fade away, sort of thing you know. I had no job. But I was umm... at uh well retirement age. And then it followed on... But none of this ever occurred to me at all... I was one of these fools you know, I thought it would be alright until the, until it happened, and they put it to me and I just purely guessed, that you know, that I was out of work. Uh, [sighs] but that didn't lead me to dementia. (80-99)

In extract 62, Brian's attempt to make sense of his redundancy experience by convincing himself that he was in control, reveals his sense of shame in feeling not in control of his situation. There are parallels between Brian's experience of redundancy and his experience of receiving the dementia diagnosis, in that both involved the receiving of bad news; *"our GP rang up and said "I'm afraid, I've got a disappointment for you, you know... he's got dementia"* (8-11), and that both involved being unprepared and not knowing what was happening.

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63. Brian: *I used to read about dementia... people suffering from it. But it never, you know, I it won't happen to me [laughs] yeah, yeah. Yeah, it's uh, what it is, it's like being smacked in the eye with something you weren't expecting.*

Researcher: *Right, and what did that feel like?*

Brian: *Well I wasn't working then, I had to finish work then. Uh, but I just didn't know what it was about. No, no. Uh, you know, my doctor did what he could as far as telling me what I'd got. Then... that was it sort of thing. You know and there's [sighs], no medical or anything. You, you've got dementia... end of story. (106-122)*

Brian's use of a simile, "it's like being smacked in the eye" emphasises the painful and violent shock of receiving the diagnosis. He describes a lack of ongoing support from his GP. The experience of receiving the diagnosis of dementia therefore leaves Brian feeling out of control and helpless.

For George, a strong paradox evident throughout his transcript is that although he discusses an inability to remember basic things, e.g. why he walked into a room, or what he went to the shop for, he conveys a perception of himself as holding advanced knowledge and skills for a number of things. For example, at one point in the interview he shows off his advanced driving tests certificate, he later recites an extract from Shakespeare's Hamlet, and he talks about his crossword abilities, "I do the uh (pause) the advanced arithmetic, and the intermediate" (60-61). He seems to be wanting to hold onto the things that make him feel intelligent, in order to avoid the shame of losing his intelligence, and admits that remembering the things he has learned prevents him from feeling negative about himself, "if I'm on my own anywhere and I'm bored to tears, I remember the things that I've learned, yeah so you don't get bored with yourself" (348-352).

George and Thomas both refer to concepts of attitude, belief, opinion, theory, or perspective often. George uses phrases, poems and sayings to inspire him and maintain a positive outlook, motivate himself, and reassure himself: "Grow old along with me the best is yet to be" (306-307); "Nothing is bad but thinking makes it so, you know, it's this it's alright George I mean you're getting old and it's going to happen anyway so don't let it upset you. That's how I look at it" (32-36).

Thomas uses lots of powerful imagery, externalising the dementia and the worry surrounding it: "you've got to put it to one side and glare at it, and shoo it away" (149-150); "I glare at it, and grit my teeth and say "I'm not a damn fool!" (154-155).

Although George and Thomas are both seemingly positive, their transcripts reveal self-

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doubt and a lack of full confidence in what they are saying. Their theories are coping
strategies, attempts to be positive, give themselves hope, reassurance and emotional strength.

Reflection 3. Personal impact upon the analysis

With guidance in mind that more thorough coding makes for a better analysis, I took care in examining each transcript in depth, attempting to capture everything that I noticed. Having had some practise in discourse analysis, I enjoyed engaging in linguistic coding. The theme of “Avoidance” is heavily influenced by linguistic coding. There were many interesting uses of language that prompted interpretation. It was important to consider how impaired language skills might interact with language that appears to expose shame: Some of the accounts reveal contradictions in ideas, a fusing together of separate experiences, and jumping between subjects. These may reflect the confusion and dilemmas that participants experience, which then comes across with less coherence due to cognitive difficulties. It was important to keep in mind how my fore-understandings of dementia influence the findings: Joe’s interview challenged my assumptions of dementia as a fundamentally frightening experience, as he appeared generally accepting of his situation, reflecting upon how he coped. Other interviews, such as Gwen’s and Betty’s, elicited more distress. Perhaps I identified more with these participants, being female, and it was therefore especially important to maintain reflexivity during these analyses. In line with my research question, I was examining the transcripts for shame experiences, where explicit references to shame were few. The nature of shame is that it is difficult to voice explicitly, and therefore expressions of shame were found largely through interpretation. The use of supervision, to check that my interpretations had not stretched too far from the data was therefore important.

4. Discussion

4.1 Overview of Discussion

Through this chapter, the key findings developed from the analysis will be discussed in relation to the research questions. This study found four superordinate themes that captured the key experiences of shame for people in the early stages of dementias: Avoidance, Negative Self-Perceptions, Relationship Matters, and Uncertainty and Loss of Control. Each of these superordinate themes contains a mix of idiosyncratic but related experiences and meanings. As described in chapter 3, the themes were developed through an intensive process involving deliberate interpretation. These interpretations of the participants' life worlds should be placed in the wider context of the existing literature (Smith et al., 2009). The research questions were developed through an identification of reports highlighting challenging experiences for people with dementia such as shame (Cheston, in press; Mitchell et al., 2013), fears about stigma (Harman & Clare, 2006), self-criticism (Langdon et al., 2006), and embarrassment (Imhof et al., 2006). Therefore, through this discussion, the findings will be contextualised within existing psychological concepts of shame (Cheston, 2005; Gilbert, 2009; Tangney & Dearing, 2002), stigma (Goffman, 1963; Link & Phelan, 2001) and relevant previous research. The limitations of the study and implications of the findings for future research and practice will also be identified.

4.2 Emotional Experiences in Dementia

A number of unpleasant, self-directed emotions are expressed by the participants. Many of these fall within the "family of self-conscious emotions" described by Tangney et al. (2007), such as shame, embarrassment and guilt. For this sample, other emotions that could be considered "self-conscious" within Tangney et al.'s (2007) model were self-directed anger, self-blame, and self-criticism. Other studies that qualitatively explored subjective experiences of dementia found similar emotional experiences (Cheston, 2005, 2014; Clare et al., 2008; Holst & Hallberg, 2003; Imhof et al., 2006; Mitchell et al., 2013). Due to this study's specific focus upon shame experiences, it was able to gain a closer understanding of day-to-day issues that can contribute towards shame and other self-conscious experiences for people with dementia. For example, some expressions of shame appeared closely related to ideas about losing control, being a burden, and devaluation by others. More of the particular, shame-focussed insights developed through this study are discussed in the following sections.

4.2.1 Positive emotional expression. The current participants express positive emotional experiences during their interviews, such as humour, acceptance, and appreciation of life and relationships. Other qualitative investigations highlighted that people in the early stages of dementia express positive emotional experiences. For example, Lishman et al.'s (2014) narrative review, reported that people diagnosed with dementia experienced hope, humour and growth. Through the current study's analysis, it emerged that some of these expressions of positive feelings can reveal an attempt to hide, or emotionally distance themselves from less positive feelings, like shame. Sometimes, the participants were explicit about this process. However, many of these examples were not explicit, such as the use of idealising or intellectualised language, and therefore only emerged through the researcher's interpretation. The findings of this study therefore question the extent to which displays of positive emotions might be used to gain distance from uncomfortable emotions. Other researchers (e.g. Cheston, 2005) noted the use of language as a mechanism to avoid shame. This can be viewed within the context of models of shame (e.g. Nathanson, 1992) that highlight how emotional distancing is used to cope with shame. A grounded theory study (Steeman, Godderis, Grypdonck, De Bal & Dierckx De Casterle; 2007) found that their participants' positive narratives of value and contentment were an attempt to counterbalance feelings of worthlessness and devaluation. One of the advantages of the current IPA study is that as well as providing an in depth analysis, it closely attends to the idiographic experiences of individuals. Therefore, it can contribute an array of examples that demonstrate how individuals uniquely use positive expression to emotionally disconnect from shame. Furthermore, some of these uses of positive expression were not previously noted, particularly the use of idealising and intellectual language.

4.3 The Forms and Functions of Avoidance

Avoidance features heavily within the findings. The withdrawal and avoidance described by participants within this study appears to be a way of them managing shame: specifically fears of embarrassing themselves, upsetting others, or being exposed as incompetent. This can be viewed within the context of Nathanson's (1997) compass of shame, which suggests that "avoidance" and "withdrawal" are two key methods that individuals use to cope with shame, as well as "attack self" and "attack other". However, this study did not find any evidence that people in the early stages of dementia cope with shame through an "attack other" response. Avoidance as a coping strategy in dementia is highlighted by previous IPA studies (Preston et al., 2007; Van Dijkhuizen et al., 2006) describing how participants cover up

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge difficulties to regulate embarrassment. Cheston (2005) suggests avoidance can take many different forms, involving implicit and explicit processes. For example, avoidance of social situations, to reduce the risk of being labelled in a shameful way, may be more explicitly noticed by others as well as the individual themselves. However, other types of avoidance are less obvious, such as a person's use of language to position themselves as competent, and draw attention away from any decline in abilities (Cheston, 2005). The implicit kinds of avoidance were particularly strong in the findings of this study. As well as the use of humour, and the other subtle uses of language described above, some of the current participants talked at length about their social backgrounds, previous occupations, and achievements in life, seemingly as a means to position themselves as a useful, practical, or powerful person.

For some participants, avoidance functioned as a means of controlling their emotional experiences and distancing themselves from unpleasant emotions, such as fear and shame. For example, George talked about a risk that feeling negative about his memory problems could lead to committing suicide. Similarly, Thomas expressed thinking that worry is dangerous and could affect his health. Shame is referred to as a "master emotion", because it has so many functions, and can shape so much of our experience (Scheff, 2003). For George and Thomas, shame presents as a "master emotion" in that it inhibits their exploration of the experience of dementia, "*Well, all I put it down to it's inevitable anyway, that's how I look at it, I don't let it get any further than that*" (George, 384--386).

4.3.1. Protecting others. Theories of shame emphasise avoidance as a response to fears about being judged and rejected by others (Gibert, 2009; Isenberg, 1940). Other IPA studies found that people with dementia express concerns about negative judgements and stigma (Harman & Clare, 2006; Van Dijkhuizen et al, 2006). In this study, the participants' avoidance functioned to maintain their identities as "normal" or "strong", and as Cheston (2005) suggested, protect them from exposing weakness and being negatively judged. Furthermore, this study found that, through avoidance of social situations, the individual perceives that they are protecting other people from themselves. For example, Brian withdraws from social situations because he is concerned that he will say something that upsets someone. Therefore, through a close engagement with the participants' words, the current findings add something new to models of shame when applied to people with dementia: that avoidance can serve to protect the person from feeling shame about causing another person distress. Betty gives a clear example of this when she discusses how accidentally reminding someone of a loss makes her feel upset with herself. Indeed, another

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge superordinate theme, “Relationship Matters”, highlights the shame that the current sample expressed about causing distress to others.

4.3.2 Awareness of avoidance. Some of the participants demonstrated an explicit awareness of how they engaged in avoidance to reduce the impact of dementia on their relationships. For example, both Betty and Brian talked about their withdrawal from social situations. In contrast, avoidance at an implicit level may reflect a person’s less conscious motivations to deny their cognitive difficulties. The more implicit, discrete forms of avoidance, such as emotional distancing, were particularly strong in this study, and appeared directly linked to the purpose of covering up embarrassment, shame and other painful feelings. Some of the avoidance demonstrated by the participants in this study appears to occur out of conscious awareness. For example, through Thomas’ attempts to push away the experience of dementia, he appears to genuinely believe that he can “fight off” dementia. Similarly, George asserts that his memory problems are age-related. This can be viewed in the context of models that suggest that people protect themselves from a shameful identity through unconsciously suppressing their difficulties, such as the APV model (Cheston, in press), and Clare’s (2003) model of the construction of awareness. Conversely, Thomas expresses that he sometimes is aware of his avoidance, and how this actually involves conscious mental effort: *“I’m conscious of the fact that I’m fighting it” (455-456)*. This fits more with Marten’s (2005) multi-model of shame, which views the construction of positive self-representations in response to shame as a conscious cognitive process. Clare (2003) argues that awareness is best understood as a fluctuating process of emotion regulation rather than fixed. Although interpretations can be made in this way about how aware participants are of the avoidance they engage in, it is impossible to say for certain, other than where they openly state that they realise they are avoiding, e.g. *“I don’t go out because I might say something that... upset other people” (Brian, 629-631)*.

4.3.3 Avoidance and spirals of shame. Theoretically, the maladaptive nature of avoidance in dementia is outlined in the application of Gilbert’s (1998) “shame inducing spirals” to dementia (Cheston, 2005). Interestingly, each of the five different kinds of avoidance that Cheston (2005) discusses in terms of “shame inducing spirals” are observable in the current study’s findings. Firstly, avoidance and concealment within social situations are discussed by both Betty and Brian. For example, Betty describes “bluffing” and pretending to understand conversations. Secondly, avoiding naming difficulties is frequently noted throughout Thomas’ interview. Thirdly, denying the impact of dementia is present within

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge Thomas' and George's accounts. Fourth, creating a perception of oneself as competent and skilled is present within George's, Brian's and Joe's interviews. For example, George makes several attempts during his interview to demonstrate his abilities. Finally, the contribution of family members' avoidance is demonstrated by Gwen, who talks about her husband taking on more housework, which leaves her feeling a burden. The current findings therefore complement the concept of Cheston's (2005) "shame inducing spirals". However, this study provides further illustrations of how avoidance does not provide the individual with any real solutions for managing shame, and can inadvertently reinforce shame. For example, Thomas suggests that he is actively involved in a mental fight against dementia, but is unable to say how this is possible, and doubts his effectiveness in this fight. Another common expression of avoidance in this study is humour. For Betty, her use of humour is meant to hide shame. However, her covering up with laughter involves the use of self-criticism and calling herself names, such as "*silly cow*" (115-144).

4.3.4 Alternative ways of responding to shame. The participants demonstrated ways of coping with shame that did not involve avoidance. It is particularly interesting how each participant demonstrates their own alternative ways of coping with their experiences of dementia. For example, Joe's faith helps him to attach virtue to his experiences of suffering, and his belief that he is valued by both his community and God appears to help him accept the dementia as a phase of his life. A need to recognise the importance of spirituality for people with dementia has been established (Ødbehr, Kvigne, Hauge, Danbolt, 2014), however research is yet to explore the meaning of spirituality for people with dementia.

Other participants' methods of responding to shame that do not involve avoidance include holding onto skills, encouraging oneself to complete activities, and looking for certainty. These alternative ways of managing shame are different and more specific to those already suggested by psychological models of shame (Elison et al., 2006; Tracy & Robins, 2004). The in-depth nature of the current study was beneficial for gaining an insight into the participants' personal histories. It is arguable that each individual's way of responding to shame reflects their unique combination of earlier experiences, personal traits and beliefs, support network, and coping styles. They are each seen to be using the best methods for managing their experiences of dementia that they have available. For example, George minimises difficult emotions, practises his cognitive skills through the use of puzzles, and uses strategies such as shopping lists to improve his sense of certainty, control, and independence. Putting this coping style into context, George describes a history of growing up in an

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge orphanage where emotional support was scarce. He describes developing self-sufficiency, and confidence in his own intellectual abilities. Therefore, George's effort to maintain his independence and skills may be a more comfortable and likely way for him to cope, than for example, using social support.

4.4 Complexities Involved in Shame

Having discussed what this study adds to the current understandings about avoidance as a process within the experience of shame, this section will now turn to some findings from this study that are less acknowledged by previous papers. These include the complex dilemmas and conflicts experienced by the participants, self-perceptions of meaninglessness, particular issues within relationships, such as trust, and concerns about losing control.

4.4.1 Dilemmas and internal conflicts. The participants in this study at times demonstrate awareness that their experiences presented them with a double-edged knife. They show this awareness through describing their dilemmas and conflicts, whereby protecting themselves from shame through an avoidance strategy involves compromising something else, such as social support, or self-acceptance. In this way, either taking the decision to avoid or opting to overcome avoidance leaves them feeling vulnerable to shame. For example, Betty discusses facing a dilemma between going out and feeling exposed, or staying in and feeling lonely. Brian discusses how withdrawing from his group of friends leaves him feeling guilty for not being present in their lives. Thomas suggests that other people with dementia face a dilemma, in deciding whether to tell other people about their diagnosis. Other participants discuss feeling uncomfortable about causing a strain for others, which conflicts with an acknowledged need to draw upon support. For example, Gwen demonstrates a need to be supported by her husband. However, as her husband is now older, she feels less able to rely upon him, leaving her feeling burdensome and at risk of abandonment. Thus, the current findings highlight a range of ways in which people with dementia may experience dilemmas and conflicts in relation to how they manage shame. Lishman et al. (2014) emphasise the ambivalence involved in dementia experiences, from the context of the APV model. However, they explain ambivalence as a function to protect an individual's self-identity. In comparison, the dilemmas for the current participants highlight the implications of such ambivalence for relationships.

4.4.2 Negative Self-Perceptions of Meaninglessness and Emptiness. The participants in this study struggled with experiences of shame that were related to negative perceptions of themselves. This was captured by three themes: "A weakening self",

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge “Meaninglessness”, and “Devaluation”. The participants described feeling that they were weaker in comparison to others and their former selves. The participants’ accounts highlighted how although they wanted to hold onto a “normal” identity, inevitable moments occurred when the participants acknowledged that there was something unusual about their experiences. These experiences could then lead to self-directed anger and criticism. Previous IPA studies have also highlighted that people in the early stages of dementia experience perceptions of weakness (Preston et al., 2007), uselessness and worthlessness (Clare et al., 2008). Theories of shame emphasise this link between shame and feelings of inferiority (Gilbert, 2009; Isenberg, 1940) and inadequacy (Ellis, 1977).

One of the current study’s findings of interest, that has not previously received attention from theories of shame or studies of dementia, is that for some of the participants, a reduction in their perceived meaning as a person causes a great deal of distress. In particular, Gwen illustrates this theme by discussing her fears about becoming empty, vacant, and meaningless. Gwen’s concerns about becoming meaningless are about losing interest and concern for things, and becoming too dependent on others. Brian discusses how his experiences of dementia can make him feel ashamed around other people when he feels that he is not contributing to a group interaction. Brian talks explicitly about how different he feels when he is at his memory support group, in comparison to when he is with his group of long-term friends. When he is with his long-term friends he seems to be aware of what he says, and finds it difficult to contribute spontaneously. This leaves him feeling like he is an empty body. However, when he is at his memory support group, he feels more supported in contributing to their discussions, and he feels like a meaningful person within the group. Interestingly, Brian suggests that past experiences of being encouraged to participate in group interactions, perhaps as a child being instructed by his parents, contributed to this sense of shame he feels as not being able to fulfil this role. Mitchell et al.’s (2013) thematic review of qualitative studies noted that fears about stigma were attached to “loss of the self”, meaning that participants experienced that their illness took precedence over their self. Although this appears related to the current study’s theme of “Meaninglessness”, Mitchell et al.’s review (2013) was not designed to explore these particular experiences. Thus, the findings of this study add depth to the “loss of self” concept and expand upon previous literature to suggest that shame in dementia can specifically involve feelings of meaninglessness and emptiness, as well as weakness and devaluation.

4.4.3 The processes of Devaluation: internal and external. In this study, perceptions of being devalued, undermined, and disconnected from others were commonly implicated in experiences of shame. Particular experiences within relationships that could contribute to their experience of shame included feeling unimportant to others, forgotten about, and mistrusted. Particular behaviours from others that were reported by the current participants and appeared to contribute to their sense of shame included teasing, dismissing, withholding, and invalidating the individual with dementia. Other IPA studies also showed that people with dementia can experience stigmatisation and exclusion from others (Harman & Clare, 2006, withholding from others (Langdon et al., 2006), a loss of respect from others (Wolverson et al., 2010), and other devaluing social interactions (Caddell & Clare, 2013). All of these findings complement Kitwood's (1997) theory of "Malignant Social Psychology" that emphasises how negative social attitudes towards people with dementia cause a host of negative outcomes for them.

Interestingly, the findings of this study highlights that often, a feeling of devaluation occurs through an internal process. In this way, the individual perceives their self in a negative way even if other people still appear to value and accept them in spite of the dementia. Betty's statement sums this up well "*they don't get annoyed or anything. But I feel more of a wally*" (214-215). Likewise, Brian talks about how his friends can tolerate his conversational mistakes, and are able to make a joke of any comments that could otherwise be perceived as offensive. However, Brian still feels as though his company is not enjoyed. Some theories of shame (Isenberg, 1940; Gilbert, 2009) emphasise that shame occurs at the threat of social rejection. In contrast, this finding suggests that a threat of rejection does not have to be present in order for someone to experience shame in relation to their impact upon others. This then brings into the picture Goffman's (1963) assertion that shame occurs when a person holds stigma towards their self, as well as other models of shame (Ellis, 1977; Tracy & Robins, 2004) that emphasise shame as being triggered by a breach of internalised social expectations. As cited in the introduction, recent quantitative research (Van der Beek et al., 2013) found that quality of life was more significantly affected by the participants' internalised stigma towards themselves than actual social discrimination. This study used a self-report scale of stigma which offers a very limited insight into the way the person experiences stigma. The current findings note that the participants sometimes discussed how they felt ashamed about their impact upon social situations even when there was no evidence that others felt negatively towards them. However, on other occasions, participants reflected upon experiences where

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other people's behaviours impacted upon how they felt about themselves. Thus, shame for
people with dementia, appears to occur through both self-stigma and the experience of
devaluation from others.

4.4.4 Trust. Trust was a major theme reported in this study that has not received much
attention in previous qualitative studies of people with dementia. The current participants
described feeling a lack of trust in themselves as well as from others, sometimes feeling
unworthy of another's trust. As highlighted by Langdon et al. (2006), the participants were
forced to trust others more as their own trustworthiness reduced. Langdon et al. (2006) used
IPA to explore social roles for people with dementia, finding that people felt it was "unsafe" to
disclose their diagnoses to others, although limited details of the interpretative process are
provided within their report. In the current study, most of the participants were able to trust
someone or a small group of people, and this appears vital for reducing shame. The current
findings suggest that a lack of trust is linked to fears about rejection, so that when participants
are with those they trust to accept them, they do not feel so ashamed. Models of shame that
emphasise a threat of rejection in the occurrence of shame (e.g. Gilbert, 2009), do not
highlight the shame-reducing nature of having trusting relationships. Through listening to the
voices of people with dementia that experience shame however, trust appears to be important
for understanding this phenomenon. Trust is particularly important for how comfortable
participants feel in sharing their experiences of dementia, and who they want involved in their
care. For example, Betty talks about how receiving care from her sister would make her feel
more inferior and unwell, and Gwen is concerned that her daughter will not be able to give her
the emotional support she needs. Furthermore, Gwen discussed her lack of trust in the medical
system to consider her best interests.

4.4.5 Social interactions with health professionals. The participants talked about
their experiences of relating to health care professionals, particularly how they were assessed
or diagnosed with dementia. Gwen describes how despite going through the assessment
process, her GP never mentioned that they thought she had dementia, and so it came as a
shock when she was referred to a memory specialist. Thomas and George do not seem to
know that they were diagnosed. Reports that 40% of people diagnosed with dementia have not
had their diagnosis shared with them (Bamford, 2010, in Mitchell et al., 2013) appear
surprising at first. However, the current findings reveal how easily this may be the case,
perhaps, as Mitchell et al. (2013) suggest, because of avoidance from clinicians. Where
participants did recall being told about their diagnosis, there appears to be a sense of feeling

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge left alone afterwards. For example, Brian describes feeling shocked and unprepared when his GP telephoned his wife to tell her that Brian had dementia. Despite being referred to the memory support group, Brian describes a lack of follow up care; *“that was it sort of thing. You know and there’s [sighs], no medical or anything. You, you’ve got dementia... end of story”* (120-122). If Brian’s account is accurate, again, it is revealing that the GP shared Brian’s diagnosis with his wife, rather than Brian himself, and also that this was done over the telephone rather than face to face. Perhaps Brian and his wife may have felt more prepared and contained if the diagnosis had been communicated with them in person. Only Joe describes the receiving of a diagnosis as a positive event, discussing how the diagnosis gives him an explanation by which to understand his difficulties. Mitchell et al. (2013) conducted a review of 12 studies investigating the impact of a diagnosis on the person with dementia, finding that assumptions about the negative impact of a diagnosis on the person, such as that it may cause depression or even suicide, were unfounded. Instead, Mitchell et al.’s (2013) review reported that the provision of a diagnosis often had a positive impact on helping the person to plan for their future and in terms of giving them an explanation of their cognitive difficulties. Although Mitchell et al.’s (2013) review is a useful overview of the impact of receiving a diagnosis, the current study provides a deeper insight and understanding of how seemingly minor details of providing a diagnosis can be experienced in a way that promotes feelings of shock, lack of preparation, and aloneness.

4.4.6 Past relationships. The findings highlight how participants’ past experiences of relationships impact upon their current experiences of dementia. For example, George’s missing out on earlier experiences made him more determined to make the most of his remaining life. In contrast, Betty’s feeling of inferiority, learned through her treatment from others earlier in life, allowed her current family members to continue undermining her. Betty discussed prevailing shame in her own past rejecting actions. These findings are particularly interesting as they emphasise how important it is to understand the individual within their own context when it comes to treating and supporting them with dementia. This is in line with person focussed care (e.g. Brooker, 2004). Previous qualitative studies with people with dementia emphasised how the individual’s relationship with their past shapes their current personhood (Van Dijkhuizen et al., 2006). However, this study highlights how a person’s past experiences of rejection from others may make the person feel more vulnerable to the concerns about potential rejection that are so closely related to shame in dementia. This can be viewed within the context of models of shame that suggest people become prone to shame

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge through earlier attachment experiences (Gilbert, 2009; Kohut, 1984). Furthermore, as argued by (Sadavoy, 1991), memories from the past appear to merge with the present for the current participants. Many of the participants drew upon their past experiences when making sense of their current experiences of dementia, and often the transfers between past and present seemed lucid. This emphasises the need for gaining an understanding of a person's history when assessing and working with a person with dementia, particularly when considering how they may be experiencing shame.

4.4.7 Loss of control and shame. One of the key findings of this study, that has been less reported previously, is that the participants struggled emotionally with feelings that they were no longer, or would be no longer, in control of themselves or their lives. Participants expressed concerns about the future, particularly about losing their awareness, their independence, their life-pleasures, and sense of self. These findings compliment Cheston's (2014) suggestion that a fear of loss of control is an important experience of dementia, particularly in terms of fears about losing one's self, and fears about going mad. As described in the introduction section, Mitchell et al. (2013) found, through their review of experiences of receiving a diagnosis, that stigma is related to loss of control. However they say very little more about this. Given Link & Phelan's (2001) assertion that stigma is dependent upon power, whereby a stigmatised person is of a lower level of power in relation to another, it makes sense that experiencing stigma and shame would be linked to perceptions of powerlessness and thus a loss of control. This study thus provides the opportunity for understanding much more about this phenomenon. Perhaps one of the strongest representations of these concepts are Gwen's fears about losing her self, and her worries about being taken out by her husband for others to see her as an empty, lifeless body: thus losing control over how she presents herself, and how she is perceived. Similarly, Betty expresses fears of losing control over how she behaves in social interactions. However, other, more subtle experiences of losing control are revealed by the findings of this study, such as losing one's influence over a conversation due to word finding difficulties, affecting someone in a way that they hadn't intended, or having their choices taken away. The theme of losing control is linked with the other main themes found, particularly "Meaninglessness" and "Avoidance". As Cheston (in press) found, fears of losing control were sometimes managed through avoidance. However, individual differences exist in the current sample, as Joe more readily accepts having limited control over his future, which appears to be linked to his religious beliefs. Joe explicitly talks about how having diagnosis helped him to feel more in control. Thus, receiving a diagnosis of dementia does not always

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge provoke perceptions of losing control. Furthermore, perceptions of not being in control do not always relate to shame, and can sometimes be linked to positive perceptions. Therefore, the ideographic nature of this IPA study is useful for examining these individual differences.

4.5 Implications for Practice

In line with the aims of this study, the findings can be used to provide a number of suggestions as to how experiences of shame for people with dementia can be prevented and responded to. This section of the discussion provides a starting point for some of these ideas. Firstly, ways in which shame can be addressed during the process of assessment and diagnosis are offered. Then, suggestions are made as to how shame experiences can be responded to through interventions with people with dementia. Finally, ideas as to how families, services, and the wider societal system can promote non-shaming experiences for people with dementia are provided.

4.5.1 Using the assessment and diagnosis process to empower individuals.

Clinicians providing assessment, treatment and support to people with dementia can help to empower individuals from the moment they enter a service. The findings from this study can be used to suggest several ways in which clinicians can promote non-shaming experiences for people approaching services with concerns about dementias. Firstly, considering how important a sense of being in control of oneself and future was to the participants in this study, and how feelings of losing control evokes shame related emotions, it is important that an individual's sense of control is protected. Helping to maintain an individual's sense of control can be facilitated by promoting choice for the individual, and making sure that they are involved in collaboratively making decisions regarding their care. Secondly, the findings around shame and uncertainty suggest that clinicians should help people with dementia to address their fears about the future, and help them to feel more prepared and knowledgeable. This can be facilitated through providing people with dementia more information about what researchers and scientists know about how it occurs and develops, and provide hopeful examples of how people cope with and respond to their dementia. The Mental Health Foundation's booklet (2011) "Still Going Strong: A guide to Living with Dementia" is a good example of a helpful resource. Considering that shame presents a barrier to adaptive adjustment (Cheston, in press) and hope (Livingston & Boyd, 2010; Tangney & Dearing, 2002), an assessment of how each case experiences shame is necessary to address any barriers to their ability to live well with dementia.

4.5.1.2 Addressing clinician avoidance. Importantly, clinicians who assess or diagnose people with dementia need to be aware of the avoidance that they engage in. Reducing clinician avoidance may help people with dementia to take more control and be more actively involved in their illness, in line with the “*National Dementia Strategy: Living well with Dementia*” (DoH, 2009). Although Gwen was the only person in this study to describe having not received a diagnosis of dementia, some of the others had vague ideas about what dementia is, and how they were assessed and told about it. Even when the participants recalled explicitly being told that they had dementia by a clinician, they described feeling discharged and left to their own devices following the assessment outcome. Clinicians must therefore become more comfortable in explaining dementia to a person, with conversations around what they can expect following their diagnosis and how they can access further support, and ideally a referral on to a service to help them feel supported.

4.5.2 Responding to shame through communication and interventions. The challenges that shame poses for adjusting adaptively to dementia, highlights the relevance of addressing shame within interventions and support groups for people with dementia. This may help people with dementia become aware of and adjust to the difficulties that shame relates to (Cheston, 2005). Memory support groups, like the one Brian attended, and cognitive rehabilitation groups are increasingly available within the NHS, and problem-solving strategies and cognitive techniques taught have been found beneficial in a number of studies (e.g Troyer, Murphy, Anderson, Moscovitch & Craik, 2008). Existing intervention groups could address some of the key shame related experiences found in this study, for example, dealing with difficult social situations. Helping people with dementia to develop strategies for managing difficult conversations and other social situations may help them to feel more in control and prepared for times that they might otherwise feel powerless. Also helpful may be to address some of the key dilemmas that people with dementia can face, e.g. deciding whether to share their experiences with others. Considering how unique each of the participants were when talking about how they managed their dementia, group interventions should attend to these individual differences and allow participants to draw upon and develop their own strategies, as well as sharing their ideas with others.

The findings of this study suggest that when addressing emotional difficulties with people with dementia, it is important to consider that the person may be avoiding their negative emotional experiences, due to their perception that negative emotions are indicative of weakness. Addressing negative emotions such as shame in a compassionate way, whilst

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge dispelling beliefs that negative emotions must be feared and avoided, may help people with dementia to develop more adaptive ways of responding to their troubling emotional experiences. As Clare (2010) argues, supportive environments that can enable people to become more aware of their functioning and situation are required for people with dementia.

There is an argument for making available shame-targeting psychological therapies for people with a dementia diagnosis. Compassion Focused Therapy (Gilbert, 2009) is one example of a psychological therapy that specifically targets self-blame and self-criticism, aiming to facilitate self-acceptance and self-compassion. Interventions for people with dementia could draw upon the key elements of Compassion Focussed Therapy, with the aim to help people overcome experiences of shame and move towards self-compassionately adjusting to the changes that dementia may bring them. Psychological therapy groups that provide a secure social environment in which people can openly share their experiences may be effective for helping people with dementia to overcome shame, as they can reduce feelings of alienation and abnormality (Cheston, 2005). A priority for group psychological therapies for people with dementia could be to share common every-day experiences that trigger negative self-perceptions within the group, for example, how difficulties with shopping or counting money might trigger thoughts of being useless. Having a group discussion about such experiences may be helpful to normalise such experiences, as well as explore, challenge, and problem solve around them.

Interventions may be beneficial for helping people with dementia become more aware of and manage avoidance that is having a negative impact upon their experience of dementia. For example, psychological therapies such as Acceptance and Commitment Therapy (Hayes, 2004) aims to help people live according to their values and overcome the competing temptations to avoid negative experiences. Therapies and care approaches may focus upon helping people with dementia to maintain meanings in their lives, particularly when they are beginning to withdraw from and avoid social and personal activities.

Psychologists, and other health professionals, should be aware of and aim to work with the common negative self-perceptions found for people with dementia, e.g. weakness, inferiority, and meaninglessness. For example, psychological therapies may address and question beliefs that having dementia means a person is weak, emphasising that dementia can happen to anyone, using examples of famous people that lived with dementia who are stereotypically "strong" and valued by society.

4.5.3 Working with families, services and the wider systems to address shame.

Given the importance of relationship issues to this study's participants, psychological interventions should be holistic, providing support to both the individual and their families. Addressing issues around shame in dependency may be facilitated by supporting people with dementia to openly discuss care with their families, provide support for family members, and ensure that external sources of care can be accessed when necessary. These steps may help to reduce feelings of burden, and reassure them that their families are supported. When working with families and carers of people with dementia, they can be made aware of the avoidance that they may be engaging in and the impact that it is having on their family member.

Access to general dementia awareness training could be increased and broadened to encompass specific information on the how shame is experienced in dementia. Given the level of avoidance demonstrated by the participants in this study, clinicians may benefit from being aware of how strong this phenomenon may be for people with dementia that they are working with. Clinicians may benefit from receiving training on the role of avoidance for people with dementia, and be aware of the less explicit forms of avoidance as well. Clinicians should be aware that a perceived lack of awareness may be a psychological function of avoidance, and consider this before assuming that the person they are working with is lacking insight.

Working with the negative self-perceptions held by people with dementia e.g. weakness, may prove to be futile unless change is implemented at a societal level. Even well-intentioned societal messages can be seen as contributing to perceptions that dementia is a sign of weakness, e.g. the Alzheimer's Society's (2015) booklet "Be head strong: A guide to help you reduce your risk of dementia". Such public messages should be reviewed.

4.6 Limitations

4.6.1 Sample criteria. As this study aimed to explore experiences of shame that were related to living with a dementia, the researchers wanted to recruit a sample of individuals who were not experiencing any additional current major life events, physical illnesses, or mental health difficulties that might cause additional shame. The criteria excluded people with anxiety or mood difficulties that were significantly impacting upon their daily functioning. Given that the sample was recruited from older adult mental health services, to whom older adults are commonly referred for significant mental health difficulties, the researcher, when meeting with teams, emphasised the exclusion of people with significant mental health problems. Recruitment of the six participants took time, and feedback from the assisting clinicians included that it was difficult to identify participants that met all of the criteria,

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge particularly not having significant mental health difficulties. As detailed in the introduction section, diagnosed depressive and anxiety disorders are common in people with dementia. The participants included in this study may therefore be relatively psychologically healthy and resilient, and thus not experiencing as high levels of shame. This study may have been better able to represent and understand the experience of shame in dementia more if people with significant levels of depression and anxiety symptoms were included in the study. Future studies exploring emotional experiences in dementia may benefit from taking this point into consideration when deciding on sample criteria. On the other hand, this limitation emphasises the importance of exploring shame for people with dementia further. Most of the current participants still explicitly communicated many experiences of shame in relation to their dementia, even though they were not assessed by mental health practitioners to be suffering from a mental health problem such as anxiety or depressive disorders. It could therefore be assumed that shame experiences are even more of a relevant struggle for those who have additional mental health problems, as well as those experiencing other life events and challenges that make life even more complex.

One of the sample criteria for this study was that participants have insight into their memory difficulties. Although all participants reflected upon their relationship with memory problems, the degree to which they were apparently aware that they had a memory problem that constituted an illness was variable. In some ways, analysing the data of these varying accounts with regard to apparent insight or awareness, made the findings interesting. Learned through this process is that “insight” is difficult to assess, measure, and define. As already suggested, some participants such as Thomas, who found it more difficult to give examples of his experiences of dementia and frequently suggested that he did not suffer from memory problems, may be described as pushing away his experience of difficulties, rather than lacking insight to them. However, for the purposes of gaining a fuller, deeper account of experiences of dementia, it may have been easier to recruit a more homogeneous sample of participants who were all able to talk openly about emotional difficulties with dementia.

4.6.2 Recruitment. There was an awareness that the opportunity to gain the experiences of such a relatively hard to reach group such as older people with dementia could be challenging. It was acknowledged that certain procedures would be put into place to ensure sensitivity to context, in that the research took place within an ethical framework and to safeguard the participants. The use of clinicians to access potential participants is shown to have benefits within the empirical literature (Davies et al., 2010; Dewing, 2007), not only to

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge safeguard the participants but to encourage recruitment. Although the use of clinicians was advantageous, it also had disadvantages. Recruitment for the interviews was carried out by the clinicians within community mental health teams. Recruitment was therefore reliant upon clinicians' understanding of the project and their commitment to it, especially at a time when their workload was changing and increasing, and the study was not their priority.

Furthermore, through introducing their patients to the study, clinicians may have set up various expectations for the participants about the purpose of the study, which may have impacted upon the interview process. For example, Thomas appeared to consider the interview an opportunity to share his experiences as a way of passing on advice and helping others with dementia in the future. Any preconceptions that the interview was for this purpose, may have put extra pressure on him to come up with hopeful suggestions, appear that he was coping well, and may have hindered his ability to be completely open and honest about his own difficult experiences. Clinicians' relationships with their patients may have influenced the participants' decisions to take part, for example, if they perceived that pleasing their clinician was essential for accessing health care, they may have felt under pressure to take part. Despite efforts to emphasise that this was not the case, e.g. by stating that care would be unaffected by participation in the study, these kinds of influences are unavoidable. In other instances, carers acted as an initial point of contact to the researcher, as they tended to answer telephone calls made to arrange the interview appointment. On one occasion, after a potential participant initially called the researcher to express their interest in the study and arrange an interview time, they called again later to withdraw their participation in the project, as advised by their family member. These kinds of processes within the recruitment strategy will have influenced characteristics of the final sample.

4.6.3 Interviews. This research used a flexible, semi-structured interview schedule, in order to limit restriction placed upon participants' responses. The need for a flexible and participant-led interview prompted the participants to share the essence of their idiographic, day-to-day experiences. This balance between allowing the participants this flexibility, and maintaining the focus of the interviews was a challenge. As detailed in Reflection 2, experiences of shame turned out to be a challenging subject to interview people about. The interviews lack focus on experiences of shame, instead containing a lot of data that does not directly address the research questions. In IPA, interviews can effectively address the research question "sideways on", (Smith et al., 2009) and the interview process is meant to be open, expansive, and follow the participant's lead. However, when interviewing older adults with

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge dementia, who have so many stories and experiences to reflect upon, and perhaps less ability to maintain focus, it may be more important to remind and prompt participants to stay focussed upon the interview questions. It is however difficult to assume, during the interview, what is and isn't relevant to the research questions. Indeed, some of what seemed to be "off topic" during some of the interviews, was later considered being meaningful at analysis, and other points where participants drifted onto other topics, can be seen as indicating avoidance.

The lack of a pilot interview is a particular flaw of this study, as through the process of conducting, recording and transcribing a pilot interview, the researcher's interview skills would have improved more quickly in time for the rest of the interviews. The use of a pilot interview, or multiple practice interviews, may have improved the style of interview method. It would have made the interviews more consistent if they had been conducted together within a shorter amount of time.

4.6.4 Analysis. As with other qualitative approaches the results are subjective, and it is probable that a different researcher would have alternative interpretations of the data. However, IPA acknowledges that complete suspension of preconceptions is impossible, so the researcher made a conscious effort to be aware of what influence their preconceptions have on their interpretations. Reflection 3 provides further detail of how the researcher reflected upon her influence on the analysis, as well as how she managed the analysis.

The researcher used supervision to enhance her analysis skills, particularly in gaining a deeper level of engagement and interpretation with the transcripts. To check the credibility of the analysis, excerpts of the transcripts and initial analyses were shared with the research supervisors to obtain feedback. Some sections of the data were coded by both the researcher and a supervisor separately, who then shared their initial notes to compare and discuss differences in their analyses. Supervision therefore provided feedback on the quality of the researcher's analysis, and informed the researcher of where her interpretations stretched too far from the data. As with all IPA research, the findings from this study are not generalisable but offer valuable insight into a sensitive and little known subject area, grounded in the participants' own words. Rather than assuming that other people in the early stages of dementia will share similar experiences to those in this study, the findings reveal some of the complex experiences and processes that can provoke shame for people with dementia.

4.7 Implications for Future Research

Further research could explore some of the key themes from this study in more depth. For example, given the strength of the theme of avoidance in this study, and the extent to

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge which avoidance has previously, and now currently, been related to shame; more research in this area may be valuable for understanding how to help people with dementia to overcome unhelpful avoidance. It would be interesting to interview people within the early stages of dementia about avoidance in relation to shame and other self-conscious experiences. In particular, it would be interesting to question people with dementia about their awareness of avoidance in relation to shame, in order to find out more about how aware, or not, people in the early stages of dementia are of the issues surrounding avoidance and shame.

Exploring some of the less developed ideas that have developed through this research could be useful for gaining a fuller understanding of shame experiences in dementia. For example, future qualitative studies could explore issues of trust, perceptions of meaninglessness and emptiness, or fears of loss of control and uncertainty in early-stage dementias. Exploring further the dilemma between keeping dementia a secret and sharing it with others, may lend insights into how people with dementia cope with these issues. Exploring social interactions and communication with health professionals further would be another interesting development for further qualitative research, and could recruit health professionals as participants, as well as people with dementia.

This study focussed on the experience of shame. However, a number of other experiences that are connected to shame (Tangney et al., 2007) are discussed within this study, including embarrassment, stigma, self-blame, and self-criticism. Future research may choose to study these emotions together, under a “family of self-conscious emotions”, or study any one of them individually, although the findings of the current research suggest that it is difficult to consider one emotion in isolation.

As discussed, many studies that implicate experiences of shame in dementia use IPA. As demonstrated by this study, IPA is a suitable methodology for gaining an in-depth understanding of significant life experiences, and for considering how people make sense of their experiences. However, IPA is unable to generalise findings to broad populations, or affirmatively predict relationships and processes between experiences. Now that some key experiences of shame have been developed from the findings of this study, other kinds of research may be used to investigate relationships between themes, as well as the frequency with which themes may occur in other samples.

4.8 Conclusion

The findings from this study offer a perspective of how people in the early stages of dementia can experience shame: including some of the key negative self-perceptions, fears

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge about uncertainty and loss of control, issues within relationships, and explicit and implicit cognitive and behavioural strategies that are related to shame. The current findings provide a deeper insight into these experiences, based upon the real-life accounts of relevant participants, that can be added to what was previously suggested by existing models of shame, and research.

Avoidance was a strong theme in this study, revealing many specific explicit and implicit ways that shame can be avoided in dementia. Avoidance served not only to protect the participants from the shame of judgement from others, but to avoid the shame of the impact that they perceived their dementia to have on others. Implicit forms of avoidance appear to have more of a role for emotional distancing, involving a great range of many linguistic strategies, from using humour, to intellectualised and idealised language. Participants' awareness of their avoidance varied within the accounts. Awareness of shame avoidance may be an important new area for research, particularly given that shame related avoidance appears to be a barrier to successful adaptive coping with dementia.

This study contributes further insights into the complexities of shame experiences for people with dementia, including the dilemmas and internal conflicts that participants found themselves in, particular in relation to interpersonal issues of whether they could or should rely upon and trust the support of others or not. Trust appears to be a particularly important finding that this study could contribute towards models of shame for people with dementia. Participants expressed a range of complex cognitions about themselves including that dementia meant they were weak and inferior in comparison to others, and were of less value to others. Some participants expressed fears that they would become empty and meaningless. At times, these negative self-perceptions appeared to prevail even when external social experiences were not shaming towards the person, thus highlighting the strength of self-stigma in contributing to shame.

The current findings add more to initial ideas from Cheston (in press) about the relevance of experiences of loss of control for people in the early stages of dementia, whilst highlighting the importance of experiences of uncertainty. The current study found that particular interactions with health professionals around receiving a diagnosis can contribute to these experiences of loss of control, thus strengthening arguments (Mitchell et al., 2013) for improvements to be made in communicating diagnoses.

Through advancements in clinical practise, shame can be better addressed and managed within health services that offer care to people with dementia. Clinicians must firstly

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge be made more aware of the issues for people with dementia experiencing shame, and particularly how their own avoidance may contribute to this. Assessments can be adapted to include a person's experience of shame, as well as considering how a person's earlier and current situations may be impacting upon experiences of shame. Psychological interventions for people with dementia can be used to address some of the key concerns, issues and perceptions of shame that were found by this study. Working with families and the wider systems to build an awareness of shame in dementia and promote ways of responding to this also require attention.

Now that this study provides some specific and in depth perspectives of the kinds of experiences that shame involves for people with dementia, future research would be useful to explore further the processes between the developed themes, as well as particular elements of the phenomenon in more depth, such as shame avoidance.

Reflection 4. Ending position

Although to some effect I have completed this study, my engagement with the methodology and interpretations of the data continued right through to this ending reflection. Through the entire process of the study and write up, I moved around the hermeneutic circle, considering further meanings each time I look back at the data and the surrounding context and research. My understandings of this research will never be completely finished, and I imagine that as time goes on and my experiences grow, I will continue to look back with further insights. For now, some of the unexpected learnings I developed include how much avoidance surrounds experiences of shame for people with dementia. I experienced first hand how difficult it can be to discuss experiences of shame in relation to dementia openly with people, despite the most motivated intentions. Also, the skill at which people appear to avoid, and the functions of this avoidance surprised me. I had not considered that people with dementia would concentrate so much effort into protecting others from their difficulties, although having heard the participants' views, this makes sense. I am also fascinated by the degree of complexity and variety in the participants' experiences, particularly the dilemmas they highlight. Although this was something that research previously highlighted, the experience of dilemmas and being "caught between states" were difficult to fully appreciate prior to this process.

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Appendices

Appendix A. Research Information Sheet for Clinicians

Primary Researcher: Hannah Aldridge

Trainee Clinical Psychologist

Norwich Medical School

University of East Anglia, Norwich NR4 7TJ

email: hannah.aldridge@uea.ac.uk

phone: 07871493542

Primary supervisor: Professor Ken Laidlaw

email: k.laidlaw@uea.ac.uk

phone: 01603 593600



Clinician Information Sheet: A Study Investigating Experiences of Shame in Dementia

Aims of the study

- This study aims to deepen our understanding of what experiences of shame can be like for people with dementia.
- It is documented that people with dementia can feel ashamed and embarrassed, but no published research to date has explored their perspectives.
- This study may help us to learn about difficulties with shame for people with dementia.

What the study will involve

- I hope to interview 6-8 participants with a dementia about their experiences.
- Interviews will take place within participant's homes or clinic location (if available), and will last about an hour.
- On first contact with participants, I will ask them some screening questions, answer any questions they have, and arrange a time for interview.
- The method of analysis is Interpretative Phenomenological Analysis.

How you can help

- I am asking if clinicians can help by identifying potential participants and offer information packs.
- The information packs contain information sheets and consent forms.
- Participants can choose to contact me directly on [07871493542](tel:07871493542). If they are happy for me to contact them, they can sign a consent to contact form and leave this with you.

What will happen next

- I will contact your service on a weekly basis to collect any signed forms, and update services about how many participants I would like.
- I will aim to interview participants within 2 weeks of my initial contact with them.

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- Participants will be encouraged to have a friend/relative available after the interview.
- I will communicate with clinicians and teams about the time/date of participants' interviews to make sure that support is available to them if needed.
- I will let clinicians know the reasons why any patients are excluded from the study.

People can take part if they:-

- Are able to give informed consent.
- Have insight into their memory difficulties.
- Have received a diagnosis of Alzheimer's, vascular or a mixed dementia.
- Are in the mild/early stages of dementia, as assessed by clinicians.
- Received the diagnosis at least 1 month before recruitment.
- Are currently receiving support from a community-based team.
- Are living at home. Are fluent in English.

People cannot take part if they:-

- Have a mental/physical health problem that significantly impacts on their functioning.
- Have a frontal-temporal dementia.
- Are experiencing a life event likely to impact upon their engagement in the interview.
- Have significant communication problems. Are currently misusing alcohol or drugs.
- Under the age of 60.

Ethical issues

- It is very important that participants' understand that it is their choice to take part.
- They can choose to withdraw at any point and have their data removed.
- All data will be treated as confidential and stored securely.
- If participants disclose any significant risk issues, I will inform the relevant services.
- I am hoping that clinicians can identify people with capacity but I will also check this.
- I will remind participants that they can choose not to answer any sensitive questions.
- I will aim to contain any distress that arises and not leave people distressed.
- If anyone is distressed at the end of the interview, I will inform their service and GP.

Benefits of taking part

- Participants will have the opportunity to discuss their experiences.
- Participants can claim back any travel or phone costs incurred by the study.

Who is organising the research?

- This research is funded by the UEA Doctoral Programme in Clinical Psychology.
- I have planned the study under the supervision of Professor Ken Laidlaw and Dr Paul Fisher.

Appendix B. Participant Information Sheet



Primary Researcher: Hannah Aldridge

Trainee Clinical Psychologist,

University of East Anglia, Norwich NR4 7TJ

email: hannah.aldridge@uea.ac.uk

phone: 07871493542

Primary supervisor: Professor Ken Laidlaw

University of East Anglia, Norwich NR4 7TJ

email: k.laidlaw@uea.ac.uk

phone: 01603 593600

Participant Information Sheet

A Study Investigating Experiences of Dementia

I would like to invite you to take part in a research study. Before you decide, I would like to explain why the research is being carried out and what it will involve. Please read the following information and take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

The aim is to investigate people's experiences of dementia, particularly times where people have felt ashamed, embarrassed, or upset with themselves. Not everyone with dementia feels this way, but it can be a problem sometimes which is why understanding it better is important.

2. Why have I been invited?

I am looking for people with dementia to participate. I am hoping to include 15 people in the study.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. Your participation is voluntary, and will not affect your care in any way.

4. What will happen if I take part?

If you agree to take part, I will contact you to check that you are able to take part and arrange a time to meet with you. During our meeting, I will ask you to tell me about any experiences where you have felt ashamed in relation to dementia. You can choose whether this meeting takes place in your home or at your clinic. The meeting will last about 60 minutes.

5. What will the meeting be like?

I will be interested in hearing about your own experiences. It will be like a conversation where

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we will explore things as they come up. I will **not** ask you to answer a fixed set of questions, and there are no right or wrong answers. If there are some things that you would rather not talk about that is ok too.

6. Can I stop taking part if I change my mind?

Yes. You can choose to withdraw from the study up to 2 weeks after the interview. You do not have to provide a reason and your care will not be affected. If you withdraw, any information you have provided will not be used in the research.

7. Will my taking part in this study be anonymous and kept confidential?

All your data will be treated as confidential. However, if you disclose any current risk to yourself or others, the researcher has a duty of care to inform the relevant services. I will tape record and transcribe our discussion. Your transcript will be identifiable using a code. The code will be linked to your details on a separate and secure list. You may request a copy of your transcript. All data will be stored securely.

8. Who will know that I am taking part in the study?

If you would like to take part, I will need check with you that it is ok to let your GP know, as they have a responsibility for your care. Your care co-ordinator will also know that you are taking part. It is also a good idea to tell a relative or friend that you are taking part and have somebody with you after our meeting.

9. What will happen to the results of the research study?

The information collected will be written up and potentially published in a journal. Your discussion may be quoted in the article but you will not be identified personally. If you are interested in finding out about the results from the study, you can request a summary to be sent to you.

10. What are the possible disadvantages or risks of taking part?

The study does require you to talk about your experiences of dementia. At the end of the session, I will take care to talk with you about any distress raised during the discussion so that you are left feeling ok.

11. What are the possible benefits of taking part?

This is an opportunity for you to discuss your experiences of dementia and help others to understand these experiences. Although there may not be any direct benefits to you, it is hoped that this research may help to develop psychological therapies for people with dementia in the future.

12. Will participating in the study cost me any money?

I will travel to your home so that you do not need to pay for travel. If you would rather meet at your clinic, you can claim back any travel expenses. You can also claim back any costs for phone calls that you make to me.

13. Complaints

If you have any concerns about the study you can contact Dr Paul Fisher at the Faculty of Medicine and Health Sciences, University of East Anglia, Norwich NR4 7TJ. Tel.: +44 (0) 1603 456161.

If you would like to contact someone who is independent of the research please contact Marie McKearney, PALS and Complaints Co-ordinator. Freephone: 0800 052 1411. Tel.: 01223 885709 Email: pals@cpft.nhs.uk

14. Who is organising and funding the research?

This research is funded by the University of East Anglia Doctoral Programme in Clinical Psychology. It is being carried out by a trainee clinical psychologist, Hannah Aldridge, and Clinical Psychology programme director, Professor Ken Laidlaw.

15. How do I contact you?

If you would like to take part in the study, please complete the Consent to Contact form enclosed, and give this to your health professional. If you would rather contact me (Hannah) directly, you can call **07871493542** and we can discuss any questions you have before you decide whether you would like to participate.

Appendix C. Participant Consent Form



PARTICIPANT CONSENT FORM

Title of the project: *A study investigating experiences of dementia*

Researchers and contact details:

Hannah Aldridge (hannah.aldridge@uea.ac.uk)

Tel. 07871493542

Professor Ken Laidlaw (k.laidlaw@uea.ac.uk/ telephone 01603 593600)

Please initial each box and sign/print your name at the bottom if you agree to participate.

1. I have read the Participant Information Sheet relating to this study (dated 05/05/2014). I understand what my role will be in this research.

2. I understand that I do not have to take part and that I can stop the discussion at any time without giving a reason. I understand that this will not affect my care.

3. I understand that the information I provide will be confidential.

4. I give consent for the researcher to tell my GP and my care co-ordinator that I am participating.

5. I understand that they researcher will have to tell someone if I disclose any current risk to myself or other people.

6. I understand that relevant sections of my data may be quoted in the reporting of the study but no personally identifying information will be included. I give permission for these quotations to be used.

7. I understand that I am free to ask any questions at any time before and during the study, and have the contact details of the researcher

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge
should I wish to discuss the study.

8. I give permission for the interview to be tape-recorded.

9. I would like a written summary of the research findings to be posted to my
address.

10. I agree to take part:

Name of Research Participant:

Signature: _____

Date: _____

Name of Researcher: Hannah Aldridge

Researcher's Signature: _____

Date: _____

Please save a copy of this for your own records



Understanding mental health, understanding people

CONSENT TO CONTACT FORM

Title of project: A study investigating experiences of dementia.

Researcher contact details: Hannah Aldridge (Hannah.aldridge@uea.ac.uk), telephone number **07871493542**

Please initial each box and sign/print your name at the bottom if you agree to be contacted by the researcher.

1. I am interested in taking part in an interview.

2. I have read and understand the Participant Information Sheet about the interview.

3. I give permission for the researcher to contact me on the telephone number below to discuss the research, what it would entail, and whether I would like to take part.

4. I understand that if I no longer wish for the researcher to contact me or change my mind about taking part, I can withdraw from the research at any time.

Name:

Telephone number:.....

Signature:

Date:.....

Please return this form to your health professional

Thank you.

Appendix E. Interview Schedule

Thank you for giving me this hour of your time to talk about your experiences of dementia. I am interested in your own experiences and there are no wrong or right answers. You can take your time in thinking and talking about your experiences. This interview may feel a bit like a one sided conversation as I will say very little. If at any time you feel distressed, please do let me know and we can stop the interview at any point. There will be some time at the end to talk about any difficult issues raised today. Do you have any questions?

1. General experiences of memory problems.

Can you tell me about how you like if affected by dementia at the moment?

Can you tell me what it is like to live with memory problems on a day-to-day basis?

Prompts: What is that like? How do you feel about that?

2. Experiences of shame/embarrassment.

Can you tell me about any experiences where you have felt embarrassed or ashamed about having memory problems?

Prompts: What made you feel that way? What did you think about dementia then?

3. Experiences of self-perceptions.

Can you tell me about any times that you have felt bad about yourself because of memory problems?

How do your memory problems affect your feelings towards yourself?

How do your memory problems affect the way you see yourself?

4. Coping/managing with these feelings.

What did you do about those times?

How did you cope?

5. Closing questions.

Is there anything else that is important for me to know/understand about your experiences?

How do you feel after our conversation today?

Thank you very much for sharing your views and experiences with me.



Telephone: 020 797 22561
Fax: 020 797 22592

12 June 2014

Miss Hannah Aldridge
1 Burton Bank
Yeate Street
N1 3EP

Dear Miss Aldridge

Study title: Perspectives of people with dementias: Experiencing
and managing shame
REC reference: 14/LO/0647
IRAS project ID: 146318

Thank you for your email of 02 June 2014, responding to the Proportionate Review
Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website,
together with your contact details, unless you expressly withhold permission to do so.
Publication will be no earlier than three months from the date of this favourable opinion letter.
Should you wish to provide a substitute contact point, require further information, or wish to
withhold permission to publish, please contact the REC Manager Mr Atul Patel,
nrescommittee.london-surreyborders@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above
research on the basis described in the application form, protocol and supporting documentation
as revised.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the
study.

**You should notify the REC in writing once all conditions have been met (except for site
approvals from host organisations) and provide copies of any revised documentation**

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	Zurich	22 May 2013
GP/consultant information sheets or letters	1	05 March 2014
Interview schedules or topic guides for participants	2	05 May 2014
Other [Indemnity Letter]		19 March 2014
Other [UEA Cover sheet]		13 February 2014
Other [Summary CV for Academic Supervisor - Dr Paul Fisher]		05 March 2014
Other [Summary CV for Academic Supervisor - Prof Ken Laidlaw]		05 March 2014
Participant consent form [Consent to Contact form]	1	05 March 2014
Participant consent form	2	05 May 2014
Participant information sheet (PIS)	2	05 May 2014
REC Application Form		27 March 2014
Research protocol or project proposal	2	05 May 2014
Response to Request for Further Information		
Summary CV for Chief Investigator (CI)	for Hannah Aldridge	05 March 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known

Doctoral Thesis. Perspectives of People with Dementia: Experiencing Shame. Hannah Aldridge
Appendix F. Ethical Approval Documents (continued)

please use the feedback form available on the HRA website:
<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/LO/0647	Please quote this number on all correspondence
-------------------	---

With the Committee's best wishes for the success of this project.

Yours sincerely



pp

Sir Adrian Baillie
Chair

Email: nrescommittee.london-surreyborders@nhs.net

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Mrs Susan Steel*
 Professor Ed Bullmore, Cambridgeshire and Peterborough NHS
 Foundation Trust

Understanding children, young people and families

Research and Development Department

23rd July 2014

R&D Ref: M00604

Ms. Hannah Aldridge
Norwich Medical School
University of East Anglia
Norwich
NR4 7TJ

Joint Research Office
Box 277
Addenbrooke's Hospital
Hills Road
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CB2 0QQ

Direct Dial: 01223 596472 ext 6472
E-mail: alexandra.leech-faragher@cpft.nhs.uk
www.cpft.nhs.uk

Dear Ms. Aldridge

Perspectives of People with dementias: Experiencing and managing shame

In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.

R&D have reviewed the documentation submitted for this project, and has undertaken a **site specific assessment** based on the information provided in the SSI form, and I am pleased to inform you that we have no objection to the research proceeding within CPFT.

Sponsor: University of East Anglia

Funder: University of East Anglia

End date: 01/11/2015

Protocol: Version 2 dated 05/05/14

Conditions of Trust Approval:

- The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management. Any mobile devices used must also comply with Trust policies and procedures for encryption.
- You and your research team must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998 and are aware of your responsibilities in relation to the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.



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A member of Cambridge University Health Partners

Norfolk and Suffolk 

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Miss Hannah Aldridge
1 Burton Bank
Yeate Street
N1 3EP

16th June 2014

Dear Miss Aldridge,

Re: 2014MH08: Perspectives of people with dementias: Experiencing and managing shame

Thank you for submitting the above project for local research governance approval. I am pleased to inform you that your project has been given full approval and you may begin your research at the following site:

- Norfolk & Suffolk NHS Foundation Trust

I have enclosed two copies of the Standard Terms and Conditions of Approval. Please sign both copies returning one copy to the Research and Development office, at the above address, and keeping the other in your study file. Failure to return the standard terms and conditions may affect the conditions of approval. **Under the agreed Standard Terms and Conditions of Approval you must inform the R&D department of any proposed changes to this study and submit annual progress reports to the R&D department.**

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If you have any queries regarding this or any other project, please contact, Tom Rhodes, Research Facilitator, at the above address.

The reference number for this study is: **2014MH08**, and this should be quoted on all correspondence.

Yours sincerely,



Dr Jon Wilson
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Line	Transcript 2: Joe	Coding Descriptive, Linguistic, Conceptual	Themes
1.	I: So Joe, firstly I want ask you, what is it like for you to live with memory problems on a day to day basis?		Certainty and embarrassment - ashamed of not knowing (5)
2.			
3.			
4.			
5.	P: Embarrassing, (laughs) yes and uh (pause)		Shame of being wrong (8-9) "there's a bit frustration because I can't get the right answer"
6.	uh a bit irritable really (pause) it's it's difficult to describe really, umm embarrassment is is one, and uh the other is (pause) there's a bit frustration because I can't get the right answer. Yes if I give the wrong answer, um Ellie gets embarrassed (laughs) and I probably don't realise that I (laughing) I've made a wrong answer (lots of laughing).	Embarrassing laughing covering emotion? (sounds certain of this - comes easily) Irritable pause - indicating difficulty describing, Difficult to describe stutter, fillers, repeat of "really" pause Frustration repeated use of a bit, Frustration at not knowing, not being able to find the answer - at being wrong Answer - to what? first use of "I" - I can't, "get" and "give" - giving embarrassment to Ellie Causing Ellie embarrassment Right and wrong answer, Ellie Embarrassed, Ellie present, Don't realise. Wrong answer repeated use of I and Wrong answer, laughing ++, using present tense Being wrong and not knowing are painful and current issues. When does he realise that he was wrong? Cough and hesitation, "we're" - he and Ellie, Travelling example "anywhere" - vague - indicates confusion? Travelling something seems right/wrong Seems not right "something" - vagueness, it can be happens across other situations think one thing, try to persuade, it's hard to persuade laughter - before being corrected, future tense, "no" - predicting future rejection, disagreement "she", hesitant, "A and B", Ellie finds frustration, it makes them both frustrated right	
7.			
8.			
9.			
10.			
11.			
12.			
13.			
14.			
15.	I: Ok, so can you give me an example of a time when you might give the wrong answer?		Blaming self for Ellie's embarrassment (10-11)
16.			
17.			
18.	P: Coughs (Long pause) if we're travelling anywhere and and um it seems to me as we're not heading for the right platform, the train or something like that, umm, and it can be that I think that train A is the one that we want to be on, and Ellie will try and (laugh) she will say no, it's train B that we (laugh) want not train A, um and uh, she finds this frustrating um, and so do I		Shame of not realising that he is wrong (11-13)
19.			
20.			
21.			
22.			
23.			
24.			
25.			

Appendix G. Example of an Initial Analysis: Coding and emergent themes (continued)

26.	really, (laughs) she's usually right, and I have to accept that.	"have to" forced to accept not knowing/being wrong, having ideas rejected, accept being wrong	disagreements (23)
27.			
28.			
29.	I: Ok, so it can be frustrating for both of you.	yes really - it is frustrating for them both Married nearly 60 years, laughter, "Used to" each other, they know, trust, feel comfortable with, and have grown accustomed to each other, take each other for granted, depend on each other?	Shame of having to accept being wrong (27-28) "(laughs) she's usually right, and I have to accept that"
30.			
31.	P: Yes really (pause) we've been married for very nearly 60 years (laughs), um and we are pretty well used to each other.		
32.			
33.			
34.			
35.	I: Ok, so does that make a difference that you know each other so well?	helps enormously, repeat of, "it does", repeat of "really", other people, its more frustrating to accept being wrong with people he doesn't know so well, cross, feel angry - with himself? stutter on she, "read my thoughts" she knows what I'm thinking/doing, Ellie knows and he is dependent on her for this, without her I'd be stuck, pause and stutter indicating difficulty with this, repeat of really. Pause before "without her I'd be stuck" Difficulty thinking about life without Ellie? Couldn't cope without her, because he doesn't "know" and she does, and he trusts her more than others - is that why he feels cross when with others?	Trust (32-34) "we've been married for very nearly 60 years (laughs), um and we are pretty well used to each other"
36.			
37.			
38.	P: It does it does help enormously, and it's really probably really with (pause) with other people that I would get into a sort of cross, um, because she she she can read my thoughts pretty well (laughs loudly) And she knows what's going on (pause) she she's (pause) without her I'd be stuck, really.		
39.			
40.			
41.			
42.			
43.			
44.			
45.			
46.	I: Ok, so what happens then with Ellie when you've not got something quite right?	"and" continues my sentence he's done the wrong thing, this happened, "or", another example, it has happened more than once, being/doing wrong is real and current, "one" and "another" - one is right and another is wrong - he can make the wrong decision. "very much" - he got it very wrong? Could he make a big mistake? He feels lucky that she knows her own mind and his. She's very strong willed, fortunately - he	Anger towards self when with people he doesn't trust (40-41)
47.			
48.			
49.	P: And bought the wrong thing in a shop, oh yes (laughs) this happened, and (coughs) or if there's um if it's a birthday card, I got one out and she thinks another one would be very much more preferable (laughs). Um (pause) I'll tell you she's very strong willed, um, and fortunately I'm		
50.			
51.			
52.			
53.			
54.			

Appendix G. Example of an Initial Analysis: Coding and emergent themes (continued)

55.	learning not so strong willed and um a little bit more flexible (laughs). She isn't flexible (laughs) she knows what she wants and goes for it (laughs). And so in a way this is good because we've got a solid benchmark.	sounds sincere, but sad about it, learning to be more flexible, it's sad to learn not to be strong.	Shame in accepting weakness and uncertainty (55-57)
56.		Laughter, "in a way this is good", "we've got", but not in every way, he can rely on her, but can't rely on himself.	"she's very strong willed, um, and fortunately I'm learning not so strong willed and um a little bit more flexible"
57.		"Solid benchmark" - certainty about where they are, a safe measure, guide.	
58.		she wins, he loses, laughter, "you win love" - let her win, vagueness - generalising to every situation,	
59.		sounds quieter - indicates sadness? "in the present circumstances" - because of his memory, all the time she is always right it's guaranteed, definite, if there is any difference at all - it is absolute, there are no grey areas. It's guaranteed that his memory means he has lost/is wrong.	Certainty of losing/ being wrong (64-67)
60.		"Eat humble pie" he has to be humble about it, laughter, repeated yes - certainty, lower voice = sadness? It's a shame that he has to face humiliation, accept the lower ground/inferiority, apologise for the mistake, embarrassment.	"I probably have to say "you win love...it's guaranteed that she's right"
61.		Hesitation, They're both used to it, "pretty well", it's better now than it used to be, hesitation around the past, "in fact" - now he realises his position, in the past, when he didn't realise his position, his situation - it was distressing, it's a particular difficult situation, it's an external situation that is causing this, change from different to difficult - it's not just different, indicates compassion towards self, use of "very", "she won't do anything indicates trust, there is a reason for why he is not right, he trusts her, stutter at frustration, frustration	Acceptance of inferior position (72) "Eat humble pie"
62.			Shame in not having a reason for being wrong (77-81)
63.			No choice but to trust - losing control
64.			
65.			
66.			
67.			
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81.			
82.			
83.			

Appendix H. Example of a Table of Main Themes for an Individual Participant

Transcript 4. Gwen

1. Holding onto being normal, but losing value/worth
Using denial/refusal to hold onto a sense of being as good as anyone else, but feeling comparatively inferior to others, reduced as a person, not “as good”, worthy, useful, or important.
1100: “I try and feel normal yes yeah, uh but I mean I sometimes you latch on to things and then if somebody says oh I can’t remember that I can’t remember oh I said I’m glad I’m not the only one, you know, yeah.”
114-118: “I think you used to be really bright, and now you’ve gone down a level, or two, and you’re not as good as you used to be, so I’m referring you”
428-431: “I think they’d think “she’s had to come down a peg or 2” (laughs) or I don’t know perhaps they think - oh I don’t know. I don’t know what they think of me”
512-515: “But um, no it was awful, I wouldn’t want my husband to take me out, if I got like that, that’s what I think. I wouldn’t want people to pity me so much”.
<i>Told I am not as bright and not as “good”. Devaluation as a person, 115-118</i>
<i>She feels inferior to her former self, 1046-1049</i>
<i>Shame as a loss of pride, forced to accept inferiority, 428-431</i>
<i>A sense of good and right, usefulness and competence, 17-19</i>
<i>“Good” means being competent and able, 238-240</i>
<i>Feeling that she is not taken seriously - feeling undermined, misunderstood, blamed? 334-340</i>
<i>Treated as unimportant, 346-349</i>
<i>Denying/apologising - feeling unimportant, 477-478</i>
<i>Feeling incompetent/ stupid, 181=184</i>
<i>People pity you - they think you are “poor” - being unfortunate/ inferior, 512-515</i>
<i>She fees incompetent and de-skilled in comparison to him, inferior, useless, 527-550</i>
<i>Difficulty admitting that he has taken over her responsibilities - she feels useless, 527-550</i>
<i>Thinking that she is useless to others because she can’t remember - “it’s no good asking me”, 411-412</i>
<i>Fear of not being trustworthy, by self and others (husband), 157-167</i>

2. Aging, disconnection and loss

A sense that everyone is quickly aging; meaning that she is less able, less supported, particularly by family, increasing a sense of vulnerability and being unwanted.

75-76: “it’s too far for my husband to go, so um, and not only that they’ve got busy lives themselves.”

601-603: “if he dies first he’ll be cremated, but I definitely don’t want to be cremated, so he knows that and then uh, he’ll go in my grave eventually”

Feeling vulnerable/insecure, 77-83

Feeling alone and unsupported, 460-464

Vulnerability of being alone, 89-95

So scared of being alone that she accepts death, 621-626

Loneliness and distance - feeling unwanted, 44-47

Feeling devalued/ unimportant to the family, 67-74

Feeling alone and disconnected from the family - missing the closeness, 72-77

Craves closeness with family, feeling distant, 627-633

Loneliness and emptiness in being old alone, 710-714

Fear of being isolated, lonely and without support, 867-870

Family busy and moving on - feeling devalued, 39-47

Confusion and lapsing in age and time 5,6; 26-28

Lapsing of age and time, 307-309

Vague sense of age and time - time lapsing? (Gaps/ confusion) 63-66

Preoccupation with aging- fearing loss of reliance on husband, 231-237

Aging - Feeling physically weak, disabled, 286-288

Aging - Practical difficulties - the stairs, the light, 289-303

Physical difficulties linked with aging: sleep problems, bladder weakness, decreased mobility - preoccupation with age, 289-309

The burden and worry of preparing for death - who will die first? 598-606

Wanting to know that her husband will live longer than her - using generational links as a coping strategy, 616-620

Old age and retirement - being old means stopping, 5-7

Everyone is getting older and moving on - fear of being left alone (by children AND husband), 56-70

Everyone getting older and moving on - feeling forgotten, 24-28

Family are all getting older and all moving on - leaving her alone, 890-900

Husband is an older man now - dying, 495-499

Family getting older and less able to support her? 52

3. Avoidance of emotion

Avoidance of difficult feelings towards others and herself, hiding her fears and shame from others.

382: "I think it serves you right (laughs)"

876-877; "see I think they think I'm a bit of a ditherer (laughs)".

Avoidance of difficult feelings - isolation from family, needing daughter's help, 15-17

Projection of feelings towards herself onto others, 876-877

Unexpressed anger - internalised and developing into shame, 100-121

Avoidance of the memory problems, 310-316

Others also conceal to manage her embarrassment/ shame, 734-738

Minimisation of her own challenges, 707-709

Avoidance of thinking about how the dementia impacts on her feelings towards herself, 27-28

Minimising the impact of dementia as a coping strategy - wanting to escape/ avoid the issue of the impact upon her own feelings - shame/ self directed anger, 382

Worrying about the impact of dementia on other people as a distraction away from the impact of the dementia on her own feelings, 125-126

Ashamed of her fears - and so hiding them, 488-489

Hiding shame, 382

Keeping it secret to avoid shame, 121-122

Difficulty admitting that she cannot cope because of dementia - using physical problems as a distraction, 275-281

Using physical difficulties as a distraction away from dementia, 286-309

Keeping feelings hidden out of fear of being a burden, 270

4. Losing trust and battling for control

Experiencing a loss of control of and trust in herself. A fear of losing the person she trusts and having to trust others with her care. Using choice and routine to retain a sense of predictability and control over her life.

249-251: “you know I trust him driving, and I’d be lost without him because nobody else would have the patience”

354-358: “Well I don’t know who this gentleman is, I mean he’s somebody who who to do with my doctor’s surgery I suppose. So do people find medication to help?”

512-514: “I wouldn’t want my husband to take me out, if I got like that, that’s what I think”

Preference for certainty and predictability - in a confusing time? 8-14

Replacing confusion with certainty, 40-43

Opting for certainty/predictability (routine) - at a time of not knowing (vagueness), 89-91

Exerting choice and decisions - holding onto control, 8-14

Wanting predictability - wanting her mind to be organised but experiencing chaos/ mess, 128-132

Wanting to retain her choice and control, 326-328

Needing to retain the choice not to be a strain on others, 669-670

Not having a choice, 512-513

Unable to manage - loss of control, 542-547

Wanting choice in her future care, 666-669

She lost control and husband had to take responsibility, 542-550

Not being able to trust herself and her memory - that she has done little/ important things, 1030-1034

Knowing something that is not validated - experiencing a lack of trust from others which is then internalised, 100-111

5. Loss of self/emptiness

Fear and shame about becoming empty, vacant, gormless, a wimp, without thoughts, feelings, and awareness.

500-501; “he had his his wife with him, and she’d (quietly) lost it she just s stood there and smiled”

502-504; “he did sort include her in the conversation, and she just like, something hanging on his arm”

995-997; “I don’t want to just be gormless”.

1108-1111; “That you haven’t got, any idea of things, you just shrug, sort of shrug your shoulders you don’t know this and you don’t know that, and you don’t care really (laughs)”

986-988; “it’s just like you’re walking, and you don’t got any - I don’t want to look like that”

Observing an emptiness/vacancy in pwd - “losing it” - losing yourself? 500-501

Being an object without a mind/ awareness - empty, 502-504

Shame in being vacant of thought and feeling, 818-823

Shame in being empty and vacant, 840-844

Fear of being aware of being empty and vacant - because this would cause shame, 849

Shame in being unaware, but shame also in being aware of an empty self, 840-844

There’s a shame in not knowing, not feeling, not thinking - just being gormless, emptiness, 1108-1101

Feeling a ditherer, a wimp, weak, empty, 882-883

Fear of being “gormless”, 995-997

Not knowing anything and not caring. Bing empty/ vacant of thought and feeling, 1108-1111

Fear of becoming an empty body, unable to do the necessary things, 985-990

Fear of missing out on life, having to give up things she enjoys, 948-954

Forgetting important things - why are they important? Because they are who she is - forgetting to be myself, 189-191

Having to give up the things she loves, 974-978

6. Shame in increasing vulnerability

Losing the competency to be who she is, getting lost, increasing dependence. Perceiving that she is weak and less able to cope than others.

172-175; “Well if all of a sudden I can’t think where I am, and I have to ask somebody, if they can tell me if I can’t remember my road or something, I worry about, what *might* happen”.

1136-1138; “looking at it that way I think he would cope better that way than me having to cope if he should die before me”.

854-855; “I feel I’m a bit wimpy sitting here (laughing)”

257; “I don’t really know how I could cope”

Linked to a fear of the unknown 998-1000 “I don’t know how it develops this dementia what happens, what what do people do with dementia?”

<i>Fear of forgetting important things, 157-167</i>
<i>Fear of getting lost/ being vulnerable, 172-175</i>
<i>Fear of losing independence, all competencies, 172-175</i>
<i>Fear of being beyond help - shame of being helpless, dependent, incompetent, 172-175</i>
<i>Not wanting to be dependent, but having to be, losing control and her choice, 470-473</i>
<i>Increasing difficulties and dependence, 547-550</i>
<i>“I don’t know what I’d do without him” - feeling incapable, 868-869</i>
<i>Believing in others’ ability to cope - as a coping strategy, 1136-1138</i>
<i>Shame in handing over her share of responsibilities, 548-550</i>
<i>Shame in admitting that she wasn’t managing, 586-590</i>
<i>Shame of feeling weak and less capable than other people, 698-705</i>
<i>Feeling weak and afraid, 854-855</i>
<i>Fear of not being able to cope with normal things, 257</i>
<i>Concern about coping in the future, 998-1000</i>
<i>Uncertainty about the future - fear of it getting worse. Fear of not being able to cope, 1022-1023</i>
<i>Feeling that she has changed - she is less capable/ competent, 1046-1049</i>
<i>Feeling weak, indecisive, a wimp, 926-927</i>
<i>Worry about forgetting serious things. Not being able to trust herself, 934-939</i>

7. The burden of dependency

Burdening others means being a strain and feeling guilty. Depending upon others comes with a risk of losing them, being rejected by them, losing yourself, being out of control, and having to trust them more.

124-126: “people say “you’ve told me that already” and they tend to get annoyed - or (laughs) a little bit irritated with it”

250-253: “I’d be lost without him because nobody else would have the patience with me, I couldn’t live with my daughters, because it’s not fair on them”

223-225 “I’m very dependent on my husband really, and he’s good but the poor man’s having physio himself”

610-611: “I don’t want to be - we don’t want to be a burden to the children”

675-679; “Well it was (laugh) it was worse than having a baby because you couldn’t take a baby up,

you know, you had to, keep thinking what was going to happen”

1130-1132, “I just think I’m going to be, hard work, I just worry about the sort of burden I’m going to be on my husband”

207-211: “Because they, they take it for granted don’t they - I don’t know. I don’t know - because of the way they say it “I’ve told you that”. And I thought, you know and then they’re going to lose patience with me or something”

231-232: “it’s suddenly crossed my mind he might die before me”.

250-252: “I’d be lost without him, because no-one else would have the patience with me”,

882-884: “Uh, well I think she thinks I’m a bit of a wimp you know (laughs) oh sometimes my sister says oh “oh pull yourself together”

Being an irritation/ annoyance to others, 124-126

Guilt of being a burden, 77-81

Worry about being an embarrassment to people - and not having their understanding, 1132-1134

Feeling a burden on her husband, 223-225

Fear of being a burden on her children, 610-611

“Worse than having a baby” - a burden, a restriction, a strain, demanding, 675-679

Certainty of not wanting to burden her children, 654

“The main thing is being a burden on my husband”, 1134-1135

Guilt of feeling like a burden husband, 1130-1132

Security of her husband being there - but fear that he may die first, 598-604

Becoming dependent means losing yourself, 715-717

“I’d be lost without him, because no-one else would have the patience with me”, 250-252

Fear of no-one helping, 279-281

Needing emotional and practical support, 661-664

Practical support (problem solving) is available but not emotional support, 873-877

Conflict between enjoying being looked after and guilt at being a burden, 579-585

Worry about being a burden - worry that others won’t be able to cope with her, 1127-1130

I don’t want to depend on others because it would burden them, but I’d be lost without them, 908-912

“I’d be lost without them” - links with I can’t trust myself not to get lost, 902

Feeling out of control in her dependency, 811-813

People want her to be stronger, 882-884

8. Fear of the unknown

Fear of what will happen to her in the future, and wanting to find a reason for the dementia

183-184; “I don’t know what I’d do, but I worry about being in that situation”

828-830; “Well I don’t know do I, I don’t know how I how they how they feel (pause) I don’t know if you realise you’re you’re just like that or not”

Knowing it will get worse, and not knowing what I’ll do, 183-184

Fear of the unknown that is to come, 828-830

Fear of not knowing how she will feel - fear of her own feelings, 828-830

Uncertainty about the future and not knowing how bad it will get, 1022

Wanting to know the cause, 1059-1061

A sudden overwhelm without explanation - what is it, how did it appear? Lack of preparation, 119-121

9. Self-blame

Being self-critical, perceiving herself as selfish or mean, and blaming herself for her dementia and other people’s reactions to her.

369-372, “and I think, possibly, I might have been a person like that myself, I might have said “I told you that” you know and so ooooh it’s all coming back to me that’s what you get for being mean”

382 “I think it serves you right (laughs)”.

891-894, I think, there’s me full of my own problems, well full of things wrong with me and she might not be as well as I think she is

909-911; “They say “come come on” laughs, and you know I do feel I’m a bit of a ditherer”.

396-397; “I sometimes nowadays feel I could have been c- (stutter) perhaps I could be a bit nicer”

1034-1037; “I thought don’t be daft just tick it off these days you know, your list, just just help yourself don’t just, you know just you throw the flour in throw the fat in get on with it”.

Telling herself off - it’s her fault - self criticism, 382

Self-criticism is part of who she is, 387

Being self-critical “don’t be silly” - telling herself off for being afraid to go out, 940-941

Criticising herself for needing support “I shouldn’t want to be dependent on people”, 493-440

Self-criticism - don't be daft, silly, when questioning herself/doubting herself, 1034-1035

Shame in having made judgements, 500-501

Feeling selfish, 891-894

"I could be a bit nicer" - shame of who she is. Thinking she is bad, 396-397

Handing over responsibilities feels like being mean, selfish, or bad, 573-574

I should have been nicer. I'm bad/ not a nice person, 404-405

Feeling faulty/ she is to blame for these issues, 908-911

It's my fault that they get irritated, 665-666

People can't cope with her and that's her fault, 909-911

Getting impatient with herself, 1034-1037

It's her punishment, she deserves it, it's her fault, she is blaming herself, 369-372

10. Hiding/concealment from others

Out of a fear of pity, a want to avoid her own shame, and a desire to appear normal

420-423; "Well I'd feel embarrassed that they'd go away and think "god she's losing it isn't she?" (laughs). You know I'd wonder what they were thinking about me"

512-515; "I wouldn't want my husband to take me out, if I got like that, that's what I think. I wouldn't want people to pity me so much".

876-877; "see I think they think I'm a bit of a ditherer (laughs)".

734-737; "I sometimes bluff my way through it, you know they they say, you know we sort of - I just keep quiet and pretend I understand what what they said"

Ashamed of other people noticing that she is losing control: "god she's losing it isn't she?", 420

Too ashamed to go out - fear of pity - would rather hide, 512-515

Concerns about appearance - keeping up appearance, 561-562

Concern about what others think of her, 876-877

Concealing lack of understanding as a way of managing Gwen's shame, shame of not understanding, 734-737

Wanting to avoid others knowing how she feels - feeling ashamed of her feelings, 797-798

Keeping her feelings to herself, covering up and keeping quiet, 859-860

Pretending to be normal, concealing difficulties - "bluff my way through it" - to avoid embarrassment, 734-737

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**Appendix I. Table Showing the Prevalence of Support for each ‘superordinate theme’
 from ‘main themes’ for each participant**

Themes→ Participant ↓	Pushing Away, Avoidance and Secrecy	Weakness, Meaninglessness and Devaluation	Relationship Matters	Uncertainty and Loss of Control
Joe	2	2	2	2
George	2	3	1	3
Betty	3	2	3	2
Brian	1	3	3	2
Gwen	2	4	3	1
Thomas	3	2	1	1
Total	13	16	13	11

Note. This gives only a rough indication of how relevant each superordinate theme is for each participant, as each participant’s Themes vary in size, according to the number of emergent themes per Theme.