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**Exploring the lived experience of becoming cared for from the perspective of women with Alzheimer's disease**

Submitted for the Degree of Doctor of Professional Practice  
At the University of Northampton

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Gayle Borley

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## Abstract

This thesis presents a study exploring the lived experience of becoming cared for from the perspective of women with Alzheimer's disease (AD). The objectives of the study were to reveal the experience of receiving assistance with instrumental activities of daily living (IADL's) from the perspective of women with AD, to explore the care relationship between women and their spouses and to examine the changing role and identity of those women. Interpretative Phenomenological Analysis (IPA) was used as the methodology to explore the meaning given to becoming cared for. This methodology promotes the recognition of the unique ways individuals experience the world and is regularly used to better understand how illness affects behaviour and lifestyles.

Eight women with AD took part in two semi-structured interviews and their transcripts were analysed individually, before exploring convergences and divergences across cases. Three key experiences emerged from the final analysis; 'It's a togetherness', 'Me being me' and 'Seeing cobwebs'. The findings identify becoming cared for as a relational phenomenon for the women, influenced by their experience of ongoing connections with their husbands. Some participants attempted to maintain their sense of self and womanhood in relation to completing IADL's, comparing their past selves to the present. However, this experience was often negatively affected by how others treated them. Other women viewed the changes they experienced in a more positive way, accepting becoming cared for as a part of life. There was a clear sense of contentment in their evolving lives, seeing beauty where they had not seen it before.

This adds an alternative view to current literature, as some women appear to embrace the change in themselves when becoming cared for, rather than experiencing a loss of identity. Humanisation theory provides a conceptual framework to aid change in healthcare professional's practice, by encouraging them to regard women with AD as holistic human beings. Whilst change may be viewed by healthcare professionals as a negative symptom of AD, it should be considered that becoming cared for may be experienced as a positive transition in life.

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# 1 Introduction

The number of people who are living over the age of 65 is rising significantly due to an increase in life expectancy and the ageing of the baby-boomer generation (Morciano *et al*, 2015). The resulting ageing population brings an escalating risk of illnesses such as dementia, which leads to an increased need for care (Nordberg *et al*, 2007). There are an estimated 850,000 people in the UK with a diagnosis of dementia and the annual cost of caring for each individual is approximately £32,250, presenting a huge economic challenge for the country (Alzheimer's Society, 2014). Domiciliary care provided by health and social care professionals, and long-term residential facilities are formal care services that add to the economic pressure, therefore caring associated with dementia often falls on family carers (Erol *et al*, 2015). It is known that supporting carers of people with dementia is essential (Newbronner *et al*, 2013), however there is also a need to ensure the experience of receiving care promotes a good quality of life for those people directly affected. This is an important issue which has received little attention.

Caring as a concept is characterized by a sustained emotional investment in a person's well-being and a desire to take action to benefit that person (Weiner & Auster, 2007). Thus, care is identified as both emotional and physical acts that add to a number of dimensions of care which already make defining the concept complex. Dimensions, such as the identities of the carer and care recipient and where the care is taking place, plus the nature of the care, are variables that will help delineate the concept (Thomas, 1993).

Caring has been recognised as a basic human need for many years (Leininger, 1988) and is synonymous with the nursing profession. It is a concept that is defined by attitudes and actions of nurses, such as building relationships, being empathic and accepting a person as a fellow human being (Brilowski & Wendler, 2004). Nursing care has also been defined as a process that is planned and evidence based, resulting in positive patient outcomes (Dalpezzo, 2009). What appears at the heart of caring is

acknowledgement of the existence of the person being cared for. How care is provided can affect a person's subjective experience of health and well-being (Svanstrom *et al*, 2013) and it is important for healthcare professionals to recognize and respond to this and also support informal carers to promote a positive caring experience.

Caring, in the form of household tasks and personal care, are seen as extensions of the nurturing activities of women, as mothers and wives (Neno, 2004). It is well documented that caring, however defined, is a predominantly female activity (Bamford & Walker, 2012; Erol *et al*, 2015; Ward-Griffin *et al*, 2006). Social norms and expectations have traditionally positioned women as primary carers in families (Finch & Groves, 1983), therefore it is these informal carers who are believed to carry the biggest burden in these relationships. This concept of caring again leans toward understanding the experience from the carers' standpoint, rather than the care receiver, however the study of care is also important, as it can lead to a greater understanding of the needs and interests of those receiving care (Thomas, 1993).

Older women diagnosed with dementia, who have previously held the traditional position of carer in their families, may find themselves in need of care as their illness progresses. This poses a challenge for both carers and healthcare professionals to promote the well-being and care of women with dementia in the context of this new situation (Svanstrom *et al*, 2013). Subsequently, there is a need to understand these women's experience of receiving care and it is the experience of the transition from 'carer' to 'cared for' that is the focus of this thesis, which explores the lived experience of becoming cared for from the perspective of women with dementia.

In this first chapter, I provide the reader with an overview of dementia and the challenges this affords the individual and the UK as a nation. This demonstrates the importance of understanding the effects of dementia and how healthcare professionals and carers can support people with this diagnosis. I provide an explanation of who I am as the researcher and why I am best placed to complete this work and finally outline what can be expected within this thesis.

## **1.1 Dementia and Alzheimer's disease**

Dementia is not just memory loss. Dementia is an umbrella term given to a number of diseases including Alzheimer's disease, vascular dementia, lewy body dementia and many more (Bourgeois & Hickey, 2011). The majority of people living with the disease will be diagnosed over the age of 65, but some experience early onset dementia and can be diagnosed at a much younger age (Jefferies & Agrawal, 2009).

Alzheimer's disease (AD) is the most common type of dementia in the UK and is distinguished from other types of dementia by its gradual progression and early symptoms including decline in short-term memory, reasoning and language difficulties such as decreased word fluency (Cayton et al, 2002). As the illness progresses through the mild to moderate stages it also begins to affect a person's ability to function independently, and the need for care and support with instrumental activities of daily living increases (Castilla-Rilo *et al*, 2007). This could include managing finances, shopping, cleaning and cooking. In the more advanced stages of AD, individuals will become completely dependent on others for their care needs including washing, eating and toileting and will often require a move into a long term care facility in order to receive specialist care (Warner & Graham, 2012).

Current national statistics report that two thirds of people with dementia in the UK live in the community and two thirds of people diagnosed are women (Alzheimer's Society, 2012); women being more commonly diagnosed with AD than men (Warner & Graham, 2012). This indicates that women with AD are a large group of people who could benefit from further study. The focus of this research is the impact of AD on women, specifically in relation to their ability to complete instrumental activities of daily living, such as the shopping and cooking. These tasks have been viewed as feminine tasks and taken on by women who have been described as carers and homemakers (Bamford & Walker, 2012). So how does the reduction in ability to complete these fundamental tasks due to AD affect a woman in terms of her identity? And how is the transition 'becoming cared for' experienced?

## 1.2 A national problem

The goal of understanding dementia and providing optimum care for those with this diagnosis is a national concern. The National Dementia Strategy published by the Department of Health (DoH, 2009) is a strategic framework for making quality improvements to dementia services and addressing health inequalities. It offers advice and guidance to care providers, promoting high quality care for people with dementia, including AD, in England. The strategy identifies three key steps to improve the lives of people with dementia: firstly to ensure people have a better knowledge of dementia and how it affects individuals, secondly to increase the rate of diagnosis as early as possible to enable people to make decisions for themselves and thirdly to develop services to meet the changing needs of people with dementia. The strategy also encourages people who have concerns regarding changes in their memory or functional ability to seek help early to enable an accurate diagnosis. This will assist the individuals to adjust to the diagnosis of dementia and reduce fear, whilst putting the necessary supports in place (DoH, 2009). During this time it is important to understand how it feels to accept help as the relationship between the person with dementia and their spouse begins the transformation into a caregiving relationship (Quinn et al, 2012).

UK Prime Minister David Cameron launched a challenge on dementia in 2012 (DoH, 2012); promising improvements in health and care, dementia friendly communities, and better research. Funding into dementia research, including social science research, will continue to increase over the coming years with the aim of finding more effective treatments for people with dementia. Trials of investigational medicines can take over ten years to complete and although this is important, we must also continue to look to discover how we can maintain quality of life from the time of diagnosis onwards (Steeman *et al*, 2006) .

Public Health England (PHE) is an executive agency sponsored by the DoH to protect and improve the nation's health and well-being. They have set priorities to try and reduce the prevalence of dementia in the UK and also support the development of

dementia friendly communities to promote a societal response to dementia (PHE, 2013). PHE recognise that dementia presents a global public health challenge, so is an important issue for everyone. Guidelines have also been written by the National Institute for Health and Care Excellence (NICE) offering guidance on supporting people with dementia. These highlight services that should be delivered through memory assessment clinics focusing on early diagnosis and promoting the quality of life of people with dementia and their carers (NICE, 2013).

Memory clinics are well established in the UK and viewed as best practice for supporting people with dementia and AD (Simpson *et al*, 2004). Early diagnosis allows the person with AD to decide for themselves how they want to live their lives and what care they would like when the time comes. However, memory clinics have reduced the opportunity for healthcare professionals to see people in their own homes. I believe this removes a human element from care, taking the person out of context and making it difficult for healthcare professionals to truly understand the world the person lives in (Todres *et al*, 2009).

Dementia research currently prioritises looking at the early stages of the illness, even before symptoms begin to appear. Changes in the brain indicating AD can begin many years prior to symptoms such as memory loss becoming apparent (Drzezga, 2009). This heralds a more positive future for younger generations as prevention and treatment continue to develop but those who already have the disease should not be forgotten. Helping them to live with the disease and their carers to understand the experience from the perspective of the person with AD is vital to support a good quality of life for those with the diagnosis (Stewart-Archer *et al*, 2015). This will also promote the delivery of services which fit with individual needs.

The Prime Minister's challenge on dementia 2020 (DoH, 2015) has pledged that every person diagnosed with dementia will have meaningful care following diagnosis. I contend that we still do not recognize the feelings of people living with AD and unless this changes we cannot provide care which is meaningful. The current focus for healthcare professionals remains the provision of practical support, such as arranging



respite for carers and monitoring effects of medication. Despite these policies and guidelines repeatedly stating the person with AD should be listened to and care should be offered in a person centred way (DoH, 2009; NICE, 2013), caregivers often remain the priority.

### **1.3 My position**

Since qualifying as a mental health nurse in 1996 the majority of my career has been spent caring for people with dementia. From 2001 I worked as a community psychiatric nurse (CPN) for older people. My role involved visiting those people in their homes; offering advice and support to enable them to remain independent for as long as possible. For those with a diagnosis of cognitive impairment a care pathway was always followed, which provided a structured outline of anticipated care. A full assessment was completed, including physical tests such as blood tests and an ECG, to ascertain whether anti-dementia medication was appropriate. I would refer to social care services for support in the home and also complete a carer assessment.

My main aims were to ensure that the person with dementia was safe and their health maintained as long as possible. The carers of people with dementia were more often the individuals I spent time speaking with; their fears and anxieties acknowledged and dissipated where possible. I often listened to their view of the problems facing the person with dementia, rather than asking the person directly. Completing this care pathway led me to believe I was fully supporting the person with dementia. However, the carer was the person I saw as an emotional human being who required understanding and empathy. This is an approach I believe many healthcare professionals take, therefore this research will provide them with an alternative perspective to consider.

Working in my current position as a research nurse, I facilitate the recruitment of people with dementia into studies, including randomised controlled trials, observational and psychosocial studies. These are all based in the positivist paradigm, providing objective and generalisable data on the success of clinical interventions,

including medication. Whilst the benefits of this type of research are not being argued here, I question how the human element is incorporated. I suggest a more specific understanding of the lived experience of AD, especially related to receiving care, will support healthcare professionals in providing the meaningful, person-centred care government strives for. In my position as a nurse and academic, I am well placed to bring the worlds of nursing and research together, to help inform services and change the way healthcare professionals view people with AD.

## **1.4 Aim**

To understand how living with Alzheimer's disease (AD) and requiring assistance with instrumental activities of daily living impacts on a woman's sense of self.

### **1.4.1 Objectives**

1. To reveal the lived experience of receiving assistance with instrumental activities of daily living from the perspective of women with Alzheimer's disease.
2. To explore the care relationship between women and their spouses from the perspective of women with Alzheimer's disease.
3. To examine the changing role and identity of women within their relationships with their spouses and their families

## **1.5 What to expect**

This research builds on our understanding of what it is like to live with AD. In this thesis I explore the personal experiences of women with Alzheimer's disease at a time when instrumental activities of daily living (IADL's) such as shopping, cooking and housework are becoming more difficult to manage alone. I will present findings illustrating that in these mild to moderate stages of AD, the care relationship between a woman with AD and her spouse and her view of herself are experienced in unique ways.

The following chapter begins by introducing the reader to current literature concerning the experience of living with dementia from the perspective of both the person with dementia and their carer. This will provide context for my research and justify the need for this phenomenon to be further explored. Chapter three presents my chosen methodology in more detail and justifies the underpinning philosophical position taken. Chapter four describes the design and the methods used to undertake the study. Chapter's five to eight present the findings of the study, initially introducing the individual case of each woman in chapter five, followed by interpretation of the detailed meaning of becoming cared for, from the perspective of women living with AD. Finally, chapter nine provides a discussion and conclusion; presenting my reflections on the research process, implications for practice and indicating recommendations for future research in this area.

## **2 Living with AD and becoming cared for: A literature review**

To enable a comprehensive understanding of the phenomenon of becoming cared for, it is important to consider what is already known about the area under study. . Prior to the commencement of my research I reviewed the literature surrounding women with dementia and instrumental activities of daily living to discover how living with AD and more specifically how the experience of becoming cared for, is currently understood.

This chapter begins with an exploration of the lived experience of AD and focuses on how this is perceived to impact on a person's sense of self. I will go on to explore the gender perspective in relation to living with AD and finally I will draw on current understandings of the concept of becoming cared for.

### **2.1 What it means to live with AD**

Living and coping with Alzheimer's disease has been the focus of a growing number of studies undertaken over the past twenty years (Steeman *et al*, 2007, Wolverson *et al*, 2009). There is a vast difference in people's experience of dementia, which has been found to range across a continuum from 'not a big deal' to 'hellish' (Hulko, 2009). MacQuarrie (2004) terms the lived experience of AD as a tension between agency and objectification. Here an agency refers to the autonomous individual who demonstrates independence and a determination to take control of life. The objectified self reflects a disempowerment the person may feel as they transition from 'agent' to 'patient' due to their need for assistance with daily activities. These experiences are shaped by their interactions with others (MacRae, 2011). Langdon *et al* (2007) asked twelve people with dementia their views on how others reacted to them following a diagnosis. Participants showed concern that other people did not talk openly and honestly about the diagnosis, resulting in a fear those people could be talking about them 'behind their backs'. More recently research supports the promotion of agency in people with dementia confirming that independence and

freedom enables a person to experience happiness and a good quality of life in spite of a diagnosis of dementia (Shell, 2015; Stewart-Archer *et al*, 2015).

When people are diagnosed with AD, they try to adjust and experience uncertainty about the future (Harman & Clare, 2006). They develop coping strategies in the early stages in the form of self-protective strategies such as sticking to a routine to provide a sense of normality, hiding the fact that memory problems exist and relying on others. Alternatively, some people will attempt to understand the illness, talk about it openly and demonstrate a fighting spirit (Clare, 2002). Similar themes of self-maintaining or self-adjusting behaviours have been described by people with AD when managing threats to self, such as normalizing the effects of the illness or acknowledging the illness and its difficulties and creating a new sense of self (Clare 2003).

Research undertaken with people in the early stages of dementia found that an inability to perform normal functions, such as leisure activities and using the telephone could have an impact on sense of self and close relationships (Caddell & Clare, 2011). Such impacts included negative views of self, which were induced by a lack of ability to complete tasks and activities they had found easy in the past. Indeed, MacRae (2010) suggests that self-identity is likely to be questioned when illness prevents a person from performing valued roles and engaging in activities which have given meaning to their lives. In this respect people with AD have expressed the need to feel valued and to preserve some level of autonomy to help them maintain a positive view of themselves (Steeman *et al*, 2006; Svanstrom & Dahlberg, 2004). These findings present a clear indication that accepting help is difficult for people who have been independent in their activities previously. The results showed people with mild dementia being able to display signs of positivity and express feelings of being valued; however in reality there is actually a struggle to maintain that sense of being of value (Steeman *et al*, 2007).

Exploring the experience of women with AD in relation to identity, the maintenance of self is achieved through a continued connectedness with family, friends and the social environment (van Dijkhuizen *et al*, 2006). Case studies have also shown that some

women construct their sense of self by maintaining important roles, such as housekeeping (Robertson, 2013), whilst others present a positive view of themselves despite losing the ability to perform these tasks (Borley *et al*, 2014). In 2011 Caddell & Clare identified the need for further research to examine possible differences between genders with respect to changes in self and identity, as men with dementia were more confident of remaining the same person than women with dementia in their study. Further research exploring the perceived change in roles for women with mild to moderate AD has begun to emerge, however remains limited when related to the experience of becoming cared for.

## **2.2 The gender perspective**

Across the developed and developing world women are viewed as nurturers (Bamford & Walker, 2012) and the needs of others, whether they are children, partners or ageing parents, are often given priority in women's lives (McKie *et al*, 2002). There is an assumption that women will take on the role of carer and that this is perceived as natural and freely given (Ward-Griffin *et al*, 2006). Bamford & Walker (2012) have described family care as a euphemism for female care and suggest that conformity to specific gender roles due to societal pressures, has meant women, rather than men, have more often assumed the role of 'carer'. In 2011 approximately 3.34 million women were providing unpaid care across England and Wales compared to 2.44 million men (Office for National Statistics, 2013). Women are, in part, the way they are because of the way they are perceived (Oakley, 2005) and instrumental activities of daily living have traditionally been seen as feminine tasks and thus a woman's responsibility (Beagan *et al*, 2008). Socially constructed characteristics such as gentleness and sensitivity underpin the notion that women will take care of the home, whilst men will go to work.

The issue of housework as a gendered phenomenon was recognised in early research conducted in 1974 involving interviewing women about their experience of being a housewife (Oakley, 1974). For them, housework was viewed as 'work' despite some aspects of the work being enjoyed while other aspects were monotonous and socially

isolating. These women supported the gendering of domestic tasks as they felt 'real' men went out to work while women were better at understanding their children and taking care of them than men. Here, pre conceived ideas about their own gender impacted on how they viewed themselves and their responsibility. Such views may well frame how these women think about the division of labour as they age. For example, the women Oakley interviewed would now be over the age of sixty-five, potentially living with AD while attempting to maintain gendered tasks at home.

Feminine tasks, such as cooking and providing food have been documented as desired responsibilities by some women (Furst, 1997). In her study, Furst (1997) found that food was prepared by women as a gift to their husbands and families. It was an opportunity to receive positive feedback on their efforts, which gave meaning to their work and them a sense of satisfaction (Siddenvall *et al*, 2000). However, Siddenvall *et al* also found that some women saw cooking as a duty, something they had to do whether they enjoyed it or not. Despite this, as housework and caring appear to be primary factors in the social construction of femininity, women may find the loss of this responsibility problematic (Furst, 1997).

The importance of housework to women; the amount of time spent on it and the meaning women give to it has been little explored since 2005. Women may not enjoy the role of housewife necessarily (Oakley, 2005), however when that responsibility is taken away, arguably so too is their role and identity, despite a shift in attitudes to gender roles over the past 30 years. In the 1980's, 43% of people supported a gendered separation of roles believing a man's job is to earn money and a woman's to look after the home and family (NatCen, 2013), however research shows that women continue to undertake more of the housework and caring for family members than men despite more women having careers (Yee Kan *et al*, 2011). The support for gender specific roles reduced to 13% in 2012 (NatCen, 2013) indicating a change in people's views, however the backing for a traditional division of labour remains much more pronounced in older people. The reality of caring relationships now is somewhat different to those anticipated from a gendered perspective, as in the UK, men aged

over 75 are now more likely than women to be caring for their spouse (Office of National Statistics, 2005).

## **2.3 Becoming cared for**

As AD progresses it is known that certain cognitive, emotional and behavioural functions will become more difficult for the person, for example, once previously taken for granted thoughts and activities can become effortful. This highlights a clear 'slowing down' when completing tasks and holding conversations, as described from the perspective of the person with dementia (Phinney & Chesla, 2003). Instrumental activities of daily living (IADL's) such as housework, preparing meals and shopping, along with managing money and using the telephone are not as essential as basic activities of daily living such as washing, dressing and eating but they are a required aspect of life (Warner & Graham, 2012). So for people with AD, activities that once were transparent and seemingly thoughtless become conscious reflective acts (Phinney *et al*, 2003). What is currently known about how this is experienced and managed will now be discussed in relation to the person with AD both as part of a couple and as an individual.

### **2.3.1 Becoming cared for as part of a couple**

Past studies on the lived experience of AD have indicated that there is a common strategy used by people with AD to help them cope with the illness. This strategy involves a reliance on family and spouses for support and the majority of provision of care for people in the mild to moderate stages of AD living at home is reported to come from family members (DoH, 2009). As discussed in chapter one, the definition of 'care' is broad and can be defined as an emotional or physical act (Weiner & Auster, 2007). For many people with AD, care is interpreted in both ways; as practical support, such as remembering appointments and being an advocate (Preston *et al*, 2007) and emotional support in the maintenance of relationships (Wolverson *et al*, 2009). However, some acts of care, although well meant, can be interpreted by men and women with AD as a diminishment of their personhood (MacQuarrie, 2005).



The caring role in spousal relationships has been explored and is perceived as a natural part of the marital role (Paun, 2003). MacRae (2010) found that spousal support made a significant contribution to individual's abilities to live normal lives and manage their sense of self. However, past AD research has emphasised the lived experience of being cared for from the caregivers' perspective alone (Siriopoulos *et al*, 1999; Paun 2003; Perrson & Zingmark, 2006; Walters *et al*, 2010) disregarding the voice of the person with AD. This body of research points to the sense of obligation and strength of belief in marriage vows which underpins the caring relationship in many caregivers accounts (Siriopoulos *et al*, 1999; Paun 2003).

Nevertheless, relationships between couples have been found to change over time due to dementia producing a heavy burden of responsibility for both female and male caregivers (Svanstrom & Dahlberg, 2004; Walters *et al*, 2010). Becoming a burden on family due to changes in an individual's personality and functional ability is a concern for people with dementia, especially in the early stages of the illness (Snyder, 2001; Steeman *et al*, 2006). This fear of being a burden relates to expectations that another will have to provide and care for them; a concept that does not promote a positive sense of self for the individual (Svanstrom & Dahlberg, 2004). From these research studies, the concerns of the person with AD appear to be justified. This negative perception of self could affect the individual's relationship with their spouse and family. The experience of having a spouse labelled as a carer has also been found to produce a shift in personal relationships creating a feeling of disempowerment for the person with dementia (Martin *et al*, 2012).

Couples have been interviewed in a study exploring the shared experience when one spouse is diagnosed with dementia (Svanstrom & Dahlberg, 2004). The essence of living with dementia was found to be heteronomous, meaning the couple's lives were seen to be controlled by the fact that one of them was diagnosed with dementia. They were no longer able to live an autonomous life; the person with dementia unable to live without his or her spouse and this responsibility on the spouse meant they were unable to be independent either. This noticeable increase in responsibility on the

carer was stressful and the person with dementia was found to feel powerless and insecure.

As highlighted earlier in this chapter, having a level of autonomy is important to a person with dementia; however the research by Svanstrom & Dahlburg (2004) suggests they are often left to watch a spouse take over roles and tasks they once completed themselves. This situation evoked hopelessness in participants in a similar study by Robinson *et al* (2005), where some spouses made negative assumptions about the abilities of their husband or wife with AD, believing them less capable than they were. This occasioned expressions of depression and anxiety for some people with AD.

### **2.3.2 Becoming cared for as a woman**

A number of studies have been conducted exploring men and women's experiences in relation to specific IADL's. Johansson *et al* (2011) interviewed men and women with dementia about their experience of managing mealtime tasks. The findings show that people use different strategies to enable them to maintain their independence, such as reducing the complexity of meals, accepting meals-on-wheels and being supported by significant others with cooking and shopping. Despite this, being unable to complete mealtime tasks led to feelings of emptiness in some of the participants. More women than men were interviewed in this study, which could suggest the results are more indicative of women's views. The women wanted to maintain responsibility for managing meal times believing their husbands would not be able to handle these tasks. However, this view could be an attempt to help preserve the image of the woman as independent (Haak *et al*, 2007). Other than this, there was little distinction made between the experience of men and women.

Locher *et al* (2010) describe patients and carers experiencing distress surrounding food preparation and mealtime activities in cancer research. This was specifically related to the distress experienced by female patients who could not participate fully in these activities, which they felt were central to their self identity. Older women in the same

study found it especially uncomfortable to relinquish cooking tasks they had undertaken all their lives. This suggests that age, as well as illness, can impact on the experience of becoming cared for. Gustafsson *et al* (2003) also looked at food related work in relation to women with chronic conditions such as rheumatoid arthritis, Parkinson's disease and stroke. This highlighted frustration for women when their husbands failed to do things as they felt they should be done. The women were found to have feelings of inadequacy if they had to rely on others for help. They preferred to receive help from family and spouses rather than from professionals, although this still caused the women to feel burdensome.

Conversely, this sense of frustration is not seen in studies by Crist (2005) and Lysack & Seipke (2002). Crist (2005) interviewed elderly participants about receiving assistance from their families. Receiving help had positive meaning for these participants within the context of ongoing positive family relationships and maintaining a sense of control in allowing tasks to be completed for them. Lysack & Seipke (2002) found that women considered themselves healthy despite facing some form of chronic medical condition. They did not define their health on this diagnosis but on their occupational ability and they were able to find ways to compensate for things they could no longer do. The contradictory findings in these studies may be due to the experience of care being explored from different perspectives. This highlights the complexity of the concept of care discussed in chapter one and the different dimensions that influence the notion of caring (Thomas, 1993).

There is limited research on becoming cared for from the sole perspective of women with AD, who, as discussed above, are still perceived to hold the roles of homemaker and carer. The relationship between mothers with AD and their daughters exploring the experience of receiving and providing aspects of care has been examined (Ward-Griffin *et al*, 2006). The findings suggest that women with AD suppress their needs due to their daughters having families of their own to worry about and only accepting help with certain tasks such as shopping and banking. These were viewed as 'normal' chores to perform, which did not restrict the independence of their daughters. Identifying specific tasks to be assisted with enables some control to be maintained by

the mothers and supports the findings of Crist (2005). The expectation that a daughter would complete these normal daily chores demonstrates the traditional belief that these tasks are a normal part of a woman's role and also suggests the care would not create a burden for the daughter, enabling the mother to maintain a positive sense of self (Svanstom & Dahlberg, 2004).

## **2.4 Summary**

This literature review has highlighted that, as the need for care increases, the experience of living with AD involves a constant need for adjustment and development of coping strategies. Support received from a spouse or family, can on one hand assist the person with AD but can also create feelings of being a burden. The literature suggests that the experience of becoming cared for does impact on a woman's life; however there is some inconsistency surrounding how this is experienced. This is dependent on the nature of the care being received and who the carer is. There is limited qualitative research on IADL's and AD particularly focusing on the perspective of women with AD when receiving care and living with a spouse.

Therefore, this study extends our understanding of women's lived experience of AD in the context of IADL's since IADL's form an intersection between the woman, her needs and her social world. This needs to be carefully negotiated in order to enable care to be provided appropriately from both healthcare professionals and family carers. Understanding the meaning of becoming cared for from the perspective of women with AD will increase care providers understanding of the lived experience and enable more effective care delivery.

In the following chapter I will outline the methodology I have used to explore this phenomenon giving justification for my choice. The chosen methodology provides a framework for the research, which has enabled the perspective of women with AD to be heard.

## 3 Methodology

Appropriate study methodology is imperative to achieving accurate and worthwhile data (Bowling, 2002). In this chapter, I discuss Interpretative Phenomenological Analysis (IPA), my chosen methodological approach; explain the reasoning behind this choice and how it enables exploration and understanding of the meaning women with AD give to becoming cared for. In the first part of the chapter I also introduce IPA and the philosophies underpinning this methodology. Following this, I discuss the challenges involved in applying IPA as an approach and provide the reader with an insight into how those challenges were managed.

### 3.1 Hearing the voice of the woman with AD

A qualitative methodological approach was felt essential to achieve my aim of exploring the lived experience of becoming cared for from a woman's perspective. The particular paradigm within qualitative methodology however, needed further exploration and the reasoning for my decision to use IPA will be explained here. Three other major types of qualitative research were considered; grounded theory, ethnography and case study methodology and I will now explore each of these.

Grounded theory aims to generate or discover theory and has been used to explore dementia from both the perspective of the person with dementia (Genoe *et al*, 2010; Brorsson *et al*, 2011) and from caregivers (Brown *et al*, 2007). Grounded theory is used in these studies to establish processes by which experience happens, for example the process of help seeking by older husbands caring for wives with dementia (Brown *et al*, 2007) and the process of maintaining social relationships and exploring group behaviours and how this affects individual's lives (Crooks 2001). This methodology did not fit with my aim of exploring the individual lived experience of AD. I wanted to uncover the meaning women give to becoming cared for in the context of their day to day lives, rather than develop a theory on how this experience occurs. The possibility of exploring women's experience of AD in their own settings points towards ethnography.

Ethnography studies groups of people in naturally occurring settings using methods such as interviewing and observation, to capture the social meanings of ordinary activities (Brewer, 2000). It has been applied as a method to study the lived experience of people with AD in relation to subjects such as the meaning they give to activity (Phinney *et al*, 2007) and managing mealtimes (Johansson *et al*, 2011). A number of rationales for using ethnography have been provided. People with dementia have not been seen as reliable research participants due to a perceived lack of ability to communicate (Hubbard *et al*, 2002), therefore the method of observation could help the researcher to see the person in their own environment and make interpretations from this alongside interviews (Nygard, 2008). Interviewing people in the advanced stages of dementia who may have difficulty with expressive speech or thought processes and therefore be difficult to understand, would also potentially necessitate additional data (Godwin & Waters, 2009). My chosen sample (discussed in chapter 4: 4.3) were not in the advanced stages of AD and rather than exploring women's experiences as a group or culture, my aim was to understand how women make sense of becoming cared for in the context of their individual lives. For this to be achieved I needed a methodology that would assist me in revealing the individual voices of those under study. This desire to hear the voices of women with AD as individuals, led me to consider case study methodology.

Case study methodology enables an in-depth look at specific cases, single cases or cumulative cases, gaining the perspective of all people involved in the care of the person with AD, catching the complexity of a situation that gives it particular relevance (Hellstrom *et al*, 2005). Case study methodology has been utilised to explore couplehood in dementia and involved interviewing both the person with dementia and their spouse to gain an understanding of a couple's experience when one of them has a dementia (Hellstrom *et al*, 2005). The perspectives of all individuals involved in the care of a person with AD are important, however it has already been argued that people with dementia have a voice that is meaningful and should be listened to directly, rather than using carers as proxy reporters (Nygard, 2006). As a person with AD begins to decline, it is acknowledged that their capacity to grasp a situation and understand enough to create meaning from it also declines (Jacques & Jackson, 2000),

however a distinction can be made between the cognitive self, that is affected by memory and the experiencing, feeling self that is much less impaired. This necessitates a level of interpretation in order for the meaning of the experience to become visible to others, which indicates IPA as an appropriate approach.

IPA explores how people ascribe meaning to their experience (Biggerstaff & Thomson, 2008); it focuses on the meanings individuals attribute to being-in-the-world and how these meanings influence the choices they make (Lopez & Willis, 2004). This process described, is similar to symbolic interactionism, a theory that takes a small scale view of society and focuses on interactions between people. The term Symbolic Interactionism was first introduced by George Herbert Mead (1863-1931). Mead believed that anything, of which a human being is conscious, is something which he is indicating to himself.

Self-indication is a process through which an individual notes things, assesses them, gives them meaning and then makes a decision regarding the action he or she will take based on the meaning (Blumer, 1992). Mead recognised that this does not happen in isolation but always takes place in a social context. The individual is continually interpreting the symbolic meaning of their environment, including the actions of others and they then act on the basis of this meaning (Bryman, 2004; p14). This theory has been criticised as it focuses on micro-level social interactions, neglecting macro-level social structures, such as the larger scale social forces which can change human society (Barkan, 2012). However in doing this, symbolic interactionism gives the person the same level of importance as society as a whole (Blumer, 1992). It can be argued that society exists because of human interaction; therefore one cannot be understood without the other. Small interactions between individuals can illuminate how people perceive the world around them and offer explanations for behaviour. The acknowledgement of the need for interpretation and the central focus on the individual in symbolic interactionism is an important theoretical touchstone for IPA (Smith, 1996).

IPA is a suitable methodological approach for my thesis, as I wanted to explore how women view themselves and their interactions with their spouse in relation to the phenomenon of becoming cared for. As a woman begins to need help, her behaviour and interactions and those of her spouse will inevitably change. The meaning she gives to these interactions with her spouse produces her view of herself and her lived experience. IPA is now being promoted and used more in nursing research, as it allows a better understanding of how illness can affect health behaviour and lifestyles (Roberts, 2013). The process of becoming cared for occurs over time and it is over time that the processes in which IPA is interested unfold (Brocki & Wearden, 2006). I will now look in more detail at IPA and the underpinning philosophies, which make it most suitable to my research.

### **3.2 Interpretative Phenomenological Analysis**

Interpretative Phenomenological Analysis (IPA) is concerned with understanding people's experiences of life events which are of significance to them (Smith *et al*, 2009) and how individuals make sense of those experiences (Smith, 2004). IPA is an approach developed by psychologist Jonathan Smith in 1996, to enable exploration of the embodied, cognitive, effective and existential issues surrounding an experience. IPA recognizes a number of different philosophies in order to reach this goal; phenomenology, hermeneutics and idiography.

IPA incorporates phenomenology whilst highlighting the importance of interpretation and the single case. It is essentially interpretative but allows the participant to express an account from their perspective, and what the participants say has central focus (Roberts, 2013). Researchers using IPA aim to make meaning out of experiences that happen in people's lives by recognizing the unique situatedness of individuals in the world. IPA enables exploration of participants experience, understandings, perceptions and views (Reid *et al*, 2005). This involves detailed examination of an individual's personal world (Smith *et al*, 2009). Each of the philosophies combined to form IPA will now be introduced and discussed in relation to this thesis.



### 3.2.1 Phenomenology

Phenomenology is the study of phenomena; how things appear to a person and the meaning those things have. Its emphasis is on the lived world and how this is experienced by individuals at a point in time (Lavery, 2003). IPA is phenomenological as the principle focus is on individuals experience (Smith *et al*, 2009). Edmund Husserl is described as the founder of phenomenology. His goal was to understand consciousness in all its manifestations (Giorgi, 2005) and he termed the word intentionality, meaning experience or consciousness is always consciousness of something.

The way things appear in conscious experience may be different to the reality of the way things are, however Husserl was unconcerned by the reality and more interested in how an individual could come to know their own experience of things (Gallagher & Zahavi, 2012). If this could be achieved it would allow that individual to identify the essential qualities of that experience (Smith *et al*, 2009). The aim of descriptive phenomenology therefore, is to describe essential meaning structures of a phenomenon (Finlay, 2009). In order to achieve this, day-to-day activities normally engaged in, in the taken for granted world, must be examined and reflected upon. In Husserl's words, a phenomenological attitude should be adopted. This involves a process of *'retaining a wonder and openness to the world while restraining any pre understandings'* (Finlay, 2008). In order to achieve this, Husserl describes 'bracketing the natural attitude'. This means suspending prior knowledge and preconceptions of the world, to produce fresh impressions of a phenomenon.

The ability to suspend or 'put to one side' the taken for granted world, has been debated by many, including Martin Heidegger, a student of Husserl. He argued that humans are, in their existing, already caught up in the world they are thrown into and therefore cannot choose to detach themselves from it (Moran, 2000). Heidegger's major work, 'Being and Time' (1978), describes this as Dasein (there-being) and implies a degree of reflexive awareness in individuals and the essential existence of others (Smith *et al*, 2009). Heidegger's aim was to understand the meaning individuals give

to experiences in relation to the broader socio-political and cultural context rather than look for the essence of a phenomenon (Wojnar & Swanson, 2007). The philosopher Merleau-Ponty shared Husserl and Heidegger's commitments to understanding our being in the world, however he was more concerned with describing the embodied nature of our relationship (Smith *et al*, 2009). Our perception of things develops from our individual embodied perspective, meaning one person can never share entirely another's experience.

One aspect of IPA follows the core principles of phenomenology through paying particular attention to a person's individual experience and by encouraging stories to be told in the individuals own words, however it differs in techniques. IPA requires interpretation and differs from the practice of bracketing advocated by Husserl. In IPA, when engaging in analysis of a participants experience, the centrality of the researcher must be recognised (Brocki & Wearden, 2006), and it is the process of interpretation from the researcher which ties IPA to a hermeneutic perspective (Smith, 2011).

### **3.2.2 Hermeneutics**

Whilst Husserl was interested in learning about one's own experience, hermeneutics allows us to explore our engagement with the world through interpretation (Smith *et al*, 2009). Heidegger advocated a hermeneutic phenomenology arguing that Dasein, the experience of living-in-the-world, cannot be achieved without a level of interpretation (Dowling, 2007). A concept he termed 'intersubjectivity' describes our relatedness to the world and accounts for our ability to make sense of each other. He claimed the distinction between phenomenology and interpretation is that phenomenology implies the revealing of something as itself, whilst interpretation instead demands something is revealed as something else (Dreyfus, 1995 cited in Larkin *et al*, 2006). So, the appearance of the phenomenon is given more meaning by the facilitation of the phenomenologist (Smith *et al*, 2009).

It can be argued, that if you give a descriptive account of an experience, you are only offering an outside view of that experience, whereas a more interpretative approach, demonstrates the more active role the researcher can play in analysis. Central to Heidegger's phenomenological approach are sensitivity and responsiveness; any object of attention should be approached in a way that allows that object maximum opportunity to show itself 'as itself' (Larkin *et al*, 2006). The fore-structure of understanding; what an individual already knows and what they think they know due to their own socio-cultural background, are always present, however the new object or phenomenon being explored, should be given priority (Wojnar & Swanson, 2007). Some parts of fore-structure will be irrelevant, however it is only once engagement with a text begins that this may be highlighted.

The interpretative process as described by Heidegger, is a cyclical process, moving back and forth between the whole and its parts (Wojnar & Swanson, 2007). In order to understand any given part you must look to the whole and to understand any whole, you must look to the parts (Smith *et al*, 2009). In other words, the meaning a person gives to a specific experience, can become clearer when seen in the context of the life that person lives. The meaning of that life is dependent on the meaning given to individual experience. This hermeneutic circle aids the researcher when thinking about method and encourages iterative thinking about the data. In IPA a double hermeneutic is used, in that the researcher is making sense of the participant making sense of their world (Smith, 1996). The meaning individual's give to specific events is of central concern in IPA (Biggerstaff & Thompson, 2008). This commitment to examining individual perspectives draws on the third philosophy of idiography.

### **3.2.3 Idiography**

Idiography is the study of specific individuals who are dealing with specific situations or events in their lives (Larkin *et al*, 2006). IPA studies typically involve an intensive and highly detailed analysis of the accounts of a small number of individuals to gain an in-depth understanding of a particular phenomenon (Smith *et al*, 2009). The

idiographic influence commits the researcher to a thorough and detailed analysis of a particular individual in their particular context, before moving to more general claims.

Idiographic analysis is used in other qualitative methodologies, however its purpose differs. As discussed, descriptive phenomenology is utilised to find the essence of phenomena and ethnography to understand a group or culture. Although an idiographic analysis forms part of these methodologies, the aim is to understand the phenomenon as a whole. This means discarding individual concerns in favour of a more generalized view (Finlay, 2009). IPA uses idiography in an attempt to understand individual's experiences whilst also looking for similarities and differences across cases. People's lived experience of AD varies from one individual to another and therefore a case-specific approach is required in order to support the best care provision (Lloyd, 2006).

These underpinning philosophies make IPA the most suitable methodology for this research. The aim of understanding the individual meanings women with AD give to becoming cared for embeds itself within phenomenology. Adopting an idiographic analytic procedure, enabled me to move from single cases to more general statements, whilst allowing individual claims to remain of equal importance (Smith *et al*, 2009). Simultaneously, it is recognized that becoming cared for is not a solitary experience and involves others who provide that care both formally and informally. The hermeneutic element of IPA therefore allowed acknowledgment of my background as a nurse and the knowledge and preconceptions I hold, whilst helping to reveal the experience of the women in the context of their lives.

Having offered the reader an overview of the philosophies underpinning IPA and justification for choosing this methodology, I now move to the challenges involved in undertaking an IPA study. For this I return to the interpretative element of IPA and in the following parts of the chapter, I discuss the importance of critical self-reflection and reflexivity when using IPA.

### **3.3 Being aware of being**

One assumption in IPA is that human beings self-reflect (Smith, 1996). It is my intention, with the use of IPA, to explore women's self-reflection and form an understanding of their understanding of the experience of becoming cared for (Reid *et al*, 2005). The theoretical stance of IPA identifies a person as a cognitive, affective and linguistic being and assumes a connection between people's thinking, speaking and behaviour (Smith *et al*, 2009). Whilst this connection is made, it is also acknowledged to be complicated, as some individuals find it hard to express their thoughts and feelings.

When caring for a person with AD, how they think and feel in relation to what they say, their behaviour and their level of insight, requires acknowledgement and some understanding of the disease. For example, confabulation is a coping strategy which can be used by people with AD who mistake over-learned information for actual experience (Attali *et al*, 2009). One challenge for me was to acknowledge an awareness of this, reflecting on the prior knowledge and preconceptions I have, without allowing it to impact on the interpretation process. The focus of the research was on gaining an understanding of the meaning women give to becoming cared for in their world and not mine. This process of critical self-reflection, termed reflexivity, was essential to ensure the voices of the women were heard and will now be explored further.

#### **3.3.1 Being reflexive**

IPA is an approach which requires the researcher to use reflexivity throughout the process (Smith *et al*, 2009). Reflexivity is defined as

*' a theoretical, critical and analytical process, not a simplistic rendering of biography for its own sake.....based on the fact that in research the access we do and do not have to participants, the data we gather and do not gather, the questions we ask and do not ask, and the interpretations we make and do not make, are all mediated by the different identities we inhabit '* (Pini, 2004).

Reflexivity therefore involves me being fully aware of the phenomenon under study, whilst also considering my own assumptions and behaviour and how that might impact on the research (Watt, 2007). As already highlighted, hermeneutic phenomenology advocates the use of the hermeneutic circle and the need for the researcher to utilise reflexivity throughout the research process to identify pre conceptions. By using reflexivity, the researcher is viewed as *'implicated in the construction of knowledge through the stance that she assumes in relation to the observed and through ways in which an account is transmitted in the form of a text'* (Bryman, 2004; p500). As the researcher, it was important for me to be self-reflective and transparent (Lee, 2009) and acknowledge personal expectations and assumptions or bias which may have influenced my findings.

As stated in 3.2.3, the double hermeneutic in IPA reiterates the researchers involvement in the discovery of the meaning of phenomena. I played a dual role in the research process; as the participant is in-the-world, so am I, drawing on everyday human resources to make sense of the world. I am not the person experiencing the phenomena under investigation, therefore the participants reports of the experience along with my experientially-informed lens is what is required to make sense of becoming cared for (Smith *et al*, 2009).

Seeing and describing another person's experience purely as 'itself' is inevitably an unreachable target for me, as I am situated within the meaningful world that I observe (Larkin *et al*, 2006). As a younger woman and a nurse, my world is different to the women in the study, therefore accepting my prior knowledge and preconceptions was necessary in order to make sense of the participant's personal world through a process of interpretative activity (Smith *et al*, 2009). This required me to reflect on the impact I might have on gathering and analysing data (Shaw, 2010). It was also important for me to remember that in being reflexive, the focus was not totally removed from the women and the phenomenon under investigation (Finlay, 2009).

To provide the reader with knowledge of my self-reflections during the research process I have presented a reflexive account in Appendix 1. This will offer an insight into the influences my 'being in the world' had on the developing interpretations.

### **3.4 Summary**

In this chapter I have introduced IPA as the methodology I used to conduct my study. I have argued that although IPA, like all qualitative research methods, has its challenges, it is the most appropriate framework to explore the lived experience of women with AD in relation to them becoming cared for. The biggest challenge is ensuring my involvement in the process is recognised and openly expressed and using reflexivity I have identified myself as a central part of the research. The following chapter will describe the methods used to enable this study to be carried out.

## 4 Method

Having presented the chosen methodology for this study, I will now discuss in detail my study design and the chosen methods used to achieve the aims. Firstly, I will outline the design of the study, then I will explore in more detail the sample chosen to be researched, the recruitment of that sample, the method used for the collection of data, and the analysis of data. I will consider this in relation to my chosen methodology of IPA, to further demonstrate the appropriateness of the approach. Ethical considerations for this study can be found in Appendix 2 and approval was given by the East Midlands Research Ethics Committee (Appendix 3).

### 4.1 Research design

In order to understand the lived experience of becoming cared for from the perspective of women with AD the chosen study design was based on the methodology of IPA (as discussed in the previous chapter). Using IPA committed me to exploring, describing and interpreting how the participants make sense of their world (Smith *et al*, 2009). To elicit the thoughts and feelings of women on their experience of becoming cared for I chose to use semi structured interviews; a method preferred by most IPA researchers (Reid *et al*, 2005).

When using IPA, the researcher is acknowledged as part of the research process, therefore one-to-one interviews fit with this model (Smith *et al*, 2009). Semi-structured interviews in IPA allow the researcher initial control of the topic of conversation but ultimately encourage the participant to lead the discussion in the direction they want to take it. This enables exploration of spontaneous issues raised by the participant in the discussion (Bowling, 2002). When conducting a phenomenological interview the role of the researcher is that of facilitator (Balls, 2009) and the focus should be on gaining clarification and requesting examples and descriptions to ensure the participants world is entered (Jasper, 1994). IPA requires rich data and this can be obtained by offering participants the opportunity to speak freely and develop their ideas at length (Smith *et al*, 2009).



Interviewing as a method of generating data is complex in its construction (Nunkoosing, 2005) and interviewing people with AD adds to that complexity. This will be discussed in further detail in part 4.2, however taking into consideration the unpredictable nature of dementia on communicative capacities (Hubbard *et al*, 2002) I chose to conduct two interviews with each participant. The aim of this was to assist in developing rapport and empathy with the women, promoting the disclosure of meaningful experience. Asking follow up questions at a second interview also supported the credibility and dependability of the data by increasing the richness of data available for interpretation (Beushcer & Grando, 2009) and providing the opportunity to highlight any longitudinal shift in the women's perception of care. Previous studies using IPA have found this an extremely useful method of gaining an in-depth understanding of the lived experience of people with dementia as it provided an opportunity to follow up on the first interview and to collect more detail from participants (Clare, 2002; Clare, 2003). This also creates an environment that is safe and supportive for the participants, as it allows them time to consider their responses and experiences over time (Pratt, 2002).

Completing semi structured interviews provided adequate in-depth data to produce an account of each woman's individual experience, which is the main focus of IPA analysis (Larkin *et al*, 2006). This analytical process goes beyond a thematic analysis which focuses on finding patterns of meaning across participants. Different to thematic analysis, IPA interpretation occurs on two levels; firstly the participant offers their interpretation of the experience of becoming cared for and the second level occurs when the researcher attempts to understand the meaning of that interpretation; the double hermeneutic (Smith *et al*, 2009).

A considerable range of interpretation can be drawn on to achieve the generation of an insider's perspective provided the account is central to the individual and contextual (Smith, 1996). This can be influenced by a number of things including the participant's ability to articulate and express themselves. The women chosen in this study were in the mild and moderate stages of AD, meaning they may have language

difficulties as discussed in chapter one. The following part of this chapter looks at the potential challenges of interviewing women with AD.

#### **4.1.1 Interviewing women with AD**

When planning and undertaking the interviews, I had to consider issues related to interviewing women with AD. AD can affect an individual's attention and concentration; they can have difficulty with communication and show fear and anxiety (Beuchser & Grando, 2009). Despite this, there is growing evidence, as first asserted by Kitwood (1997), that a person with dementia has a sense of self, thoughts and feelings, which can be expressed. Any experience will be described in the way a person has interpreted that experience; however the ability to account for time and events in sequence is influenced by AD, even in the mild stage (Nygard, 2006). This made story telling difficult for the women on occasions but did not exclude their stories from the research, as all experiences are interpreted through individual perspectives, regardless of any cognitive impairment.

Allowing sufficient time when interviewing women with AD was imperative to elicit feelings and experiences which may be hampered by the individual's word finding difficulties (Haak, 2002). During the interviews I used the women's wording, for example 'memory problems' instead of 'AD' to ensure understanding (Beuscher & Grando, 2000). I offered reassurance as much as possible and provided cues if they appeared to be struggling (Nygard, 2006). I also redirected the conversation if repetition occurred (McKillop & Wilkinson, 2004). The collaboration between myself and the women enabled stories to be uncovered that may otherwise have remained untold (Nunkoosing, 2005). Completing the interviews in the woman's own home, where the phenomenon under discussion takes place, appeared to serve as a reminder for some and optimized the responses of three of the women who used the room we were sitting in as reference when talking about housework.

During the interviews, attention was paid to the positive things each participant could achieve along with those they now struggle with, to create an approving and

optimistic atmosphere (Pesonen *et al*, 2011). I was able to draw on my nursing skills during the interviews and being aware of the unpredictability of AD (Beuscher & Grando, 2009), I was able to approach each interview with a flexibility and the ability to improvise when the women appeared to lose focus of the conversation (Nygard, 2006).

To ensure the interviews being undertaken would deliver sufficient rich data for analysis it was deemed appropriate to complete a pilot interview prior to the commencement of the study. This was done to ensure the suitability of the questions devised and enable me to familiarise myself with my role. The questions needed to be clear, understandable and provide the required data focusing on the women's lived experience of becoming cared for (Gill *et al*, 2008). The analysis of the pilot interview was written up as a case study for publication (Appendix 4).

#### **4.1.2 Pilot interview**

The pilot interview was conducted with a woman of 84 years, with a diagnosis of mild Alzheimer's disease. Prior to the interview I devised an interview schedule (Appendix 5) following guidance from Smith *et al* (2009) who advise that questions should develop in complexity and sensitivity as the IPA interview progresses. The aim of this was to facilitate a comfortable interaction with the participant to encourage analytical thought and expression. Therefore, the interview schedule began with basic questions of 'Tell me about yourself?' and 'Tell me about who did what in the household when you first got married?' These questions were asked in order to gain an understanding of the woman's lived world, prior to the AD. The questions developed to explore more complex issues, such as 'Tell me what has changed in you since your diagnosis?' and 'How do you think the need for help has changed how you think of yourself?' to understand the meaning she gave to her current experience.

To gain the depth of data required, open-ended questions were necessary, however phrasing those questions to avoid complex concepts and provide clear sentences was also important (Lloyd *et al*, 2006). Poorly expressed questions within an interview can

be misinterpreted or lead to confusion in people with AD (Lloyd *et al*, 2006) and the pilot interview demonstrated the need to introduce topics such as, asking about roles in the household in more concrete terms, before exploring the meaning of the experience in more detail. It was felt this would enable a fuller description of the lived experience to be presented (Nygard, 2008).

During the visit, I was continually aware of the woman being interviewed and her overall experience (Nunkeosing, 2005). My role as researcher differs greatly to that of nurse and I was conscious that my relationship with the woman and my interactions would influence her responses in some way (Wimpenny & Gass, 2000). In an attempt to avoid this happening I introduced myself as a nurse researcher and clearly explained my role during that visit. This was the first research interview conducted by myself and although my background as a community psychiatric nurse had provided numerous opportunities to complete clinical interviews with people with dementia, this was a new and challenging prospect. Research interviews require a more fact based, neutral enquiry in comparison to clinical interviews in a psychiatric setting (Targum, 2011). Despite there being similarities in the conduct of an interview, such as employing similar interpersonal skills, the intention in an IPA research interview is to listen in order to acquire more knowledge about the research subject and not to offer any form of advice or help (Gill *et al*, 2008). Employing this behaviour assisted me in maintaining my role as researcher, rather than creating a potential power differential due to my nurse status (Balls, 2009).

Reflecting on the pilot interview, slight changes were made to the interview schedule to assist my exploration of the women's experience (Appendix 6). I was very aware of the need to delve further into the feelings and experience of the women, specifically related to their perceived role in the home. Therefore, questions were simplified using more concrete terms such as 'Tell me about a day in your life when you were first married? And 'Tell me about who did the housework, shopping, cleaning?' I also added prompts, for example 'tell me more about that' and 'how did that make you feel?' to encourage the women to expand on topics of interest.

Throughout the pilot interview I acknowledged feelings of anxiety in myself due to the change in my role from nurse to researcher. To help manage this anxiety I used a reflexive diary to document my experiences. I read more on practical approaches to interviewing people with dementia for research purposes and discussed the interviews with my supervisors. This enabled me to develop and improve my interview technique and build my confidence in undertaking further research interviews. Following the pilot interview and subsequent changes to my interview schedule, I began the search for women to take part in my study. The methods used for this and how my final sample were chosen will be discussed next.

## **4.2 Recruitment**

There is growing evidence of public demand for research (Association of Medical Research Charities, 2011); however recruitment to dementia research can be problematic due to the complex nature of studies such as randomised controlled trials (Marcantonio *et al*, 2008). These often involve lengthy clinic visits and invasive procedures such as MRI scans and lumbar punctures. There is also still a belief that people with dementia are unable to communicate their lived experience (Nygard, 2006).

Research networks were set up in the UK to promote recruitment to high quality studies and enable staff working in those networks to embed themselves within hospital trusts gaining access to people who would fit the criteria for specific studies, such as dementia (DoH, 2014). As a member of a Clinical Research Network, I have access to my employing Healthcare NHS Foundation Trust research interested database. This database holds the details of patients with dementia and their carers who have expressed a wish to be contacted about potential research studies. This wish is expressed to their clinical care team who then pass their details onto the local research team. If at any point a person expresses the desire to be removed from this list, this is done so immediately and a note put on their electronic patient record stating they are not interested in research.

Potential participants were identified via the Trust research interested database and I also attended community mental health team meetings to inform teams about the study. Teams were asked to refer any potential participants to the research interested database. Possible participants were then screened via the electronic patient record and through their clinical care team for any potential issues that could exclude them from the study, for example a patient currently showing signs of agitation or depression due to diagnosis or worsening of symptoms. A letter was sent to all patients' interested in hearing more about the study, including an invitation letter (Appendix 8) and full participant information sheet (Appendix 9). The invitation letter stated that I would contact them in a week's time to see if they were interested in taking part and to answer any questions they may have. If the patient and carer were happy, an appointment was made but if more time was required, I arranged a convenient time to make contact in the following week. If a patient or carer stated they did not wish to take part, no further contact was made regarding this study.

### **4.3 Sample**

When considering the sample required for this study I needed to ensure the participants would be able to give me access to the perspective of the phenomena of becoming cared for (Smith *et al*, 2009). Below is a list of the final criteria chosen, which is followed by a discussion of the rationale for these choices.

#### **4.3.1 Inclusion criteria**

- The participant must have been given a diagnosis of mild to moderate Alzheimer's disease as categorised by the Mini Mental State Examination (mild 26-21 moderate 20-11, Folstein *et al*, 1975)
- The participant will have capacity to give fully informed consent.
- The participant must require assistance with a minimum of three instrumental activities of daily living as categorised by the Lawton scale of IADL's (Lawton *et al*, 1969).
- The participant must have a spouse who is happy for the person to be interviewed.

- The participant must speak English and be willing to be interviewed.
- Each participant will live in the community with their spouse.

#### **4.3.2 Exclusion criteria**

- The participant cannot speak English/no longer speaks English.
- The participant has any other diagnosis of dementia or symptoms that may indicate a dementia type illness, but is not Alzheimer's disease.
- The participant's carer is not happy for the participant to be involved in the project.
- Participant care is received from the Younger People with Dementia Team.
- The participant's main residence is a nursing/residential home.

#### **4.3.3 Sample rationale**

I chose to interview women for this study due to the previously discussed relationship between women's perceived responsibility for completing IADL's within the family environment and the increase in women now being diagnosed with AD (Shriver, 2010). To truly understand how this is impacting on women's lives I focused specifically on them and their experience.

The age distinction was made as AD is rarely diagnosed in those under the age of 65 (Warner & Graham, 2012) and the social and family context may be different in this age group (Beattie *et al*, 2004). In IPA it is suggested that if five or six participants are recruited this will provide sufficient data to develop meaningful points of similarity and difference between individuals (Smith *et al*, 2009). I decided upon eight due to the nature of cognitive and language difficulties which are common in AD and restrict some people's ability to express themselves. The risk of using smaller numbers was that the data would be limited to superficial description with a lack of depth (Nygard, 2006).

Participants were recruited using purposive sampling, as the nature of the research question required each participant to be at a specific stage of their AD (categorised by Mini Mental State Examination scores: mild to moderate Alzheimer's disease 26-11, Folstein *et al*, 1975). The Mini Mental State Examination (MMSE) has been used as a screening tool for dementia and AD for many years and is used in clinical practice in the recruiting NHS trust (Appendix 10). The validity of the MMSE has been questioned when using it to assess a person's suitability for drug treatment in AD due to inconsistency of scoring (Davey & Jamieson, 2004), however it is widely used to screen for cognitive impairment in older people. The NHFT Electronic Patient Record holds up-to-date records of individual patients and their MMSE scores. MMSE's were accepted if they had been completed by NHS staff within the past twelve months. The annual rate of progression of AD has been found to be between two and four points when using the MMSE (Sarazin *et al*, 2007), which suggests even if the women's MMSE had dropped four points they would still have remained in the mild-moderate category chosen for this study. Three women were in the mild category and five in the moderate category.

AD was chosen as it is the most commonly diagnosed of all the dementias (DoH, 2012) and although people with AD are individuals, there are commonalities in symptoms as described in chapter one, which created as homogeneous a sample as possible. The aim of the study was to explore the experience of women with AD. As people with mild and moderate AD have been found to be able to contribute to research in a meaningful way (Cahill *et al*, 2004), it was felt appropriate to include women in both categories.

Having identified the area of study of becoming cared for with respect to IADL's, I had to use a scale to determine the women's ability to complete these in order for them to meet the criteria for the study. This would enable me to ensure that I included only those who were already having problems with some areas of daily functioning and needed assistance from their spouse. Lawton *et al* (1969) produced a scale which can be used to assess change over time (Lawton & Brody, 1969) but it has also been found useful in demonstrating current level of functioning (Graf, 2007) and has been used



extensively in dementia research (Phinney & Chesla, 2003). The scale covers eight domains; using the telephone, shopping, preparing food, housekeeping, doing the laundry, using transportation, handling finances and managing medication (Appendix 11). In this study I used the scale to confirm that there were limitations in the women's ability in at least three of the domains to enable worthwhile discussion to be held and meaning to be given to this change. A score of one in each domain would mean the person was managing that particular task with no problems, therefore in at least three of the domains a score of zero was required.

I evaluated the women's abilities by reading assessments completed by memory clinic and community mental health team staff. The NHFT Electronic Patient Record documents current assessment of each patient and through this I could clearly identify problems in the domains described by Lawton *et al* (1969). I also confirmed that potential participants required help with these IADL's when I discussed the study with them and their carers on the telephone and face-to-face.

#### **4.3.4 Final sample**

Using the research interested database and screening for possible participants, two hundred women with a diagnosis of AD were found. Fifteen of those women met the inclusion/exclusion criteria; six declined involvement when approached by clinical staff. The resulting participants were women aged 74-84 with a diagnosis of AD and mini mental state examination scores ranging from 16-26. All were white, from the UK and all had worked in some capacity during their adult life. Participant demographics are detailed in the table below. Participant names have been changed to ensure anonymity.

	<b>Participant name</b>	<b>Age</b>	<b>MMSE score /30</b>
<b>1</b>	Jean	77	15
<b>2</b>	Ruby	74	26
<b>3</b>	Edith	83	22
<b>4</b>	Margaret	74	19
<b>5</b>	Phyllis	78	18
<b>6</b>	Dorothy	74	19
<b>7</b>	Betty	82	26
<b>8</b>	Ann	83	15

**Table 1** Participant demographics

#### **4.4 Data collection/procedure**

Informed consent was gained from each woman prior to the interviews taking place (Appendix 9). Fully informed consent denotes the person must be given all of the information in terms of the nature of the research, including any benefits and risks, whilst understanding that they can withdraw at any time should they choose, without this affecting their care in any way. I was aware that each individual's ability to understand information related to my study could be different (McKeown *et al*, 2010), therefore further clarification of the research was given prior to the consent process, if it was necessary. All the women who were approached were deemed capable of consenting themselves and were happy to take part knowing the study was related to AD.

Two interviews were completed with each woman within four weeks of each other. As stated in 4.1, this was to support the maintenance of the relationship between them and myself enabling the collection of quality in-depth data. Each interview was booked at a time that suited the individual and the researcher made no other appointments on the same day, to ensure there was no pressure on either party. Where possible, I made the appointment for the second interview as soon as I could after the first. Seven of the eight women were interviewed within the four weeks; one woman was interviewed with a gap of six weeks due to a pre-booked holiday shortly

after the first interview. All participants stated they recognised me at the time of the second interview and were more than happy to talk to me again.

The second interviews were based on the stories and experiences the women had described the first time I interviewed them. The questions were developed following transcription and initial analysis of the first interview, so were different in each case. An example of interview questions asked at the second interview can be found in appendix 7. In total sixteen interviews were completed. The interviews were all undertaken in the women's homes, as this provided a comfortable environment and allowed the participants to feel more relaxed (Holloway & Wheeler, 2012). I attempted to interview each woman in a room with little distraction, although this was not always easy as I was a guest in their home.

The length of each interview was not stipulated, as it was dependent on the participant and the particular experiences they chose to impart, however the total combined time for the two interviews in each case was 60-130 minutes. The second interviews were shorter in length in all cases but were found to be beneficial to data collection due to the consistent nature of the information received. This provided confirmation of the credibility of the women's experiences (Lloyd *et al*, 2006) and demonstrated trustworthiness in the data (Nygard, 2006). Topics explored included the women's experience of daily life following their diagnosis, how they felt about their ability to manage tasks now, compared to when they were younger and how this influenced their relationship with their husband. All participants agreed to their interviews being tape recorded for analysis.

The aim of the interviews was to provide a first person account of the experience of becoming cared for by women with AD. To achieve this, it was decided that the interviews would be undertaken with the participant alone, as although carers can be valuable contributors in dementia research (Pratt, 2002), the nature of the phenomenon of care relationships could have involved sensitive discussions about the informal carer. I wanted to ensure all the participants felt comfortable to

communicate fully on the subject (Cowdell, 2006). Each couple who were approached about taking part agreed to this with one exception (See 5.8).

Following the pilot interview and changes to the interview schedule, subsequent interviews proved to elicit more in-depth information from the women in the main study. However, as further interviews took place I was also aware of the developing confidence in myself and my behaviour during the sessions. As discussed earlier in this chapter, the conduct of the interview has a bearing on information gathered (McKillop & Wilkinson, 2004). I was aware that building relationships and rapport with participants with AD was essential to obtaining good data (Smith *et al*, 2009). Utilising nursing skills such as, effective communication, active listening and empathy, assisted me in developing a relationship which promoted trust and openness in the women (Haak, 2002). Accepting hospitality, showing gratitude and retaining a personal interest by remembering things from the first to the second interview were also effective approaches during my time with the participants. This self awareness and sensitivity shown to the women also aimed to promote the credibility and quality of the data (Pesonen *et al*, 2011).

Following completion of each visit the interviews were transcribed verbatim from the recordings made. Field notes were written directly after each visit detailing observations of body language and interactions between husband and wife, to assist in contextualising the women's thoughts and feelings and to ensure aspects which may not have been captured on tape, were available for analysis. This helped with analysis, as actions can make meanings explicit and the participant may not have been consciously aware of these things (Nygard, 2006). How the data was analysed will be discussed in the following part of this chapter.

#### **4.5 Analysis and interpretation**

The data gathered from the interviews was analysed using the guidelines outlined by Smith *et al* (2009). Firstly the data collected from individual interviews was read and reread and initial notes were made under three headings; description, language and

emerging concepts. A sample transcript and process of interpretation can be found in Appendix 13. The objective during the initial stage of analysis was to achieve an account from the participant, which was constructed by the participant and myself to form a third person account, getting as close to the participants view as was possible (Larkin *et al*, 2006). These notes were discussed between myself and my supervisors and challenged until I was happy with the developing emergent themes.

The next step was to explore connections across the emergent themes and create super-ordinate themes or key experiences; the aim being to develop the interpretative analysis, setting the participants description of her experience in the wider social, cultural and theoretical world (Smith *et al*, 2009). Both interviews for each participant were analysed as one and this was repeated with all individual cases and the themes and key experiences drawn from the transcripts and field notes can be found in Table 2 (pg 43-45). Following this, patterns across cases were identified and master themes were developed (Table 3, pg. 46). As interviews were undertaken at two separate time points, I have indicated whether quotes were drawn from interview one or interview two within findings chapters six, seven and eight (Interview 1, Interview 2).

#### **4.5.1 Returning to reflexivity**

In IPA, acknowledging oneself as a part of the research is an essential element in the process (Smith *et al*, 2009). Discussing findings with participants following analysis has been a way of reducing researcher influence during the interpretative stages of a study (Jeanfreau & Jack, 2010), however in this case, the participants memory deficit was felt likely to impair their recollection of the interview and was therefore not undertaken (Lloyd *et al*, 2006). I have discussed the importance of reflexivity in the previous chapter, however I feel it is important to reiterate that I employed an iterative approach during the analysis stage to ensure I continually returned to the voice of the women (Smith *et al*, 2009).



PARTICIPANTS	THEMES	SUPER-ORDINATE THEMES (Key experiences)
<b>MARGARET</b>	<p>View of self/view of world  Decision maker  A woman of standards  Positive view of self through activity.  In control  Self as unchanged  Sense of value and worthiness - Busy doing nothing  Decision maker – change of role.</p> <p>Assessment/reflection on life and what is important  Freedom from responsibility  Contentment  Detachment  Unworried  Enjoyment of new role.  Changing priorities  Being free of expectation</p>	<p>Contentment</p> <p>Liberation</p>
<b>DOROTHY</b>	<p>Move from central position to outer circle of family  Feeling surrounded by family  Sense of claustrophobia  Feeling left out  Being left behind  Understanding the burden but feeling restricted  Being involved – being active</p> <p>Battling  Struggle  Rebelling  Being told what to do as a child/Being treated like a child  Feeling stupid</p> <p>Change to self  Feeling/being normal  Expectation  Feeling valued  Loss of freedom/independence  Being in control  Maintaining self</p>	<p>Belonging</p> <p>Disempowerment</p> <p>Loss of self</p>
<b>PHYLLIS</b>	<p>Identity – who she is  Changing self creates a negative view of self  Experiencing fearfulness  Showing weakness  Helplessness  Being in control/ loss of control  Purposelessness  Feeling like a child</p> <p>Hiding her true feelings  Being grateful  Thinking of others  Putting others first</p> <p>Loss of freedom and independence  Taken over  Loss of togetherness  Feeling useless</p>	<p>Losing oneself</p> <p>Never saying no</p> <p>Being taken over</p>

PARTICIPANTS	THEMES	SUPER-ORDINATE THEMES (Key Experiences)
<b>BETTY</b>	<p>Capable woman who still wants to be seen as capable            Husband helping does not affect this.            Having/making the choice            Behaviour of others helps her maintain her sense of self            Acknowledging change            Feeling lucky</p> <p>Togetherness vs independence            Perception of togetherness  <i>'He's my prop'</i>            Reciprocal caring</p> <p>Happy accepting outside help            Contented. Happy            Safety of home</p>	<p>Maintenance of self</p> <p>Togetherness</p> <p>Contentment</p>
<b>ANN</b>	<p>Togetherness            Supported            Togetherness            Adapting            Security            Reliance on others</p> <p><i>'I was somebody'</i>            Sureness            Can still achieve            View of self            Feeling pride            Still the same person</p> <p><i>'What will be will be'</i>            Feels lucky            The black side  <i>'What you can't change you've got to accept'</i></p>	<p>Togetherness</p> <p>Contentment</p> <p>Positive acceptance</p>



<b>Table 3 Master themes from all participants</b>	
<b>SUPER-ORDINATE THEMES</b>	<b>MASTER THEMES</b>
Togetherness  Takenoverness Disempowerment Taking over Loneliness	'It's a togetherness'
Being me Loss of self Losing oneself Maintenance of self Never saying no Loss of trust  Doingness Being valued Belonging	Me being me
Liberation Contentment Positive acceptance	Seeing cobwebs

## **4.6 Summary**

This chapter has described the design and methods used in order to carry out my study. I have offered a discussion around issues related to undertaking IPA research and more specifically interviewing people with AD. I used semi-structured interviews to gather data, and the guidelines for analysis suggested by Smith *et al* (2009) were followed producing individual experiences and shared themes. This method of analysis ensured my research focused on making sense of the participant making sense of their experiences, whilst ensuring the wellbeing of all the women was maintained throughout the process.

The following chapters present my findings. The first will provide the reader with an introduction to the women who took part in the study. In line with IPA, I will offer an individual analytical view of each woman's experience before moving on in subsequent chapters to explore key experience's found across cases.

## **5 The lived experience of becoming cared for**

This chapter presents an analytical view of the individual women who were involved in this study. In line with the holistic principles of IPA, the everyday lived experiences of the women and the ways in which these are individually inscribed with meaning is important to understand. This chapter therefore, offers an insight into each woman's life; who they are, what is important to them and their individual experience of becoming cared for.

### **5.1 Jean**

Jean is 77 years old. She was diagnosed with AD five years ago and now scores 15/30 on an MMSE indicating a moderate AD. Nevertheless, she demonstrated insight into her condition throughout the interviews. She grew up in a village with her mother and step father and one sister. She revealed that her paternal father died following an accident when she was very young; however she got on well with her stepfather. She did not have such a good relationship with her sister who she has not heard from for many years. She and her husband have been married for fifty-six years and they now live in a house that they built. They had no children but Jean did not expand on this or the reasons why.

From her description it appears that Jean and her husband lived fairly independent lives throughout their marriage. He enjoyed sport and went out to play golf a lot, while she spent her time in the home. He worked for himself, which kept him away from the house for long hours. Jean took responsibility for looking after the home, doing all of the cooking and cleaning. She enjoyed crochet and sewing; making herself all her clothes when she was younger but she does very little of this now, justifying that it is not needed as people buy clothes more these days.

She depicts her husband as a perfectionist who wants everything done in a certain way and this is becoming much harder for her to achieve as she gets older and more

cognitively impaired. She often remarked on her level of intellect during her interviews using words such as 'stupid'.

Jean talked with a fondness about growing up and her early married life. She remarked that she was happier then than she is now and stated she would like to go back to living in her old house. She talked about having a routine and knowing what her responsibilities were then. This routine may have offered Jean stabilization in her world and given her a sense of identity. As she reflected on the changes that had occurred due to her diagnosis it appeared she was fighting to remember who she was as an individual, prior to the AD.

Jean acknowledged several times during the interviews that she understood that she needed help and praised her husband's ability to manage the IADL's. However her experience of receiving this help causes her frustration, sadness and sometimes anger as it destabilizes her routine and her identity. This is further explored in chapter seven, Me being me.

Jean's experience is greatly affected by her husband's behaviour towards her. The perfection that she felt her husband expected throughout their marriage was a standard she had always previously managed to maintain. Although she continues to strive to meet those standards, she claims her husband now often takes over the jobs around the house. She explains his need to take over by putting herself down and stating he has always been cleverer than her. She feels he does the IADL's now because he can do them quicker and better than her and he is not prepared to give her the time to try. Jean experiences this as a loss of self, as she tries to hold on to who she is and her position in her relationship. She expressed anger towards her husband at times because of his perceived lack of patience with her. She also expressed anger towards herself, stating she should not be so stupid.

The description Jean gives of her husband taking over the IADL's in their house affects how she feels about him and herself. She does not feel cared for despite him completing all the IADL's. She feels that her husband is doing the household jobs as a

means to an end; he needs to eat so he cooks, he needs clean clothes so he washes. Her sense of value as a woman has been lost, as she is hanging on to a memory of who she was prior to the AD and what she was capable of. This experience of feeling 'taken over' will be expanded upon in chapter six, Togetherness.

## **5.2 Ruby**

Ruby is 74 years old. She was diagnosed with AD four years ago and now scores 26/30 on an MMSE indicating a mild AD. Although she acknowledged that she has the diagnosis of AD she showed partial insight into the meaning of this and how it was affecting her abilities. She was not aware of her need for help with certain aspects of her life now.

Her childhood was spent living with her aunt for many years following the death of her mother. She was unable to remember how old she was when her mother died but stated she was very little at the time. Her father eventually remarried and she was able to move home to him, however again she does not remember much about this time. She stated she was a young woman of independence and keen for adventure and when she was given the opportunity to work abroad, she took it and moved away. She and her husband lived abroad for the first six years of their marriage and had one son. Whilst living abroad they had busy jobs and so servants helped with the housework, shopping and cooking. Ruby and her husband returned to the UK and Ruby got a job as a home carer. She enjoyed this work until she retired. She was always involved in local groups; attending Women's Institute (WI) meetings and other similar groups, however she no longer attends these with such regularity. She now stays at home and does not go out much unless with her husband.

Ruby described her relationship with her husband as one of 'togetherness' and talked of their life as a sharing of responsibilities ever since they were first married. She did not see herself as a housewife who took responsibilities for the IADL's and had become accustomed to others doing those things for her whilst she lived abroad. Having worked as a paid home carer herself, she may also view caring tasks as part of

an employment role rather than a personal responsibility. This view appears to assist her in maintaining a positive sense of self and will be discussed in further detail in chapter seven.

She stated that her husband now makes the bigger decisions for them, for example financial decisions, however this does not pose a problem for Ruby. She maintains a sense of independence and activity as she continues to make decisions about small things she does, for example choosing to go to WI. This helps her to believe her AD is not having a huge impact on her life. Her experience of becoming cared for gives her a sense of being valued and supported by her husband. She expresses that she relies on him for certain things now but this is an expected part of life when you feel the closeness Ruby feels with her husband. Ruby sees him helping more around the house but he has retired so this makes sense to her. She explains this change less in terms of her becoming unable but because his life has changed. Ruby believes she can still complete most IADL's and what appears to contribute to this belief is a sense that her husband and family are close by if she needs them. The conviction that if she required help, her family would immediately support her, gives her confidence to do the things she does, whether she does them well or not. Throughout the interviews the overarching experience Ruby expressed was of feeling being cared for emotionally, not just physically and this will be discussed further in chapter six.

### **5.3 Edith**

Edith is 83 years old. She was diagnosed with AD four years ago and now scores 22/30 on an MMSE indicating a mild AD. Edith disagreed with her diagnosis of AD, stating she could not remember anyone telling her she had it. She had no insight into her lack of abilities.

She grew up with her mother and father and one sister. She spoke very fondly of her mother, who died when Edith was a teenager. Edith blames this on others putting too much pressure on her mother, who she said 'worked herself to death'. She stated on a number of occasions that she was '*not going to go the same way*'. Edith met and

married her husband and revealed that her first child had been stillborn, so her second child was very special to her and her husband.

Their daughter was a central focus for Edith and she felt very strongly about how she should be brought up. In early adulthood their daughter had a car accident resulting in her moving to a specialist home due to a debilitating head injury. Edith and her husband spent long hours at the home and she died before she reached the age of thirty. This was a huge loss for Edith who had focused her time on caring for her daughter.

Edith worked all her life and had fond memories of her secretarial jobs. She talked of good friends she met during her working years and of high standards in her work. Following retirement Edith volunteered as a visitor for older people who were unwell and spent many hours sitting with elderly villagers. She found this rewarding whilst also giving her a sense of thankfulness that she was healthy. Edith talked at great length about dogs she had always owned and her love of these was evident. She would take them for regular walks with a friend who also lived in the village and this created a social network for her. She complained that she no longer has dogs and misses them greatly but her husband refuses to have any more. This was a decision which, she stated, was made without her input and about which she was angry. Edith was a very independent lady who also enjoyed taking care of the home, doing the shopping and cooking for the family. She took responsibility for the home finances and expressed pride at her ability to do so effectively.

Her experience of becoming cared for produced feelings of anger and confusion in Edith. She blames her husband for the changes in her life stating that he now does all the IADL's and the responsibility for running the house and managing the finances, which she was very proud of, have been taken away from her. The anger is experienced by Edith due to her belief that this change was not discussed with her and that her husband just started doing everything. She feels she must have done something wrong to have brought about this change, however she has no idea what this could be. This experience has had a huge impact on how Edith now views her relationship with her husband. She spoke of having a lack of trust in him and believes

he can have no trust in her if he feels he needs to take on her responsibilities. Despite her husband doing more for her, Edith's experience of becoming cared for is one of a sense of loneliness. Questioning the strength and longevity of their marriage, she talks of preferring to live apart than live with the current situation. Chapter six will explore this experience for Edith.

During Edith's life she has always wanted to care for others; she misses her daughter greatly and expressed that she always wanted a bigger family. This did not happen, however she found ways to care by involving herself as a 'sick visitor' and by owning dogs. She believes she is no longer the woman she was and her sense of self is diminishing as her husband assumes her place in the family and their relationship. This caring role and how it defines Edith is discussed in chapter seven.

#### **5.4 Margaret**

Margaret is 74 years old. She was diagnosed with AD five years ago and now scores 19/30 on an MMSE which indicates a moderate AD. Although her initial presentation was of someone in the more advanced stages of AD she showed a good level of insight into her diagnosis and her ability to complete activities.

Margaret stated she had a good childhood, living with her mother, father and one sister. She qualified as a nurse at a young age and worked as a district nurse for many years. Margaret revealed that her father was diagnosed with AD as he got older, although she was unable to elaborate on this with regards to any care he received or who provided that care. She and her husband live in the UK having spent a couple of years living abroad where she continued to care for people in her nursing role and they have two children. On returning to the UK, Margaret and her husband took on the management of a nursing home, caring for people with dementia and ran this together until they retired. Margaret stated she was a very particular lady, with high standards for herself and her residents; she was not happy unless they had the best of everything. She worked long hours to ensure her standards were met and also took



responsibility for managing her own home; cooking, cleaning and bringing up her children.

Margaret now spends her days sitting in a chair in her conservatory watching what goes on outside. She enjoys watching the birds and waving to people who are out walking their dogs across the fields.

Throughout the interviews Margaret demonstrated a cheerful disposition and a good sense of humour. She claimed to be unworried about her diagnosis and the changes that were occurring for her and her husband. This may be due to her prior knowledge of AD and its effects on her father and the people she cared for. The life she leads now differs greatly from the one she had prior to her diagnosis; she no longer works long hours and the standards of cleanliness she used to set for herself appear to have no importance in her life anymore. Her view of things she used to find stressful, for example keeping the house free of cobwebs, are of little bother to her. In fact she can now see beauty where she did not see it before. Margaret experiences contentment in doing very little and seeing her husband doing the IADL's reinforces her sense of value in the relationship. She feels worthy of his care and expressed a positive sense of self stating she is happy for him to do things now because she has *'taught him well'*.

Her experience of becoming cared for gives her time to enjoy the simpler things in life and she feels no compulsion to do anything other than sit in her chair and knit. This experience of liberation, brought about by the change in her, will be discussed further in chapter eight, Seeing cobwebs.

## **5.5 Dorothy**

Dorothy is 78 years old. She was diagnosed with AD three years ago and now scores 18/30 on an MMSE indicating a moderate AD. Dorothy showed a good level of insight into her diagnosis and the problems this causes and could continue to cause in the future.

As a young girl she was responsible for taking care of her younger siblings while her mother and father went out to work. This meant she developed a very strong bond

with her siblings who still live close by and who she talked about frequently when we met. She met and married her husband and they had one child. Dorothy and her husband had their own interests during their marriage; her husband enjoyed sport and she spent time socialising with her sister and looking after her child. She also took responsibility in the house; shopping and cooking. She described a happy marriage and stated her husband is responsible for the hoovering, which he has done every Sunday morning since they married without fail and continues to do now.

She described herself as the person everyone used to rely on for advice and support and she talked of regularly having family and friends drop into her home. Her family is central in her life; she continues to see her sister when she can and her grandchildren and great grandchildren visit regularly. Despite the happy life Dorothy portrayed, the themes drawn from her interviews of her experience of becoming cared for focused on a negative change in her life. Dorothy talked of her experience as a mounting frustration. She still has a strong sense of who she wants to be and what she can still do as an independent woman, however her family is trying to protect her by removing any responsibility for the home from her. She is fighting to retain her sense of self and her right to make decisions about her life. Dorothy is aware of why her husband is doing more around the home and why she is being discouraged but she is struggling with a sense of claustrophobia and disempowerment and a need to feel normal in light of this behaviour.

Dorothy describes her experience as a role reversal explaining that she is often made to feel like the child in the relationship when she is not allowed to make decisions for herself. Her husband and family try to help by doing everything for her but this highlights to Dorothy that she is no longer the person she was and is not viewed as the same by her family anymore. This causes mixed emotions, as again she appreciates what they are trying to do, nevertheless the loss of responsibility influences how she feels about herself. It also impacts on her relationship with her husband and Dorothy describes becoming angry with him at times, which she states is not like her.

Dorothy portrays herself as the family member who everyone comes to for help and her position in the family has always been central which has given her a true sense of

belonging. She is now finding that this is happening less and sees people approaching her husband instead. She questions why this is happening and describes the experience as feeling left out.

## **5.6 Phyllis**

Phyllis is 74 years old. She has been diagnosed with AD for four years and scores 19/30 on an MMSE indicating a moderate AD. Phyllis was very aware of her diagnosis and of what this meant for her and her family and showed great concern for her husband and his ability to deal with what might happen as the illness progressed.

She had a happy childhood; talked of many happy hours discussing and debating issues as a family, which continued throughout her adult life too. She remembers a mother who would entertain her and her three siblings by singing and dancing and a father who was a hard worker. She met and married her husband and they have two children and two great grandchildren. She was a very independent, well educated woman who worked all her life and looked after her children and the home. Her work involved caring for children and for many years she managed a residential care home for children with difficult behaviours. She spoke with fondness of this time and expressed a sense of satisfaction when one of 'her children' left the home to get on with their lives.

She stated that her and her husband had a good marriage; they spent time travelling and enjoyed each other's company. The enjoyment she described of discussions and debates she had with her family was also evident between her and her husband. They continue to go out together at times whilst Phyllis also sees her daughter regularly. Phyllis describes experiencing a change in herself and in her relationship with her husband since her diagnosis of AD. She is becoming more reliant on him which makes her feel useless. As an intelligent woman she tries to understand her new self but has difficulty seeing anything positive in herself now compared to her previous 'capable self'. She is fearful of the future and expresses a sense of inevitability to her life that she has no control over.

Phyllis' main concerns involve her husband and how her needs will impact on him. Becoming cared for in her world means she becomes indebted to her husband, as the burden she perceives she is becoming intrudes on the life he thought they would have. This has led to Phyllis hiding her feelings from her husband and allowing him to make the day-to-day decisions related to the activities they do, the food they eat, even the television programmes they watch. Her experience of becoming cared for is about ensuring that her husband's life is made as easy as possible and this will be discussed in more detail in chapter six.

Despite her husband doing more of the IADL's now and therefore caring for her, she describes feeling more distant from her relationship now. The fact that her husband has taken over the shopping and cooking means she feels she is not the woman he married or the woman she believed herself to be. The conversations and debates they use to have are limited now, as she no longer keeps up with what is being said. This experience creates a sense of loss of self in Phyllis, which makes her feel hopeless and unhappy.

## **5.7 Betty**

Betty is 82 years old. She has been diagnosed with AD for eighteen months and scores 26/30 on an MMSE, indicating a mild AD. She was aware of her diagnosis but she talked about it as an inconsequential event stating it had little effect on her and her ability to function.

Betty grew up with an older sister and a younger brother. Her mother and father worked hard throughout her childhood and she recalls this as a happy time. Despite her mother working, Betty did not help her mother with chores; she and her sister went to secretarial school and Betty worked in this role throughout her adult life. She met and married her husband and they had three children. They moved a number of times due to her husband's job, however once her children were all settled at school, they did not move again and Betty went back to work herself.

Betty describes a happy marriage; her husband worked away a lot, which left her at home taking care of the house and the children but when he was home she stated

they did things together. Betty worked part time when the children were small but the job was important to her and her self identity. Her family is important to her and she is proud that she and her husband have raised three independent children who have prosperous lives of their own. She speaks to them daily on the telephone and is visited regularly by one who still lives close by.

Betty stated that she does not feel she is being cared for in any way differently to any other normal couple of their age. She believes her relationship with her husband works on a reciprocal basis whereby he does things for her and she for him. She described a close relationship with her husband, stating he has always been there for her, despite working away a lot and now is no different. The sense of togetherness she experiences does not necessarily come from the proximity she has with her husband but an emotional connection, which will be explored further in chapter six.

Betty did identify some changes in herself due to the AD. She now becomes anxious at times and her daughter will not allow her to take their grandson out in the car alone. She accepts these changes, and feels a sense of value that her family would show this concern. She feels no less capable as a woman compared to her old self.

## **5.8 Ann**

Ann is 83 years old. She has had a diagnosis of AD for three years and she scores 15/30 on an MMSE indicating a moderate AD. Ann was aware of her diagnosis but did not like to talk about it. Ann's ability to recall her childhood was limited; she stated she had a lovely mother and father and she had two sisters. Ann met and married her husband over fifty years ago and they had two children. Whilst Ann took care of their home her husband worked and they built their current house together when the children were small.

Ann was very anxious during the first interview and asked that her husband be present as we were talking. This enabled her to visibly relax and talk more; however it is acknowledged that the conversation became one of their shared experience rather than her own. She and her husband reported that they had always done things together and still do. This included going out shopping and cooking, however the

cleaning and taking care of the children was Ann's responsibility. They are a very artistic family and the house was full of paintings and pottery that had been completed by either Ann herself or one of the children.

The second interview was conducted with Ann alone. She talked about her children at length; how proud she is of them and her love for them. She also spoke of a time when her daughter-in-law passed away, which she stated was a very difficult time for the whole family. She had a very clear recollection of this time and it was evidently still very upsetting for her to talk about. Ann was very aware of the fact that she no longer does what she used to do around the home acknowledging that her husband now does everything. Despite this, Ann showed a great amount of pride in what she has achieved throughout her life and showed no loss of self esteem from her lack of ability. She was able to express her care for her husband and family through emotion rather than the physical act of caring and it became evident that change due to AD has not stopped her 'being' and enjoying the life she has now for what it is. This experience of positive acceptance and contentedness is explored in chapter eight, Seeing cobwebs.

Despite evidence of a strong reliance on her husband, the connection that Ann described between them demonstrated a feeling of security in her life. Her experience of becoming cared for means feeling continued value in the family and she focuses on what she can still achieve rather than things she is no longer able to do.

## **5.9 Summary**

This chapter has provided the reader with a description of each woman involved in this study and an interpretation of their unique position in the world and their individuality. What was strongly identified from the narratives of the women on their lived experience of becoming cared for, was the overarching theme of self; who these women are and who they were and how that affects them and their sense of identity within a couple and as an individual.

I have discovered during analysis that some of the individually described experiences cut across all the women in various ways and these super ordinate themes are

presented in the following three chapters. I will detail convergences and divergences in these key experiences, rather than exploring each woman's personal experience case by case and draw on existing theory to aid my discussion. Firstly I explore the experience as shared with the spouse in Togetherness, secondly, as an individual experience where identity and self begin to be questioned in Me being me. Thirdly I look at the positive view of change experienced by some of the women, as they become cared for in Seeing cobwebs.

## 6 It's a togetherness

In this chapter I will discuss the care relationship between the women in the study and their spouses. The need for care and becoming cared for immediately identifies the need for two people to come together in a way they may not have done before. It creates a togetherness that potentially, even in marriage would not have been experienced previously. Six of the eight women talked specifically about what becoming cared for meant to them in terms of their relationships. This suggests that at the heart of being cared for is not necessarily a set of tasks but a relationship. This will be explored in more detail in the following three parts; Togetherness, Being together and Takenoverness. All the women in this study had been married for over fifty years, constituting the development and maintenance of a close relationship (Harvey & Pauwels, 1999). This chapter will explore how the change in the women's ability to complete IADL's due to AD, impacts on their relationship with their husbands.

### 6.1 Emotional togetherness

The concept of togetherness has been studied in older adults and describes amongst other things, how individuals feel their existing relationships meet their needs (Tiikkainen *et al*, 2008). In this chapter I expand on this and suggest togetherness is an experience which can impact positively and negatively on a person's life. Emotional togetherness describes feelings of proximity, safety and an assurance that help is accessible.

Chapter five introduced the reader to Ruby who used the phrase "it's a togetherness" to describe her relationship with her husband:

*Ruby: Always, all our lives it's been togetherness. Except of course when he was out working and you did everything but when we were toget...retired and that, I think it was a togetherness you know..... I did what most women did, urh and [husband] helps me around the house and things like that, cause I've got a very good husband..... [husband] washed the dishes up and I would dry them, cause I haven't got a dishwasher I was the dishwasher or he was the dishwasher and things like that you know but a lot of it,*



*a lot of our things were shared, you know, so it was, it was a, it was, it's really been wonderful really, I've been very lucky you know. (Interview 1)*

Ruby demonstrates a traditional view of the gender roles of men and women stating that her husband has always helped her around the home. The notion that he helps suggests she sees the responsibility ultimately being hers but she expresses pride in having a good husband. The experience of someone else's goodness can promote a sense of wellbeing and togetherness (Borley *et al*, 2014) and when Ruby talks about her relationship she describes a continuation of her and her husband's established way of 'being' together (Hellstrom *et al*, 2005):

*Ruby: I think in all probability it's a togetherness, you know, I mean housework and that, whatever it is, I can do all that, I think I can do most of it urh, but if there's something, [husband] will say 'well I'll do that for you', or something like that but I, maybe of late, maybe he's helped me a wee bit more with things, sometimes he'll do quite a bit of the cooking and things, not that I can't do it but he's here in the house and he, he helps about, you know, like husband and wife, you know, he's not the husband who just sits back and the little wifey goes round you know, he's a very helpful person. (Interview 2)*

She acknowledges there has been an increase in the activities her husband gets involved in at home since he retired, however Ruby believes herself still able to manage the IADL's as she always has done. Her husband supports Ruby to maintain this belief by being there when she needs him. This sense of proximity provides a feeling of security for Ruby which promotes her feelings of emotional togetherness (Tiikkainen *et al*, 2008). This positive attachment enables her to maintain her sense of value in the relationship, as she perceives little change in her reliance on her husband.

Betty talked about her and her husband's changing circumstances and viewed this togetherness as an essential part of her continued quality of life:

*Betty: I mean I can stay in the house but I'm not usually in the house on my own, I used to be at one time I suppose, when I was younger and [husband] worked away but urm, I couldn't stay in this house..... I hate to think about that but, no, [husband] is actually, he's really, he's my prop in a way..... I mean it would be a terrible thing to have to be on my own. I think I could gradually mix with people because I'm quite a good mixer but urm, I just think I, he's the prop, he looks after all the money side of things..... I like my independence in a way. I like to think I'm independent but I know I'm not independent because [husband] is, he is very good, he keeps everything right'. (Interview 1)*

She describes her husband as a 'prop' who 'keeps everything right'. These statements indicate Betty's belief that if her husband were not there, everything would go wrong as she would have no one to lean on for support. This is not necessarily an admission that she cannot cope alone but that without his presence she would struggle to maintain her independence. She speaks about the ongoing need to feel independent and goes on to tell of things she believes she can still do alone if she chooses:

*Betty: I think it means quite a lot, I would hate to be one of these little women who said 'can I have some money to go shopping today' or, I mean if I want to go, I can still go and do it, I mean I can't go driving down to Bournemouth like I use to but if I say, wanted to go to the town centre and [husband] didn't want to go, urm, I could drive there myself you know, I very rarely go anywhere without him but (laughs) but if I really wanted...I think it would be alright, I think, we've been together so long. (Interview 2)*

Despite rarely going out without her husband now, Betty believes she is still able to make choices and take some responsibility for her actions. The reassurance she gains from her husband being there helps her maintain her sense of independence (Haak *et al*, 2007). Therefore, the feeling of togetherness in her relationship is allowing her to perceive a continued autonomous life by providing her with confidence and security. In this situation being apart can still mean being together.

Betty acknowledges that although she and her husband have done things together throughout their lives there are certain things that her husband now does solely, such as the cooking:

*Betty : We've always done things together.....oh quite a, I think since he retired and he was bored, I used to do it (cooking) before that and he's a good cook so, and he gets on with it. .... Oh, I let him get on with it, I'm thrilled to ribbons, I think it's good, isn't it? Good. Well my daughter has a husband like that as well. (Interview 2)*

Research undertaken by Molyneux *et al* (2011) focused on couples where one spouse had a diagnosis of dementia. They found that where fulfillment of the typical roles of a husband and wife were no longer possible, this created confusion and turmoil. This in turn was a source of anxiety and distress for both the person with dementia and the spouse (Molyneux *et al*, 2011); however this is not presented as the case for Betty. Despite him doing more around the house, she rationalises her husband's change in

behaviour. She explains it is due to his retirement and him being bored, rather than it being anything to do with her growing need for care. She appears to experience a sense of pride that her husband is willing and able to get involved and do the jobs a woman usually does, comparing her situation to her daughters and a change in the expected traditional role of a man to a more modern way of living.

Weiss (1974) describes different types of relationships that meet different needs and the opportunity for nurturance; a relationship where a person can feel responsible for the well-being of others is experienced in this excerpt from Betty who expressed a shared caring between her and her husband:

*Betty: I mean I probably care for [husband] just as much..... I think he would have trouble, daily things, he could still live on his own and I would find that very hard to do, I don't think he'd want to live on his own, I think he'd hate it, I think it's just that we've been together so long that we care for each other. (Interview 2)*

Betty goes on to talk about how she and her husband work together as a team when managing their weekly medications:

*Betty: I bring the boxes and he puts me urh, um, 7 out for the week and I put them in and he gives me my second lot and he gives me my paracetamol (laughs), so it's teamwork. He does his own but you know, he makes sure my box is all done and urm, cause I'm quite good, I remember every morning, he always reminds me but I say it's alright I've already taken them so urh, between us but as I say, I'd be lost without him. (Interview 2)*

Betty clearly identifies that she could not manage her medication without her husband, however the fact that her husband also takes medication and they complete this weekly task together, makes Betty feel she is no different from him. This provides her with the opportunity to feel some shared responsibility for his well-being, as well as her own. This reassurance of worth enables Betty to maintain her sense of competence and self-esteem which encourages the continuation of their close relationship (Weiss, 1974).

Ruby and Betty talk about their relationships positively using language which portrays them as having close relationships built on a feeling of security. This enables them to maintain their sense of independence and worth whilst retaining their perceived

emotional togetherness. The need to maintain the contact of an attachment figure, especially seeking them out in stressful situations is a hallmark of attachment throughout adult life (Sable, 2008). Under stressful or threatening conditions, the need for closeness and proximity to an attachment figure increases attachment behaviour (Browne & Shlosberg, 2005). If a secure attachment figure is available this provides a safe base from which to explore the threat with a confidence and reliance in others. As can be seen in the next excerpt, Ruby clearly verbalises a feeling of safety and security in her relationship:

*Ruby: I mean, if I, touch wood, was ever poorly or anything, I'd be, I'd be quite safe, not safe but quite, I wouldn't be worried that [husband] wouldn't be able to do things, cause he's very capable of doing everything..... He sees that maybe because I've got this Alzheimer's and stuff like that he sort of, he's there and I'm sure if I wasn't quite doing it as, say well I think you should maybe do it... but generally not, I think we get on very well together. (Interview 2)*

Although Ruby does not class herself as being unwell, she is aware of her diagnosis and that her husband is there to ensure she does things correctly. She takes comfort in the knowledge that her husband is capable of doing this and believes this helps them work well together as a couple. If the experience of shared responsibility is lost, there is a risk that the women's sense of togetherness in their relationships may cease. Betty and Ruby's lived experience is based on their strong belief that they are still very able and are receiving assistance, not care, from their husband's. The following question to them suggests that as the AD progresses and their abilities become more limited, their feelings would change:

*Researcher (R): What about then, if you got to a stage where you perhaps couldn't do as much as you can now in and around the house and [husband] had to take over more and more of the housework, the cooking and the cleaning and things like that, how do you think that would make you feel?*

*Ruby: Inadequate.*

*R: Would it? Why is that?*

*Ruby: (pause) I think, maybe that's a wee bit strong but if, I mean [husband] does a lot, I never give that a thought because (pause) both of us have shared everything and that ma..and that of course you never think like that but if he had to do it all I'd think 'oh golly' I'd say to myself 'oh golly I can't do that' and I'd feel a wee bit you know, miffed about that. (Interview 2)*

Ruby states her and her husband have shared everything throughout their lives, suggesting her view of their relationship is one of equality. She may not be experiencing a huge change in the balance of the relationship due to her need for more help but indicates that if she did, she would find this hard to manage. Despite Ruby using the phrase 'it's a togetherness' consistently during both interviews she still wants to be seen as independent and she talks here about the importance of autonomous activity:

*Ruby: It (going out alone) makes you feel a wee bit more umm (pause) reassurance of yourself, well you know, that you can (coughs) you can go out on your own without [husband]. Like I go to the WI, you know, and urh, and urh, various things like that. You know, I don't mind doing things like that; I've always been quite capable of doing things on my own without having [husband] there all the time to do it. (Interview 1)*

The response from Betty when asked the same question was similar:

*Betty: I think...I would hate to think that I was so bad that he couldn't leave me or I couldn't go out on my own. I think I'd be very upset about that...I think I'd feel a bit irritable about it actually, yes, I really do, because when I thought I might not be able to drive I was quite irritable about it, quite annoyed. (Interview 2)*

For Ruby and Betty it would appear that the experience of togetherness is achieved when both parties are able to contribute to the relationship and are interdependent. If they were not able to contribute, this could change their opinion of themselves and their relationships.

## **6.2 Being together**

This part of the chapter makes the distinction between the feeling of togetherness and the experience of essentially being together. For Ruby and Betty the experience of togetherness was not dependent on proximity, however for Jean and Ann, being together in the literal sense was identified as an influence on their experience.

Jean's experience seems more in line with Molyneux *et al's* (2011) findings, as she showed signs of worry and uncertainty when discussing IADL's:

*R: When he's cooking, do you like to be in there with him or away from it?*

*Jean: Yeah, yeah I like to be in there yeah, I'm in there with him, see what's going on....yeah I do a bit. Umm, (long pause) but he's, he ought not to be doin that really had he? ..Um, he could get on with something else, I mean that's my job really innit?...Yeah., but um, he can do it. So perhaps I've just left him so he knows he can do it, I don't know, he'll always, he'll be alright anyhow on his own if anything happens to me..... It's mine, it were my job, I always done it ya see, and I used to do the cooking and make stuff so we had something to eat and all sorts of things like that, yeah.(Interview 2)*

Jean describes the cooking as her job and despite her husband taking this on, she wants to be involved and makes herself present in the kitchen. The task of cooking has become a shared task and this feels uncomfortable for Jean, who suggests if she could still work independently this would give her husband time to do other things. Molyneaux *et al* (2011) suggests the maintenance of relationships and togetherness can be supported by performing tasks jointly. What is evident in Jean's case however, is that although she understands the need for being together in this situation, the lack of autonomous existence means the couple is at risk of being controlled by AD, preventing them from living a good quality of life (Svanstrom & Dahlburg (2004):

*Jean: He does help, he's a really good help in the kitchen I must say that. I might knock him out the way but he's a good help in the kitchen (laughing)..... Yeah, he's good round the cooker...he sort of, I expect he wants to do it you see, and I expect I do as well, at the same time, um, we're alright.... Um, he's helping me. He is helping me I know that (pause) but sometimes you have your little, ya know, your little arguments, no, he ain't a bad sort. (Interview 1)*

The experience here is an emotional struggle for Jean, as she attempts to cling on to her sense of who she is and her position in the relationship whilst trying to come to terms with her need for assistance. She maintains a physical presence in the kitchen as a way of preserving her sense of importance in the relationship. The sharing of the task becomes challenging for Jean when she wants to do something her husband is doing. There is a reluctant sense of gratitude that her husband is there to do it for her; however their being together often results in arguments. They have been married for many years, yet in this instance an inability to accurately identify each other's needs and respond to those (Rauer *et al*, 2014) may be impacting in a negative way on this couple's relationship.

Edith also now undertakes certain tasks with her husband that she used to complete alone but describes her involvement as minimal:

*Edith: No he started doin it, and doin the shopping, ya know, I go with him to do the shopping but he never used to, I mean he just started, he just stopped givin me any housekeeping and took it all over..... Yeah. I just push the trolley. (Interview 1)*

This portrayal suggests she no longer feels valued for her abilities and unlike Jean she does not acknowledge the need for help. Her experience when they are shopping together creates a sense of worthlessness in her, as she describes her only responsibility is to push the trolley. Drawn from chapter five, it is known that Edith has always prided herself on her independence and the responsibility she took in managing the home. She believes she is still able to achieve this and feels undermined by her husband's physical presence.

*Edith: Well like [husband] would say, "No, no", probably, "I'll do it, go on, you go and sit down". I think, well I might as well sit ere as go out and urh, because I wouldn't want to be out there with him, him saying "Oh, you peel the potatoes" and things like that. If I was in the kitchen I'd like to be doing it all myself. (Interview 1)*

She suggests that being with her husband means being told what to do and so withdraws from the situation to avoid this. She appears unwilling to challenge him directly and displays her resistance to the change via her behaviour (Boyle, 2014). Potentially this strategy could help Edith maintain her sense of identity and belief in her abilities, however this creates both a physical and psychological distance between her and her husband as a couple.

Ann's experience is different, as although she appears to have begun to rely heavily on her husband being present for both functional and emotional support, his doing so promotes her feeling of togetherness. Her husband's presence during the first interview, as discussed in chapter five, meant she constantly looked to him for help with answers. She was unable to express herself in great detail, however her reflection on her experience of being together can be seen in the following excerpt:

*Ann: (We) always worked and done things in the house together.*

*R: So it doesn't seem unusual to see him doing those things?*

*Ann: Well not really.*

*R: You've always shared the jobs in the house?*

*Ann: Well no, not as much as we, not as much as we (coughs), not as much then as [husband] does now.*

*R: Right, so what does he do now that he didn't use to?*

*Ann: He does everything.*

*R: Does he.....is that a good thing or a bad thing?*

*Ann: Well I suppose from my point of view, in a way, its good isn't it? (Interview 2)*

There appears to be some reluctance in Ann to say the caring she receives is truly a good thing. She seems to weigh up the bad with the good and is able to identify positive meaning in her husband's caring behaviour, which fulfils her need to feel loved (Weiss, 1974). However she may also be struggling with the change in herself and her reliance on him to be there. It is known that perceived burden on others impacts on the self-esteem of people with AD (Steeman *et al*, 2005) and the risk of reduced self-esteem in Ann due to her fear of becoming a burden, could affect the relationship and her feeling of togetherness.

It is proposed that being together does not always equate with a positive experience of togetherness. The next section takes the interpretation a step further as it looks at the women's experience of being taken over.

### **6.3 Takenoverness**

Within three of the women's stories, there was a clear indication that their experience of becoming cared for was different. Here the sense of togetherness is now becoming a feeling of being taken over. For these women a diagnosis of AD appears to have changed the dynamic of the spousal relationship and subsequently the behaviour displayed by both partners (Svanstrom & Dahlberg, 2004). Jean, Phyllis and Edith describe a feeling of takenoverness in their relationship, however there are differences in how this is experienced for each woman:

*Jean: He's taken over, and he's taken over um, alright but I think to myself, well I used to do all that....Ya know, but I do, do it, I (said quietly) do do it but not like I used to (pause) I don't seem as if I do anyhow..... He's there you see, he's there doin it, ya know and I'm, oh get on with it then, ya know and then we perhaps have a few words. (Interview 1)*

Jean explained that her husband now takes responsibility for the cooking, shopping and organizing their appointments. As has already been discussed in the previous section, Jean attempts to create a togetherness between her and her husband by



doing these tasks jointly. This appears to create more distance in their relationship however, and creates a negative experience for her. Jean has insight into her lack of ability and she tries to make sense of why her husband does what he does:

*Jean: Every day, he does, he does take over but I'm glad of it and I know what he's doin and yeah, I do know why he's doin it... And then I have to pull myself together and ya know, go along with it.... What else can you do, if the, if you're not doin it, somebody's gotta do it, so I expect he just took over and he, and he didn't do anything in years, ya know time back but he, ya know he's one of the (pause) one of the, ya know, he takes over and that's it, he's just done it. I didn't think he was gonna, didn't think he would be like that, ya know... He likes everything just right. (Interview 1)*

She describes a man who did not do any household tasks in the past and she is surprised by his change in behaviour around the house. There is a sense of frustration that he has taken over this responsibility now but also a sense of resignation that she has to go along with it. She believes she no longer holds any control over the situation, understanding that if she is not doing it, someone has to. The negative feelings she is developing towards her husband are compounded by the way he is beginning to care for her. Jean suggests that her husband has standards which she has always had to meet; he likes everything done in a certain way. While her husband's expectations of daily life may not have changed, the reduction in Jean's ability to complete IADL's due to her AD presents a risk that she now perceives herself unable to live up to her husband's standards. This may create a loss of value in Jean and therefore increase her feelings of negativity towards herself and their relationship.

There seems to be a power imbalance in this relationship which may have developed throughout the marriage by an unquestioning superiority of her husband's priorities and needs (Knudson-Martin, 2013). As a younger woman, Jean was able to validate her position in the relationship by taking control of the IADL's. Her lack of ability to perform as she did prior to her AD means she no longer has a choice or control over whether she cooks, as her husband removes this decisional autonomy (Boyle, 2014).

There is also a difference in Jean's experience of the physical act of caring demonstrated by her husband and the emotional act (Molyneux *et al*, 2011). It maybe that Jean's belief is her husband's need to eat and have clean clothes for example, may motivate the tasks he does, not necessarily the desire to care for her. He could

be viewed as a practical man and if something needs doing he will do it himself because he can do it quicker and to a higher standard. However Jean interprets his behaviour as caring with the intention of achieving his own goals rather than with any emotion or feeling for her. Again, his needs appear to outweigh hers in this next excerpt:

*Jean: And he, and I don't say anything if he wants to go golf, let him go golf and that's me....But he does like to get up there (golf course). He likes to be with the men as well, which is a good thing ya know. I don't, I don't and they're all alright so (pause).....I think I only sit now.....Yeah, I always used to be doing, well, probably if I were, if, I would probably do a bit of gardening, not a lot, I used to do a lot of gardening (pause), cause if he, he does it you see, the garden, he wants it how he wants it. ....He's the master of the house now...Well, he thinks he is anyhow (laughs). (Interview 2)*

Jean describes how things are 'now'; she is uncomplaining when her husband goes out and is aware of his need to maintain social relationships (Weiss, 1974). She is accommodating to his needs but does not experience a similar sense of reciprocity. Instead she portrays a sense of loneliness, as she is no longer able to keep herself busy and occupied whilst he is out (Moyle *et al*, 2011). She describes him as 'the master of the house' perhaps feeling she is now unable to do anything unless he is around to help and support her. Jean experiences a threat to her sense of self, which could be a response to the perceived unavailability or detachment of her husband (Mikulincer & Shaver, 2003), or it could result from a loss of control of her perceived domain. However, she attempts to maintain some control when she claims '*he thinks he is,*' suggesting that she is allowing him to believe this to sustain the power equilibrium in the relationship (Knudson-Martin, 2013).

Edith was the second woman who described her experience of becoming cared for as a feeling that her husband has taken over. She finds it hard to deal with the silence from her husband with respect to his decision to take over the domestic tasks in the house:

*Edith: Well, I don't rely on him but he's taken over doin the cookin and everything and that's from choice, that is entirely from choice with [husband] not cause I'm not capable, I'm not saying that, I'd love to get in the kitchen I wouldn't say that, you know, if I said that to him, he might get a bit funny....Because I think he thinks I wouldn't cope because he doesn't, he didn't say anything about you know, um, if he'd said you know um, would you like me to perhaps do the cooking for a bit, give you a*

*break, it would have been, he didn't, there's nothing done, he just took over everything, everything, stopped giving me housekeeping and everything.... But um, what I find you know, I still can't find why, why he suddenly started doin it. (Interview 1)*

This perceived silence leaves Edith feeling confused and angry towards her husband and she fills the silence with her own interpretation of what this might mean, in terms of his view of her. Despite the urge to continue to do the things she has always done, she does not talk to him about this, fearing his reaction. The lack of communication between Edith and her husband creates a barrier which prevents a sense of togetherness and also requires Edith to develop a strategy to avoid losing her sense of self:

*Edith: I feel like saying "bugger ya then, get on and do it", yeah. Because I think if I didn't, I'd let me self go right down. (Interview 1)*

Avoidance of emotional involvement appears to be the strategy Edith is applying here potentially due to the fear of rejection or maybe to discourage acknowledgement of her personal faults (Mikulincer & Shaver, 2003). Key to this experience is Edith's search for answers to the change in her husband's behaviour. However her unwillingness to discuss this with him does not allow him to listen and respond in a way which could help validate her continued worth and identity (Knudson-Martin, 2013). During Edith's interviews she verbalised the feeling of loneliness despite living with her husband:

*Edith: But I do miss not having anyone about you know, I do. (Long pause) Terribly, it's um, yeah I just feel lonely all the time. I mean [husband] will go next door, I think I've told you, he'll just disappear talking next door. (Interview 2)*

It should not be assumed that someone who is married will not feel lonely (de Jong Gierveld *et al*, 2009) and Edith's experience of loneliness is reinforced by her perception of the social involvement her husband achieves with their neighbours. Edith also has a strong sense of separateness from the community alongside her feelings about her relationship and she is aware of how this loss impacts on her:

*Edith: Really if you can't help somebody, I was brought up, if you can't help somebody that, when they need it, your life's not worth much is it? Cause you feel good in yourself (laughs) yeah. Yeah, I'd do it again now if um, ya know, just to get to feel a little bit better in myself, I wouldn't mind doing it again, it*

*would get me out. I don't mean that in a selfish sort of way but no, if there's somebody sitting on their own with nobody, I'd go and sit with them now, yeah..... And that's the most important thing, there can't be anything worse than being a lonely person and never get a visit. (Interview 1)*

Edith appears to be striving for social interaction as she is unable to achieve a sense of contentedness between her and her husband (Weiss, 1974). She talks about other people feeling lonely; however it could be argued that she is also describing her fears for herself. She is feeling a sense of loneliness due to a lack of companionship that she once had with her husband (Evans & Lee, 2014). The lack of togetherness leads her to describe her sense of unhappiness in the relationship:

*Edith: Well, just the sort of sitting here, being on my own and he goes off next door and that and urh, you know, he doesn't want to be with me. I'd rather he come clean and say "let's split up" and that would be the end of it cause I'd go down to [home town] and try, to my sis, family and try and get, take a long while it would but, I mean a few years, you know, I would never have said anything like that, wouldn't have dreamt of us, of it happening but now you know I think well what life is it? .....Absolutely deflated, hmm, that's just how I feel, I just can't get myself out of it, I wish I could. (Interview 2)*

The feeling of loneliness appears to be so strong for Edith that it makes her think about a life separated from her husband, despite their marriage lasting over fifty years. If two people are in a close relationship, their lives are connected in a multitude of ways and for older adults, tried and tested strategies for coping have been found to help maintain a relatively stable marital quality (Warner & Kelley-Moore, 2012). The addition of a complex progressive disease such as AD however, may prevent an ongoing reciprocal pattern of behaviour whereby each person attempts to understand and know the other, whilst allowing the other to know him or her (Harvey & Pauwels, 1999). If this occurs there is a risk that the sense of togetherness will fade and the close relationship will no longer exist.

Phyllis has a similar experience of becoming cared for, however this creates a need in her to change her behaviour in order to avoid creating distress for her husband and she appears to accommodate his needs more so than her own (Knudson-Martin, 2013):

*Phyllis: [Husband] has taken all that over...If he suggests something, I always say yes that would be very nice.....Because, he's taken over everything, I feel I owe something to him, so if he suggests something,*

*like this holiday, urm it just goes ahead, he'll say "what do you feel about it?", I didn't even know where we were going and urh, off we go, so I think a lot in his mind is, "it doesn't really matter, it's the Alzheimer's" but he doesn't understand it and I haven't got the wit to tell him I feel that way, urm, I've tried several times because I think it's going to be very hard for him when things get harder still urh, I don't know how he's going to cope. (Interview 2)*

Phyllis' emotional reaction to her situation is one of guilt, as she perceives her husband does not understand what her diagnosis of AD actually means for them as a couple. This suggests that she is experiencing a negative change in her relationship, judged on her inability to discuss the situation with her husband and her perception that he will not be able to cope. Phyllis expresses concern that her husband lacks understanding about the progression of AD and how this will affect him. She may be experiencing self-blame for having the illness or for the change in her abilities, whilst also fearing becoming a burden. Either way, she prioritises his lived experience over her negative experience of being taken over in an attempt to maintain the relationship described in chapter five. Phyllis masks behaviour in the hope this will maintain her husband's sense of well-being and their relationship quality (Mikulincer & Shaver, 2005); however this behaviour is not always easy for Phyllis to sustain. She expresses some frustration when her husband does things she believes she should be doing:

*R: Do you help to choose the things that you need when you go shopping?*

*Phyllis: No. No, he just does it.....I feel that, I feel quite low actually, urm, (pause) I, if we're going round the shops I just think to myself, this is, urh, what I should be doing as well and I should be looking at things that I like not just what you think I might like..... I use to do all the gardening and gradually it's been taken off of me. (Interview 1)*

There is a commonality in Phyllis and Edith's narratives related to a lack of communication in their relationships now. Phyllis reveals her silence is a tactic to prevent her husband becoming upset:

*Phyllis: I mean I've never talked to him about it because he wouldn't like me to sort of talk to him about that but yes, he's urm, it's, it's this thing, taking over that's the main thing. I don't even get a choice of the television, I've started to say urm, "you do it", it doesn't matter cause that's what he does anyway.....it doesn't really matter because urm, the Alzheimer's seems to me to be going so fast urm, that I don't really have any choice in anything because I have to have other people around me urm, that's what I feel inside urm, (pause) yeah, yeah, it's a hard one really isn't it? (Interview 2)*

Phyllis is reluctant to discuss her diagnosis of AD with her husband as she believes he would not want her to. Her diagnosis makes her feel inconsequential in their relationship, her opinion no longer important. Togetherness for her is now inevitable as she needs people around her to ensure she is safe, however she portrays it as a negative consequence of the AD resulting in a lack of independent choice in how her life is lived.

## **6.4 Summary**

This chapter has explored the notion of togetherness for women with AD in relation to their experience of becoming cared for. I demonstrate recognition of the interconnectedness between couples created by the need for care. Their experiences suggest that women who are supported by their husbands to continue to manage IADL's have a stronger sense of togetherness than those whose husbands take on full responsibility for these tasks. Relationship quality prior to the onset of AD also impacts on this experience. For women who are less secure in their relationships, there is a strong sense of loss of responsibility and loneliness that influences their experience and could place a strain on relationships.

The literature referred to in chapter two describes the fight to change the traditional gender perspective, that it is a woman's responsibility to care for others by undertaking IADL's. Some of the women interviewed here however, view those tasks as identification of who they are. In the next findings chapter I will examine this further, looking at how the experience of becoming cared for impacts on the women's sense of self identity.

## 7 Me being me

In the previous chapter I highlighted a relational component to the women's experience of becoming cared for. Alongside this, it is important to acknowledge each woman as a person with her own sense of identity, as her individual experience impacts on the construction of that identity (Sabat & Harre, 1992). Therefore, in this chapter I explore the women's sense of self and identity in relation to the experience of becoming cared for.

This chapter is made up of three parts, each taking a different perspective on the women's view of their self-identity. 'Who I am' will examine how the women view themselves from a feminist perspective. 'Being me' explores how the lives the women have lived prior to their diagnosis impacts on their view of themselves now and the final part, 'Experiencing others' will return to the relational experience, as I explore how the women's view of themselves and their identity may be influenced by others.

### 7.1 'Who I am'

During the interviews a number of women indicated that their experience of becoming cared for affected their gendered view of themselves. Phyllis clearly expresses part of her experience as a loss of her womanhood:

*Phyllis: It's just that you're not a woman anymore because you're not doing the things you should be doing*

*R: What should you be doing, in your mind?*

*Phyllis: Being in the household at the moment, yes. If you're not working you know you should be doing something else and doing the gardening. (Interview 1)*

Jean also identifies herself as a woman who did everything around the house in the past but no longer has this experience:

*Jean: A little, it's taken, taken, cause you're the woman of the house and you, you do all the, I did all of it but he did, he did work... I think I only sit now.....Yeah, I always used to be doin. (Interview 1)*

Jean and Phyllis express the need to be 'doing' around the home, as they were 'doing' prior to their diagnosis. They may feel responsible for completing the tasks within the household believing the view that instrumental activities of daily living are traditionally seen as feminine tasks (Beagan *et al*, 2008). At the same time, completing these tasks may have enabled them to behave consistently with their more *feminine and expressive gender identities* (Erickson, 2005). These tasks could be interpreted as 'women's work', giving a structure, routine and meaning to the lives Jean and Phyllis live. Without those tasks they have less structure and so managing their daily lives becomes more complex.

Womanhood describes the state of being a woman and the qualities considered to be natural to or characteristic of a woman. This places women in a socially constructed category with a shared identity (Hogg *et al*, 2002). Social identity theory suggests that groups we belong to help us develop a sense of who we are and are important for our sense of pride and self-esteem (Stets & Burke, 2000). People within groups act in a way that is appropriate to the group they belong to and to maintain self-esteem the 'in-group' will compare themselves favourably with other groups. If this is the case, the women interviewed here are finding it harder to behave appropriately for the in-group that is 'Women' and thus risk their self-esteem diminishing as they feel they are failing to meet the required behaviour of that group.

Edith also expressed herself in terms of her feelings of womanhood, linking these to intimacy within her marital relationships:

*Edith: You don't feel very feminine for one thing, hmm, that side of marriage is dead, I mean, I'm not getting personal with you now but things that you normally have and normally do as a woman is just not existent, not in existence, not at all, no. (Interview 2)*

Edith uses the term feminine and although she claims she does not mean to discuss her relationship from a personal level, we are aware from the previous chapter that she feels her relationship with her husband is not as intimate as it once was. Edith is unable to invest her femininity in the more intimate side of her marriage and can no longer demonstrate her femininity in relation to completing instrumental tasks.



Femininity is a strong characteristic of womanhood, which suggests Edith is sharing a sense of loss of meaning in her life similar to Phyllis and Jean. For many years feminists have fought for equality and to be defined by things other than household tasks and child care (Malos, 1995; 7). Interestingly, the women here appear to be experiencing a loss of part of their identity because they are no longer completing these tasks. Whilst 'women's work' has been described as a subordinated identity for women in the past (Gibson-Graham, 1994) there is a sense that these women believe it gave them a purpose and meaning in life. Despite also working throughout their lives the experience of caring for the home is what provides these women with a sense of who they are now. Without this, they may experience a sense of worthlessness. The way the women view themselves relates strongly to their view of their past self and attributes which have made them the women they are. This will be explored further in the following section.

## **7.2 Being me**

The women in this study have all lived unique lives and the view they have of themselves now is intertwined with their experiences overtime. I will explore these experiences in the next part of this chapter to demonstrate how becoming cared for is influenced by the women's past experience.

### **7.2.1 Happy being me**

As detailed in chapter five, some women's experience of becoming cared for were more positive than others. Ruby's experience relates to her view of the attributes she possesses and belief in those attributes. These do not focus around her being the homemaker and could be explained in part by a time in her life when she lived abroad. In this case, women were not defined by their domestic production work and hence identity may not be strongly intertwined with such 'doing':

*Ruby: Well, what happened, it was so, it was so different because they, there (her home abroad) you were married and you had a servant, a house boy, you know but I, most people did have a house boy who cleaned the house up you know... You fitted in the way it was, it wasn't to say "I'm out here I've got somebody to do my work", it wasn't like that, you know, it was, it was funny when you thought, when*

*you think you're at home there and you're helping your mother with this and "Oh, it's my turn to do down the stairs" and stuff like that and there, you get this boy to do it. (Interview 1)*

Ruby compares her early married life to her childhood and recognises a difference between her experience and that of her mother. She describes having to adapt her view of how things should be when she allowed someone else to complete the instrumental activities in the household. This previous experience potentially has an influence on how Ruby views herself in terms of becoming cared for. As her past was not influenced by the tasks she undertook within the household, neither was her view of herself. The fact that it was a boy who helped her around the house may also have promoted a less gendered view of housework for Ruby. She also talked about a time when she worked as a home help and again, gives us an indication of how she maintains a positive view of herself now:

*Ruby: I enjoyed meeting them (people needing care in their homes) and helping them (pause) and urh, mainly being able to help someone and then meeting different people, different types of people you know, I mean you might get some old people who weren't too good and you'd help them a bit more but most of the time it was quite enjoyable doing their housework that they couldn't do, I quite enjoyed that. (Interview 1)*

Ruby states she enjoyed helping others and it would appear that she has a distinct memory of the people she used to help; those who had reached the stage of needing to be cared for. She is perhaps able to maintain her own positive identity as her experience does not resemble that of the older women she used to look after. She may also view caring tasks as a paid responsibility (employment as distinct from work); meaning her sense of self is not affected by the loss of ability to complete IADL's in her own home.

As detailed in chapter five, Betty's past involved bringing up three children, working and running the household while her husband worked away. During the interviews she was quick to state that she feels the same as she always has, however she also acknowledged some changes in herself. Betty may feel that as a person, she has continuously changed throughout her life, for example becoming a wife and a mother. These changes may not have affected her identity as an individual enabling her to

define herself as 'the same, yet different'. When talking to Betty she was keen to highlight the things she can still do, supporting her view of an unchanged identity:

*Betty: I don't think I've changed, I'm just the same..... I mean I can't drive as far, I wouldn't drive as far as I use to obviously, but I do drive, I drive on my own if I need to. [Husband] is usually with me but um, one day I wanted to go to [town] and he didn't want to go and I said "I'll go myself" and urm, I, urh, I do perhaps get a little bit anxious. I think that's the only thing to think you know.... It's alright, I think I'm getting older anyway, and you see, you do see some, I, I, I do feel, (pause) I'm a reasonably good driver, you see some awful fools on the road. (Interview 1)*

It appears that Betty is trying to come to terms with the changes she is experiencing in herself. She still manages to function to a certain degree and uses her belief in her continued skills as a driver as a way of expressing this. She sees herself as a good driver compared to others who she describes as 'fools'. This could suggest she can reinforce her positive sense of self by believing if she was so affected by the AD she would not be able to drive. Her use of the expression 'fools on the road' operates to position herself within a strong positive competency framework which helps her to define herself through skilled action as well as emphasising that she is still capable of making her own decisions and maintaining her independence. Whether she actually does function like this or not, the importance is in her belief that she is making the decisions (Haak *et al*, 2007). Betty also rationalised the changes in herself as a natural part of the aging process, which enables her to feel happy being herself despite AD.

### **7.2.2 Unhappy being me**

Whilst Betty and Ruby are able to remain positive about themselves despite their growing need for care, for some women, the experience is one which generates a more negative sense of self. During Jean's interviews she reflected on her life as a child and described a time when she was happy:

*Jean: Yeah, when [village] was [village] that was, and lovely it was, I had a smashing, smashing; when I was a little girl, I went everywhere and whatever I wanted to go, if I wanted to go in somebody's house or in the garden, or anything, yeah, could. That was just after the war like. That were alright. ....I don't know, really, um, I don't know when my best days were. When I was younger I expect (long pause) when the war were on. Everybody were frightened, they were..... Yeah, I had a good friends, friends, girlfriends as well and we used to play together. And urh, make up whatever we might, wanted to make up. Yeah,*

*that was good, I remember that. Umm, (pause) I had a good, I expect I had a good time, made me own time and I had a nice friend, one particular friend (pause) who lives at, out the back way somewhere, now. Haven't seen her for a long time but she were my friend. (Interview 1)*

This offers insight into Jean's view of herself now, as she talks about her time during the war being her 'best days', providing a contrast with her current unhappiness. Despite being frightened, Jean suggests she was not the only person feeling this way; everyone felt the same due to circumstances at the time. This gave Jean a sense of belonging in her neighbourhood and alongside the good friendships she describes, helped promote a positive self. Jean no longer lives in this neighbourhood and stated most of her friends have moved away, which could be producing feelings of disconnection with her past. Jean also talked about having the freedom to go where she wanted when she was a young girl, suggesting she felt no restrictions on her life, perhaps indicating this is not the case anymore. Jean quite clearly perceives a difference in her present self, due to her lack of ability:

*Jean: No, I don't do it (tidy up), I mean there's a machine (sewing machine) in there (points to bedroom), all clothes on the bed, oh, it's terrible in there. It is, I look, I mean, I were never like that. (Interview 2)*

She describes what she sees as 'terrible' and states she 'was never like that'. This suggests that she did not view herself as an untidy person in the past and is judging herself on her own previously set standards. Jean perhaps views the untidiness in the bedroom as a symbol of the change in her situation and herself, believing that an important part of who she is has diminished. Jean's daily occupation has been to take care of the home and this could arguably be the means through which she is able to communicate her identity as a competent woman (Christiansen, 1999). As her ability to care for the home and her husband reduces, this has an impact on her perceived level of competence and thus her view of herself and her identity.

Phyllis' experience of AD and becoming cared for is similar as it does not enable her to maintain the positive attributes and self-identity she had prior to the AD:

*Phyllis: The whole family, we came from a family who were always talking to one another, my husband couldn't understand it when he first came into my family (laughs) but he got used to it. And joined in.... We use to have big discussions but now we don't.... I mean I can't have a good conversation with*

*him now after the (news)paper for instance, it's gone, urm, I read the paper, that's daft, [husband] will say "read the paper, it won't hurt". I read the paper but I've forgotten like that (clicks fingers to demonstrate speed), it's gone. I do it because he wants me to do it, hm..... It is a loss, we should be together with things like that...He's (husband) an old man now and he just needs to get some space and he's very educated and he likes doing nice things. (Interview 1)*

Phyllis is describing her experience of becoming cared for here, as a loss of certain personal attributes. The ability to converse with her husband and to spend quality time with him and her family appear to define part of what makes Phyllis feel unique. Relationality in the form of conversation is a simple activity that can be very meaningful to all (Alzheimer's Society, 2013) and this perceived deficit can result in an overall feeling of loss, in this case, of the person Phyllis was. She uses the word 'daft', which could indicate she sees her level of intelligence diminishing. This view of herself is compounded by her fear that her level of intellect no longer matches up to her husband. The new attribute of AD appears to be creating a negative view of self for Phyllis:

*Phyllis: I feel helpless most of the time..... It's because they're, I must be a bossy boots, it's because I'm used to doing things, yes...I'm trying to think of the word, urm, (pause) it's urh, I can't find the word, but it's a feeling that you, you're useless (pause). Yeah, I think that's the feeling that you get, all these things are happening around me because I can't do it..... I would be doing everything. If they came to my house I use to, everything was, I did everything. The cooking and everything....When I see my daughter in law, she comes and she's bustling around and I feel like crying because I think to myself, I should be doing this, this is my kitchen, and it really does upset me. I mean I don't cry or anything because I know, you know, I can't do it (laughs) but it, I've got to accept it. (Interview 1)*

Phyllis describes experiencing feelings of both helplessness and uselessness. Her identity as a capable woman is diminishing, as she sees her daughter-in-law doing the things she believes she should be doing. The notion of 'doing' appears again here suggesting Phyllis sees completing IADL's as a way of expressing her gender identity. Her use of the term '*bustling around*' also suggests she remembers how it felt to be doing this. The image she sees of another woman in her kitchen, doing what she used to do, accentuates her negative feelings towards herself, as things happen that she is no longer in control of:

*Phyllis: Nobody comes for support to do, to do anything like that (laughs) or ask me anything, no.... I use to... It's nice to sit down with somebody, have a cup of tea, isn't it? And urm, try and help somebody.....(I've) always been used to doing everything all at once, people are doing things for me, you know, it's hard. Always been a busy body... I've never been cared for (laughs) I've always looked after other people.....I suppose a lot of people go through it, you just feel a bit hopeless and you want to do more things urm, and at the moment I'm not able to do more things because I do silly things, you know. (Interview 1)*

Phyllis tries to normalise the experience of AD by suggesting that others go through it, however her personal experience is based on her belief that her level of intelligence has decreased. She reiterates her negative view of herself by describing the things she does now as 'silly'. Phyllis fears she is losing her ability to support her family, not only in practical ways but also from an emotional position, no longer having the intelligence to offer advice or support where she once did. She states she has always looked after others and as with Jean, the loss of these occupations and positive attributes creates the conditions for a loss of identity (Christiansen, 1999).

In the previous chapter, becoming cared for from Edith's perspective meant feeling a part of her had been taken over. This also affects her sense of identity in a number of ways:

*Edith: I suppose really, the situation, I'm so used to not doing, it's like everything in life, if you do something for years and that and you're in a rut, I've got into the rut of not doing anything, if I'm honest....I don't want to go on living like this, what life is it, I just sit here all day, he won't let me have a little dog so I could get out for a walk.....He doesn't like me to drive, so I can't... I can't see what I've got to look forward to.... I'm not happy; it's like being in a prison really, just going out when he goes. (Interview 2)*

Rather than see her situation as a result of her AD, Edith makes sense of the experience by blaming her husband for her inactivity. There is a sense of feeling trapped in Edith's narrative and this experience of loss of freedom and control creates the very negative picture she portrays of her life. Edith feels she is unimportant and of no use and sees her husband in a position of power, as he is making decisions for her:

*Edith: It's a terrible attitude to take but I'm not here just to clean. That's it.... He pays for everything; I don't have to put my hand in my pocket at all, which again is a bit embarrassing to me..... I feel a bit*

*embarrassed at times, like we go in the butchers and they know us all you know, I take a chew, the old dog at the butchers sits waiting when he hears my voice cause I always take a chew for him, yeah and he sits at the thing and that but I do feel it, yeah, feel belittled, that's the word. I do very much so. Yes. (Interview 1)*

Edith's experience here relates to task performance, which appears to take on different meanings for her depending on the implications the tasks hold (Kroska, 2003). She states clearly that she is '*not here just to clean*' suggesting that she views this task as less meaningful than others. She appears to hold a hierarchical view of IADL's as managing the household finances in the past was an important aspect of who Edith was. Now this has been taken away from her she experiences feelings of embarrassment. This perhaps indicates to others that she can no longer cope. She may be striving to regain some equality in her relationship by refusing to do tasks which she sees as placing her in a more lowly position to that of her husband. She describes the overall experience as making her feel belittled and useless and this is different to how she was viewed in the past:

*Edith: Yes, I felt that I was useful, apart from doing the cleaning you know, apart from doing the cleaning I thought I was useful being, coping with the shopping, the money and that but um, I feel useless now (pause) absolutely, but there you are, that's life init? You have to cope with what's thrown at you as we say. I do think why at times cause I never, I never ever and I'm not just saying this, I never ever asked him for any extra housekeeping, if ever I was a bit anything, you know, cause I was earning and that, if ever I needed it I'd urh, I always had cash in my purse so I didn't need to but um, I shall never be able to understand.. I feel degraded. (Interview 1)*

This feeling of lesser importance is compounded by her lack of insight into her diagnosis and its effects and by her husband's lack of communication with her about the change. She sees no change in her abilities and holds a strong feeling that she would still be able to cope if she was given the opportunity. The experience of 'doing'; being occupied and in control of things, was a big part of how Edith identified herself, however she talked about her level of competence in her activities:

*Edith: I don't know but I feel you know if I went out and started doing anything, I wouldn't be doing it right, so I feel I'd rather than sort of be told what to do, I'd rather stay in here and perhaps be miserable or just not do it. (Interview 1)*

The level of success achieved when dealing with tasks may impact on Edith's view of herself as a competent woman (Christiansen, 1999). It appears that Edith would rather do nothing, than do it and get it wrong; therefore avoiding these tasks reduces the risk of embarrassment. There is also a risk to her reputation and view of herself if it is identified that she is no longer able. If she does not 'do' then she can continue to tell herself that her skills are maintained.

### **7.2.3 Fighting to remain me**

The experience for Dorothy differed slightly to those above and demonstrates her desire to maintain the identity she had prior to her diagnosis. Her experience of becoming cared for is a negative one, as she fights to preserve her position in her family. This began when she was younger and was tasked with looking after her brother and sister:

*Dorothy: I had to look after the kids cause I was the youngest one, I was the oldest one and had to look after the young ones. I never went anywhere without them, it involved by taking them to school, making sure they were all alright, fetching them home, looking after them at home. Um, I can't say I actually had to feed them, because there was never much in the house of course you know, I had them all the time and I'd got friends but they said you can never come out and play and you know, I wanted to, I've been so long, so many years doing what I want to do and look after the um, the family. Cause we haven't got a mother or a father now and I think they look, and my eldest brother's dead and my sister in [different country], so I'm the eldest one of the family and um, but we're very close. (Interview 1)*

As in previous cases, Dorothy's experience of becoming cared for and how this affects her is related to how she viewed herself in the past. She describes being a central person in the family, taking responsibility for her siblings and continuing to feel responsible for them as they all got older. Her ability to do this gave her a sense of value and worthiness and she prides herself on the family remaining close over the years. When asked about what has changed now Dorothy has AD, she was quick to talk about her central position in the family and the sense that this was diminishing:

*Dorothy: It's always somebody doing it for me...cause before, if, you know, [husband] would always say "Oh I don't know, you'd better ask Dorothy"...but now (pause) he don't. And I say, "I never know what's happening". He says "Well you was listening" and I say "But I don't always hear when there's four or*



*five people talking” so urm I said, “They talk to you more than they ever do, ever did before”. It was always me. But course he sent them to me to ask, but now....I wasn’t like it sort of five, six years ago I wasn’t like that, I’d think it was lovely to be looked after but now, I think it’s too fussy, I want to be left alone to do it myself, I’m capable, I’ve done it all my life, I’ve worked and things like that. (Interview 2)*

Dorothy makes an interesting observation, suggesting that a few years prior to her diagnosis she may well have been happy to be looked after. She is thinking about a time prior to her diagnosis of AD and presumably a time when she was able and fully occupied. The perception of being cared for when she was well and had control of her decision making is very different to the reality, now that her power to choose has been reduced. The loss of control in Dorothy’s decision making may mean she feels less freedom and less able to maintain a sense of independence (Haak *et al*, 2007).

Dorothy describes her current experience as ‘fussy’ and she strives to maintain her independence wherever she can:

*Dorothy: If I can get my hands in amongst them you know, I want to do it, oh yes. Cause I come in with a plant pot the other day, it’s a wooden one, somebody gave me it, with a nice big man on a horse back, so, but it was wood and I scrubbed it and I want, I put, no I didn’t put any soil in it, I scrubbed it and brought it in and I said to [husband] “Have we got any paint?”. He said, “What do you want?” I said, “I want to paint this up cause it’s gone a shabby”, I said, “Before I put it out on my new garden”, so he said “I’ll do that for you” I said “I don’t want you to” (angrily), you know, straight away. It’s my suggestion. I want to do it. And I’m afraid that’s how I am. Oh, they all want to do things. I ought to, I said I must (big angry sigh) oh I don’t know, I’m not a very nice person because I want to do what I want to do, I’ve done it all my married life sort of thing, although we’ve always been together and we do a lot together but when the young family, children as I call um, they want to do it for me and I don’t want to sit on my backside I want to be in the middle, I always was. (Interview 1)*

Dorothy makes a strong statement here, asserting that she still wants to be active, to be allowed to do things and to be involved in life, even if it means she may get it wrong. Dorothy would feel more value as a person if she was able to maintain the positive attribute of independence; however her fight for this results in her experiencing negativity towards herself. She is also battling to maintain her place in the family and her own sense of value as she expresses that she was always the one in charge and her experience now is very different. The impact of others behaviour on

how Dorothy views herself is highlighted here and will be discussed in more detail in the final part of this chapter.

### 7.3 Experiencing others

Five of the women talked of their experiences related to how others perceive and behave towards them. Kitwood (1997) has focused on the way people with dementia are treated by others and how the social world comes into play. He defined this as personhood, meaning 'a status or standing given to one person by another in the context of social relationship and social being' (Kitwood, 1997; 8). Kitwood's main concern when talking about personhood was the effect negative behaviour from others, though not maliciously intended, could have on a person with dementia and their well-being. The cooperation of others in the construction of a positive sense of self for people with AD and dementia has also been highlighted as essential by Sabat (2001). This suggests husbands and families have an important role in the construction of the women's sense of self and their lived experience.

As discussed in 7.2.1, a part of Betty's identity is maintained through a belief that she is still a competent driver. This view of herself is put at risk however, when she notices a change in her routine brought about by her daughter:

*Betty: I don't think [daughter] is keen on letting me (pause), cause I keep saying 'I'll pick [grandson] up' and I've noticed that she says "no mum it's alright". I don't think she wants me to drive [grandson] around on his own, which I used to at one time, pick him up from school. But urh, I haven't said to her "Oh you don't think he's safe with me" but urh, but if he ever has to be picked up actually, [husband], we both go do it so urh, if she needs us; we are still there for her. But if I say I'll do it on my own, she'll say "Oh he likes to see his grandpa" and I have a feeling that's how she's getting round it....I don't mind, I'm getting old, I'm lucky to be alive. (Interview 1)*

Betty makes sense of this reluctance in her daughter by avoiding in-depth discussions about it and putting it down to normal ageing. These deliberate actions suggest Betty is attempting to preserve her sense of self and maintain the image that was intact prior to her diagnosis (Beard, 2004). Despite her daughter's obvious decision to stop Betty driving alone with her son in the car, Betty is able to revise her behaviour and involve her husband to ensure she can continue to function in the tasks she has always

done. This appears to promote a continued feeling of satisfaction in her life and enables the maintenance of her values and a positive sense of self (Kielhofner, 2008). Ruby acknowledges she has a diagnosis of AD but when asked more about how her husband cares for her now, she struggles to express herself. Her level of insight into her ability to function appears to be limited; however her reflections suggest she has some awareness of how she is affected:

*Ruby: I can't think, I mean maybe, maybe, in some ways I maybe ask him for more advice you know, I can't really think cause I mean generally when you urh, like this, you think you can do it... In all probability (pause), but we've always (sighs), it's difficult when you're having somebody, urh, I think, you know, I mean housework and that, whatever it is, I can do all that, I think I can do most of it urh, but if there's something, [husband] will say "Well I'll do that for you", or something like that but I, maybe of late, maybe he's helped me a wee bit more with things, sometimes he'll do quite a bit of the cooking and things, not that I can't do it but he's here in the house and he, he helps about, you know, like husband and wife, you know, he's not the husband who just sits back and the little wifey goes round you know. (Interview 2)*

Ruby is making sense of the experience as she talks here, claiming she can do it all whilst acknowledging her husband's help. She reflects and processes the realisation that her husband does more now, but views this as a change in his behaviour and not due to her lack of ability. Ruby states that her husband has never expected her to do everything in the house alone and this continued behaviour allows her to remain in her valued position as his wife. By receiving this cooperation from him, she is able to maintain a valued and healthy persona (Sabat, 2001). When she was asked about reliance on her husband Ruby acknowledged this to a certain degree:

*Ruby: I think so, I think sometimes there is but not necessarily for everything, maybe important things and decisions and things like that there's that, but generally speaking urh, I mean it's not as if to say, well, "I think I'm going to do something, will that be alright?" most of the time we, I mean I've got my own, I go to WI and things like that. (Interview 1)*

Ruby is still able to feel in control of her own life as she talks about making decisions for herself. Her reliance on her husband for 'important things and decisions' does not appear to impact negatively on her view of herself. She believes she remains independent and does not need to ask for his permission to do things which maintains her sense of equality in the relationship and ultimately her self-identity.

Jean's relationship with her husband is very different to those discussed above but equally has a strong impact on how she views herself. As discussed in section 7.2.2, the changes in her ability to take care of the home have engendered feelings of a loss of womanhood in Jean and this view of herself is compounded by her observation of her husband:

*Jean: So what do ya think to me, nothing?.....Do you think I'm daft? I'm not as clever as him (husband), I'm not as clever as him.....I think I ought to be better, yeah, than I am.....um, um, thinking, more here (points to head)....um, does that sound daft? (Interview 1)*

She compares herself to her husband whilst also signifying a belief that others like myself, will agree with her negative appraisal. Despite her awareness of her diagnosis of AD she strives to be better than she is. Her interpretation of her husband's behaviour however, creates further destructive feelings:

*Jean: He's, (husband) he's, well he's um, he's a bit stronger in his self and a bit more um, it's, it's not reserved the word, it's he's um, (pause) he knows more and he's alright ya know. He's alright anyhow, yeah, he gets on with it and he sorts (everything)..... Yeah, yeah, I try everything, I try un do things, but he's, he's a perfectionist, I will say that, I would say that (pause) but I don't take it all....I think he thinks I aint um, good enough and quick enough, yeah. He thinks, he'll do it, he'll do it, she won't be able to do it and I can..... I get angry with him for being like it and I'm angry with myself for being like it (long pause) it's stupid (long pause) .....I don't clean up like I used to or anything like that, which I used to. Um, but (pause), I dunno what I do. (Interview 2)*

We have learnt in chapter six that Jean feels she is no longer able to match up to her husband's exacting standards. The impact this has not only affects their relationship but Jean as a person. Her husband's behaviour highlights Jean's reduction in ability and despite her efforts to maintain some sense of worth through trying, she perceives him to have little patience with her. Without encouragement and positive reinforcement from her husband she experiences feelings of anger. This compounds the negative view she has of herself, as his perceived beliefs leave her experiencing a loss of purpose and achievement (Dewing, 2008).

Despite Dorothy's close relationship with her husband and family as discussed above, at times she described frustration at their behaviour towards her:

*Dorothy: I'm not allowed out on my own (laughs). That's the biggest thing... (it's) terrible...because I'm not my own person. This is my house, and [husband] of course and um, I want to go and buy bits that I want and if anybody beside, well [husband] he knows, sometimes he lets me get away with things but if I went out with [sister] or any of the others, it's "You don't need that, you've got a house full of bits and pieces, I don't know why you don't you know, housework would be better if you hadn't got clutter" I said "I like my clutters, they're my clutters not yours"....I won't give it up. I say I don't care what happens, they're not changing me, I'm going to carry on. (Interview 1)*

The behaviour her family are now displaying towards her differs to their behaviour prior to her AD diagnosis. Dorothy struggles to understand why they will not allow her to live the way she has always lived, as the things she buys for her house have been a fundamental part of who Dorothy is. Their behaviour suggests they are now viewing her principally in terms of her AD diagnosis, forgetting the attributes that gave her a sense of value throughout her life (Sabat, 2001, p 159). Feeling that her family are trying to change her could be interpreted as meaning she is no longer the person she was. This could create a change in how Dorothy views herself, as she has always relied on her husband and family to help her maintain her identity (Sabat & Harre, 1992). She goes on to describe an experience meant to promote her feeling of being involved in life. Taken shopping by one of her granddaughters creates an experience that makes Dorothy feel childlike and out of control:

*Dorothy: Even then she treated me like she was the young girl and I was the urm, no she was the mother and I was the young girl. It was um, "Now what shop do you want to go in next?" "Well, didn't we go in that one", "You're not having more chocolate" you know, cause I wanted to go in the pound shop you see and um, then it was "Well, no you don't want that" and the best of it was, um, we went up to BHS is it? And had a cup of tea, pot of tea and um, she said "I'll have to go to the toilet, are you alright"" so I said "Yes I'm alright", "Don't you wanna go?" I said "No not at the moment", so she says "Well you sit there, don't you move, I shan't be more than five minutes and if you've moved I don't take you out ever again" and urh, I sat there and thought, I'm not saying anything, I was enjoying myself and of course then when I'd had the pot of tea I said "Before we move from here I've got to go toilet", she said, "Well I'm coming with you" I said, "You're not", she said "I'm not letting you go there on your own" and huh, I mean in one way it was nice but in another way I thought, I'm going back to me childhood.....sometimes I love it but other times I could scream. (Interview 2)*

Dorothy is very aware of the love her family have for her and she struggles with the feeling of frustration she gets, as her need for care grows. The behaviour displayed by

her granddaughter instantly reminds Dorothy of how she was treated when she was a child. The experience of not being listened to engenders a change in status within the family (Langdon *et al*, 2007), which may lead to a feeling of loss of respect. This does not support the maintenance of a positive sense of self for Dorothy and could impact on the relationality she has strived to protect over the years.

A similar picture can be seen for Phyllis as she describes how the AD has affected the way her family behave towards her:

*Phyllis: She's (daughter) always telling me off, telling me what to do, buy this get this, she can, she can be very sharp urm, but I've noticed lately that there is a big difference in her, to me, urh, yeah so, a nicer girl, I mean she's always been a nice girl, she's my girl but I think people think when you've got Alzheimer's you haven't, you haven't got anything to say (laughs) " This is it mum" you know, "This is what you do". (Interview 1)*

Phyllis tries very hard to understand why her daughter behaves the way she does and expresses her continued love for her, despite being treated differently. However, the language she uses creates an image of the reversal of the child parent relationship, as described by Dorothy. Phyllis goes on to express this more specifically when talking about her husband:

*Phyllis: I feel it's a bit like being the child, being told what to do all the time.... not in the, (pause), ye, (stutters) that's about it, I don't think that in my mind but that's the way I feel, keep it, keep it low and don't, don't do anything wrong....He used to be urm quite bad tempered if you said something silly but he doesn't say anything now. (Interview 1)*

For both Dorothy and Phyllis their sense of identity is influenced by the experience of being treated like a child. This clearly causes a reduction in their ability to view themselves positively (Sabat, 2001) and is a direct result of the behaviour of others.

## **7.4 Summary**

This chapter has discussed the women's experience of becoming cared for in relation to their sense of self and identity. Changes in identity affected by the increased need for assistance with IADL's, were expressed by the women in terms of gender and relationality. From some of the women there was a sense of being valued by their

spouses for who they are and not what they can do. Believing in themselves and their continued importance in the spousal relationship creates a sense of belonging. At the other end of the spectrum, negative experiences such as losing one's identity as a woman due to their inability to perform IADL's, feeling left out of the family and a need for perfection were expressed.

Throughout this chapter the women can be seen to be attempting to hold on to their sense of self and identity, remembering the women they were prior to their diagnosis. In the following and final findings chapter, I will explore the experience of change as a more positive transition in some women's lives.

## 8 Seeing cobwebs

In this chapter I explore the notion that some women's experience of becoming cared for can be understood as another transition in their life, as is getting older. I will discuss how a change in their ability to complete IADL's due to AD may not always be experienced in a negative way. There may be some positive aspects which have rarely been explored in the academic literature. We know from previous chapters that some people with AD differ in certain ways compared to the way they were prior to AD (Dewing, 2008), however the experience of becoming cared for from the perspective of two women in this study highlight a divergence from the experience of others.

Hellstrom & Torres (2014) describe the future for a person with dementia as a dreaded part of the illness trajectory. Margaret and Ann however, make sense of the changes happening to them, in a way that suggests their subjective view of becoming cared for and their sense of well-being and life satisfaction is different. These women made me think about acceptance and how a life can still be lived well, despite an illness such as AD.

### 8.1 'I'm not the same, but it doesn't worry me'

Margaret is a woman who experiences becoming cared for in a positive way. Here and in 8.2 I introduce the idea that change can provide a sense of contentment in women when they become cared for but may also enable them to thrive. Margaret's view of her world in relation to becoming cared for is interpreted by the way she experiences change. The over-riding interpretation here provides the title for this chapter, as Margaret creates meaning from the things she sees. Firstly however, it is important to understand her experience in relation to who she is.

It is known from chapter five that Margaret was a hard working woman who had particular expectations and standards in life that had to be achieved. These characteristics were a significant part of who she was prior to her AD and this is supported by the following quote:



*Margaret: And I was quite fussy, very particular. I used to get cross with him (husband) if he didn't take his shoes off at the front door. (Interview 1)*

She also described her working standards and her expectation of the standards of others, including the residents of the nursing home:

*Margaret: I don't know really, I think I was always a bit fussy with food myself so I expected them (nursing home residents) to be. (Interview 1)*

When asked about her diagnosis of AD Margaret was able to demonstrate awareness based on her nursing knowledge and previous experience:

*Margaret: (long pause) Well I think I probably knew before them.*

*R: What told you that then?*

*Margaret: Well, forgetting, you know, forgetting where I am or who I am but it never really worried me much cause I'm sure my father had it. (Interview 1)*

We can see from this excerpt that Margaret appears to accept her diagnosis of AD with a sense of inevitability. She believes she knew it could happen due to her experience of her father's AD and the knowledge she had gained as a nurse. This suggests her experience is being led by what she has seen over time in her father and the residents she cared for. This subjective knowledge is helping Margaret to create meaning in her current situation (Trevithick, 2008). She implies the forgetfulness she has noticed in herself is similar to symptoms she witnessed in her father. The experience is not worrying for Margaret; perhaps because her view of her father's experience was not a negative one. It may also be due to a sense of familiarity she is experiencing having been exposed to the illness in her personal and working life. This could be reducing any fear she may have had if the AD were unfamiliar to her. The ability to predict what might be happening to her and her acceptance of her situation gives her a sense of control and therefore helps to promote her subjective well-being (Hammarstrom & Torres, 2012):

*R: Can you tell me if you think anything has changed since you got your diagnosis?*

*Margaret: (pause) Well I suppose it has cause I don't go shopping or anything, I just sit and knit, I love my knitting .....I'm quite happy just sitting.....I don't know really, what I think about. If I see people*

*walking along I always wave and I used to know who they all were but I don't know, I've forgotten. Yeah, but it doesn't worry me. (Interview 1)*

Here Margaret is experiencing a change in her way of thinking and her behaviour since her diagnosis of AD. The description she gives of her daily routine suggests she does not dwell on these changes but lives in the moment and takes great satisfaction from simply sitting and knitting. Living in the present moment is a defining characteristic of mindfulness which requires a person to acknowledge an experience as it occurs and accept it in a non-judgmental way (Davis & Hayes, 2011). This has been found to be a powerful strategy for managing stressful life events that can occur for older people (de Frias & Whyne, 2015). Margaret does not appear to focus on her past; neither does she talk about the future. Her ability to enjoy the simple act of sitting, not judging herself on who she can remember or what she is thinking, suggests she is experiencing mindfulness. This may not be a conscious act, however being mindful promotes her psychological well-being and has been a positive trait found in other older adults (Hohaus & Spark, 2013).

At times during her interview, Margaret displayed a continued recognition of the need to complete certain IADL's:

*Margaret: Yeah, I ought to do more, I feel a bit guilty sometimes, like urm, I forget what day it was now and I thought this needs dusting badly so I you know, sometimes I try.*

*R: Did you get the duster out and do that?*

*Margaret: No, not when I think about...I should but (pause) urm, you know I look and (undetectable) thick dust and I think 'oh dear must get that down'. (Interview 2)*

Although she shows an awareness of need, Margaret appears to be disengaging with her past self now, showing less interest in doing things around the home and maintaining the standards she once had. People with AD are often defined by a list of symptoms which it is believed should be medically controlled (Cuijpers & van Lente, 2015). This biomedical view could assist in the interpretation of Margaret's current situation as she seems to lack motivation for doing things and is becoming apathetic (Lyketsos *et al*, 2011). She expresses feelings of guilt that she is not doing what is

perhaps expected of her. However, the experience of guilt is short lived, as she talks about how she experiences her husband doing things for her, such as the shopping:

*Margaret: Oh it doesn't worry me, and [husband] he moans but it doesn't worry me*

*R: What does your husband moan about?*

*Margaret: Me! (laughs)*

*R: Why does he moan about you?*

*Margaret: Well cause he has to do all the jobs. I don't blame him moaning but I mean he only moans and all men are good at moaning (chuckles).*

*R: So who chooses what you buy?*

*Margaret: He does.*

*R: And how does that make you feel?*

*Margaret: Quite happy, I've taught him (laughs) (Interview 1)*

During the interviews with Margaret, she demonstrated a playfulness; commenting and laughing at the behaviour of men in general and of her husband. This suggests her view of men may not conform to the traditional view that men hold the power in the marital relationship. Her experience appears to be one of contentment, despite the fact that her husband moans at her. There is a demonstration of a subtle expression of agency here as Margaret seems to absolve herself of the domestic responsibility (Boyle, 2014). She has accepted that she no longer does the things she used to, which may have involved restructuring her perceptions to enable her to deal with the situation of becoming cared for (Carver *et al*, 2010). This restructuring emerges in the form of a belief that she remains in control of the situation, as her husband is doing what she has taught him. If this is the case, she may feel the standards she set will remain to some degree; therefore she will be cared for in the way she wants to be.

Margaret expresses that she does not blame her husband for moaning, which could also suggest she understands how he feels about the jobs he has to do. There may be a part of her that is happy to see that he is appreciating the work she did throughout their married life. She may believe that she has contributed her 'bit' to society and the family, and the recognition of this from her husband promotes her sense of well-being and self-assurance (McCann Mortimer *et al*, 2008):

*Margaret: He gets on with the jobs and urm, he's good, yeah he is (pause) I mean there's a heck of a lot to do, well he does, you know. Yet, I often think if it reverse and he was just sat here like, I'd be angry with him..... Well, you know I mean I sit here, it's perfect.....Well I think I'm lucky. Urm, not many men would do it would they?*

*R: Why do you think that?*

*Margaret: I don't think my father would've done. No, no he wouldn't. But with [husband] he's ever so good. (Interview 2)*

Margaret does however, view herself as lucky. She takes a gendered perspective here as she makes the distinction between her husband and other men, including her father. She states she is lucky as her husband is prepared to take on the responsibilities she is no longer involving herself in and which are viewed as women's responsibilities. Despite Margaret's need for care, she conveyed a strong sense of continued confidence in herself and a contentment with the life she has chosen to live:

*R: What about now, are you independent now?*

*Margaret: Yeah, very.*

*R: In what way?*

*Margaret: Well, I've got [husband] to do (pause) he does a lot. (Interview 1)*

Interestingly, when asked about how the changes affected Margaret as a woman she did not take a negative view:

*R: How do you think it changes you as a woman, not being able to do the jobs around the house?*

*Margaret: Well, I suppose I look lazy. Although I'm always knitting. And [husband] gets me the wool, he gets loads for me.*

*R: Do you think it's important to remain independent for as long as you can?*

*Margaret: No.*

*R: No, why not?*

*Margaret: Cause I haven't (laughs). But I think when you marry, which was 52 years ago, you should, before you, when you've fall in love you should look at him and think ah, is he efficient (laughs). Would he work hard? (Interview 2)*

As a woman it would appear she may have taken the decision to find a man she could marry who would be effective in his role as her husband and as a carer and who ultimately is now doing what she always planned. In the quote above Margaret again observes that her behaviour is not what is perhaps expected of her as a woman and

she acknowledges her level of independence has changed. Despite this, Margaret remains positive appearing to take strength from the fact that her husband is there to do things for her. She is able to feel a sense of self assurance and control in her life, which is brought about by her perceived success in choosing the right husband.

## **8.2 'I used to worry about cobwebs, now I quite like them'**

What we have learnt about Margaret in section 8.1 is that her way of living has changed quite dramatically and this appears to be since the onset of her AD. The changes in her attitude and behaviour could be symptomatic of her AD; however there may be a different explanation. Margaret's values in old age may have changed from instrumental values such as ambition, intellect and capability to more long lasting values of freedom and a sense of achievement, indicating she has reached a position in her life she may be happy with (Kielhofner, 2008). Being able to accept her diagnosis and adjust her attitude to the standards she used to have, could be assisting Margaret to let go of the perceived stressful negative life-event that is 'becoming cared for'. It could also be argued however, that the expectations she put on herself were stressful in themselves, therefore, letting go of these offers the ultimate feeling of contentment (Swift & Chipperfield, 2013):

*Margaret: Well I was always up early, working and... But now I mean I'm quite happy, I wave to everybody that goes past and you know, in the field. No, I'm quite happy. Um, I expect I'm a bit lazy..... And I look for cobwebs because I think they are beautiful, you know I look and I see them, my granddaughters come and they say 'oh grandma you've got cobwebs', and I go 'don't move them' but they do (chuckles) but I love them.....Whereas I used to worry about cobwebs, now I quite like them. (Interview 1)*

Margaret's experience of becoming cared for is one of liberation. She appears to not just accept what is happening to her but embraces this. She has adjusted her attitude to the housework and her previous standards, to fit her new life (Morling & Evered, 2006). She no longer experiences time pressure, she can wake when she likes and does not have to go to work. It is possible that she feels liberated from the expectation she put on herself to meet exacting standards but also the expectations of the socially

constructed world around her. For Margaret the cobwebs she now sees represent a change for the better in her life. She sees beauty in the cobwebs she observes and states she is happy 'now', suggesting she may be reflecting that she was not as happy previously. Her time was perhaps spent worrying about things which she now views as less important and there is a sense of relief that she no longer has to perform to the standards she had previously set herself.

There is a supposition in Margaret's talk that she is being lazy, however this could be a view she perceives others have of her or one her old self may have believed. She appears to feel no guilt about this and takes enjoyment from what she sees when she looks around now. There is a strong sense that Margaret is now choosing to live like this regardless of her diagnosis of AD:

*Margaret: Well, sometimes I look at cobwebs or, or see if there's a dirty bit (looks at carpet) I can see dirty bits and I ought to get the hoover and I don't. I just pick a few bits up and put them in my carrier bag. I always like a carrier bag to keep rubbish in (holds carrier bag up that was by the side of her chair). Then I pick things, I see a bit over there (points to the carpet)*

*R: So why do you think you don't do it when you see it?*

*Margaret: I don't know, I don't think I know now how the hoover works.*

*R: Right.*

*Margaret: I'm not sure whether I do get it or not, I can't remember.*

*R: Can you think about how that makes you feel, to think you don't know how the hoover works?*

*Margaret: I couldn't care less (laughs) I'm ever so urm, lazy minded, which is hard on [husband]..... I don't know (pause) I don't know, cause as long as I've got a rubbish bag (laughs), my best friend is a rubbish bag. (Interview 2)*

The quote 'my best friend is a rubbish bag' was the only indication Margaret gave that a part of her old self still exists. This may indicate that she would still like to be able to maintain her previous standards or it may be a simple reminder of the life she had. The woman she was and the self she has known throughout her younger days is what has helped create her sense of who she is now. Conversely, continuing to keep a rubbish bag could suggest that perhaps Margaret's standards as a person have not dropped; she just sees other things as more important now. She appears to have changed her priorities, accepting and adapting herself to her new situation (Morling &

Evered, 2006). Holding onto the rubbish bag may be a way of still holding on to a part of her personality; she is not changing who she is but evolving as a person into the next stage in her life.

As people progress through life they move through a number of transitions such as; starting school, leaving school, getting married, having children, retiring (Hutcheson *et al*, 2010). During this time a normal process of changing beliefs and attitudes occurs due to the experiencing of new things and gaining new knowledge about life.

Margaret has decided she does not need to worry about the things she used to, as she feels much happier experiencing freedom from pressure constructed by herself and the social world around her. What needs to be acknowledged here is that this behaviour may be indicative of agency rather than symptomatic of AD (Boyle, 2014) and maybe a normal transition in her life course.

Margaret appears to manage her experience of becoming cared for by accepting and adjusting to the changes and she continues to find purposeful meaning in life through simple activities, such as knitting. This appears to be enough to warrant her feelings of continued well-being. In the following section the concept of managing change in relation to the experience of becoming cared for is explored in more detail.

### **8.3 Rejecting the dark side**

In this section I discuss an element of the experience of becoming cared for from Ann's perspective. As in Margaret's case, Ann's overriding experience is one of positive acceptance and contentment. To achieve this she appears to adopt an outlook which helps her manage change in her life:

*Ann: I try to keep busy but obviously I can't do what I used to do.*

*R: Yeah, and how does that make you feel?*

*Ann: (pause) Well there's no use looking on the black side is it? (Interview 2)*

It is known that Ann acknowledged she can no longer care for her family in the practical ways she used to (chapter six), nevertheless her sense of who she is as a person appears intact. She refers to not '*looking on the black side*' when asked how

she experiences the changes in her due to the AD. This suggests that there is a part of her who sees the changes as negative, however she does not think about this, perhaps knowing she has no way of changing the situation. She indicated that she has a philosophy in life to help her live through challenging experiences. As the first interview ended Ann continued to talk and stated simply '*Live, love and laugh*'. Although this was not recorded, at the second interview I asked her to expand on this a little:

*R: So you said to me last time I was here "live, love and laugh" yes? Do you remember saying that to me?*

*Ann: Yeah*

*R: So is your sense of humour the same now as it always has been? Have you got a good sense of humour do you think?*

*Ann: I think so, I hope so.*

*R: Why do you say I hope so?*

*Ann: Well there's no point looking on the dark side of everything is there? (Interview 2)*

Ann sees her sense of humour as an important part of her lived experience. The philosophy that she holds of avoiding negative thoughts and using laughter may have been successful in reducing stress in the past, having experienced difficult life events as described in chapter five.

A study undertaken by Soloman (1996), looked at humour and ageing well and found 'feeling in control of things that happen day-to-day' to be positively associated with finding humour in most situations. Soloman also found that satisfaction with life was related to not losing a sense of humour when confronted with problems. Further research on humour and ageing well has determined similar findings and suggests humour can play an important role in managing health issues in an individual (Marziali *et al*, 2008). Although both these studies explored humour and ageing from a quantitative perspective, Ann's lived experience appears to demonstrate comparable findings. The hope Ann expresses that she can maintain her sense of humour assists her in maintaining cognitive control of her situation by restructuring the negative aspects of becoming cared for in her mind (Soloman, 1996).



Ann's ability to accept that she is becoming cared for is founded on her use of positive thinking. She needs to believe that she can maintain her sense of humour, potentially to enable her to deal with the situation she is in. The hope that she has is grounded in realism, as she is aware of her limitations and this realistic viewpoint has been found in other people living with dementia who have a generalized sense of hope of living well (Wolverson *et al*, 2010).

Ann chooses not to look at things negatively, referring again in the last excerpt to her rejection of '*the dark side*'. This and her expression of hope, give the impression that her experience is created through optimism. Alarcon *et al* (2013) discuss optimism and hope as sharing conceptual similarities, suggesting both are goal orientated; 'optimism' being related to generalized outcome expectancies and 'hope' concerns the resolve to achieve goals and the means to do so. In Ann's case, she cannot control her diagnosis of AD or her need to be cared for; however she has control over other factors such as, maintaining her sense of humour (Gallagher & Lopez, 2009).

Alongside this hope for a continued sense of humour, Ann clearly experiences a sense of love from her family. When asked if she had always felt cared for she responded positively:

*R: In what way do you think?*

*Ann: (pause) Well it's difficult to say really isn't it, you know I know [son] loves me to bits and so does [daughter].*

*R: And how do you know that?*

*Ann: I just know it. (Interview 2)*

There is sureness in Ann's discourse. What she is experiencing now is a sense of love from her husband and family and as they begin to do more for her, this reinforces her sense of well-being and worth. Potentially she is able to view the physical act of caring as less important than the sense of emotional caring she shares with her family. This enables her to believe that she can still live a satisfying life despite her need for care (Swift & Chipperfield, 2013). She is using secondary control which enables her to adjust and accept her circumstances as they are and this leads to a feeling of well-being (Morling & Evered, 2006):

*Ann: No good getting frustrated is there?*

*R: That's good. You said to me last time that you feel very lucky, that's what you said last time I was here.*

*Ann: Yeah, yeah.*

*R: Why do you feel lucky?*

*Ann: (coughs) Well in the, as I say to you, in the respect that I've done things, I used to like to knit, pottery and we've been to America. (Interview 2)*

Ann is able to remember the meaningful things she has done in the past which helps her feel lucky in her life now. As indicated in chapter five and above, Ann demonstrates her caring through a continued emotional connection with her husband and family. Optimistic traits are evident again in the next excerpt, as Ann appears to have decided that becoming cared for is not a threat to her well-being as long as she can reciprocate the love she feels from her husband and family (Carver *et al*, 2010):

*Ann: I'm still their mum.... still as mum and dad, and wife*

*R: And what do you do to maintain that?*

*Ann: (pause) Love them. (Interview 1)*

In the previous chapter it was discovered that some of the participants found their feeling of womanhood was being lost due to their need for care. Ann identifies herself both as a mother and a wife and this enables her to demonstrate her caring, not through physical acts but through emotion. Looking at this through a gendered lens, the description Ann gives of herself strengthens her identity as a woman. The physical act of caring does not seem to matter to Ann:

*R: So how do you see your future?*

*Ann: Hopefully still happy. No good being down in the dumps is it?*

*R: So one final thing before I finish, you mentioned being independent, do you think it's important to be independent?*

*Ann: (pause) Urh, have to try and do things for yourself, from that point of view,*

*R: But if you can't do things for yourself, does that matter?*

*Ann: (pause) Well I suppose, not that I thought. But, (pause) what will be will be. (Interview 2)*

The future has been a topic of interest for some researchers in respect to people with dementia (Hellstrom & Torres, 2014, Hulko, 2009). Ann does not talk about the future but shows more positive feelings towards the 'now' she is living. Ann uses the word

'still' when describing her hope for happiness, which implies she is happy now. Having this discussion with Ann appears to have made her reflect on the importance of being independent, however maybe she had not thought about it in those terms before because she did not view it as requiring reflection or as a problem.

Unlike the women in chapter seven, Ann is not attempting to maintain the person she was but is accepting of the changes occurring due to the AD. Like Margaret, Ann's experience of becoming cared for is one of contentment. She does not dwell on the negative aspects of her life but feels contented with the life she has, experiencing both hope and optimism.

#### **8.4 Summary**

This final findings chapter has offered an alternative perspective to the view that women with AD experience becoming cared for as a negative event in their lives. I have suggested that what others perceive may be happening as a result of AD could be a normal part of the life course. Margaret and Ann appear to accept becoming cared for as a natural transition in life and one to be embraced. They do not view it as a negative experience but adjust their lives in a way that enables them to continue living well.

At the beginning of this chapter it was noted that the AD illness trajectory is a dreaded experience. The view of the 'outside world' including that of healthcare professionals is that having a diagnosis of AD means inevitable decline in cognition, function and thus quality of life. Margaret and Ann's experience offer a different perspective and suggests the need for a revision of this thinking. In this chapter I have argued that becoming cared for is not necessarily experienced as losing an identity, it is potentially just another transition occurring in their lives. The women in this chapter experience optimism and hope and the transition from caring to becoming cared for is a change which can offer a sense of liberation and contentment.

## **9 Discussion and Conclusion**

The aim of this study was to explore the lived experience of becoming cared for from the perspective of women with AD. Caring in nursing remains a difficult concept to define (Watson, 2012), however healthcare professionals, especially nurses, are now continually being asked to demonstrate the value of caring in their practice (DoH, 2012). The distinction between caring for someone and simply providing services needs to be remembered. Focusing on the human element will ensure care is meaningful, and understanding the experience of becoming cared for is imperative if we are to bridge that gap.

In this final chapter I discuss the findings in relation to my research objectives and how they relate to existing literature. I illustrate how my research offers additional insight into the lived experience of AD for women, and suggest the suitability of the humanisation theory to provide a framework to support a change in practice for healthcare professionals. I also reflect on the use of IPA as the methodology used to underpin the research process, and offer suggestions for future studies which could assist in developing further knowledge of the phenomenon of becoming cared for.

### **9.1 Theoretical Implications**

The findings of this study contribute to understanding the experience of requiring assistance with IADL's from the perspective of women with AD and suggest a person centred approach could support these women during the transition of becoming cared for. This research builds on the person centred approach which focuses on the individual (Kitwood, 1997), by highlighting a strong emphasis on relationality. Throughout my findings, the women's experience of becoming cared for is intrinsically linked to the views and behaviours of others. Therefore, I suggest the use of a framework which encourages healthcare professionals to regard women with AD as holistic human beings, whose lives are closely linked to their interactions with others when becoming cared for.

Humanisation theory offers this possibility, focusing on the individual as a human being but also the relationships each individual has with other human beings (Hemingway *et al*, 2012). This theory provides a conceptual framework of eight dimensions believed central to being human, each reflecting a continuum of humanising to dehumanising elements (Norton, 2013). These are; Insiderness to objectification, Agency to passivity, Uniqueness to homogenisation, Togetherness to sense of isolation, Sense-making to loss of meaning, Personal journey to loss of personal journey, Sense of place to dislocation and Embodiment to reductionist view of body (Todres *et al*, 2009). To promote a positive caring relationship each of these dimensions should be acknowledged and valued (Borbasi *et al*, 2012).

This framework concentrates on a person's well-being rather than ill health and has been used successfully to assist care home staff in the provision of care to residents with dementia (Borbasi *et al*, 2012). Borbasi *et al* found that encouraging carers to consider the human need of the resident by raising awareness of their individual experience of living in the world, rather than focusing on their disease, prompted better understanding from staff. This in turn, led to more effective care delivery, improving the lived experience for residents. I suggest the framework can also be applied to effectively support women with AD who need assistance with IADL's when living in their own homes.

## **9.2 Implications for practice**

Table 4 (pg. 107) provides an overview of the humanisation framework in relation to the experiences of the women in this study and begins to highlight implications for practice. Taking all the findings into consideration there are a number of ways that this research can advance the conceptual and practical knowledge useful for healthcare professionals. This knowledge will assist in promoting the effective delivery of care to women with AD and their families, as a better understanding of the phenomenon of becoming cared for is realised.

<b>Dimensions in Humanisation Theory</b>	<b>Definition of dimension</b>	<b>Becoming cared for (Implications for Practice)</b>
Insiderness to objectification	The world is experienced through an individual's mood, emotion and feeling. People should not be treated as objects or labels.	The experience of becoming cared for ranges across a continuum from feelings of worthlessness and becoming a burden, to feeling valued and feeling a sense of liberation. <b>Implication: Demonstrate active listening</b>
Agency to passivity	People express and make choices. Passivity signifies dependence and loss of control	Women with AD can express a choice regarding their continued involvement with IADL's. These activities should not simply be taken over without understanding the meaning this has for women. <b>Implication: provide time and opportunity for women to talk</b>
Sense-making to loss of meaning	To feel human a person needs to make sense of their experiences. When people are not viewed holistically and needs are compartmentalized, this can be dehumanizing.	Women are individuals with the ability to make sense of their experiences of becoming cared for, despite having AD. <b>Implication: write care plans specific to contextual situation</b>
Personal journey to loss of personal journey	All individuals have a past and a future. It is not all about the present.	A woman with AD has a past which affects her present and her future in terms of becoming cared for. She does not go through the journey alone. <b>Implication: ask about and acknowledge women's life history</b>
Sense of place to dislocation	Feelings of security and familiarity, not only in terms of physical place but in others, such as culture, will prevent dislocation and feelings of insecurity.	Becoming cared for is not experienced in isolation. Women with AD need to feel a sense of belonging within their relationships with their spouse and families. <b>Implication: Recognise relationships</b>
Embodiment to reductionist view of the body	A person's well-being is influenced by psychological, social and sociocultural aspects. The body is not simply a biological entity to be maintained.	Placing an emphasis on AD and AD symptoms rather than on individuals, living individual lives, does not recognise the humanness of women. <b>Implication: Plan care based on the woman's needs, not the AD</b>
Uniqueness to homogenization	Feeling human involves displaying individuality. Our identity should not be determined by being part of a group.	Every woman has a different story to tell of their experience of becoming cared for. How this change is experienced is unique to each individual. <b>Implication: Recognise differences between women, men and individuals</b>
Togetherness to isolation	People need to feel a sense of belonging, to be part of a community rather than feel isolated and alone.	Relationality. The experience of becoming cared for is affected by ongoing connections between women with AD and their spouses. <b>Implication: Work with couples. Support changes in roles for both.</b>

**Table 4** Humanisation Framework (Todres *et al*, 2009) – Implications for practice.

An exploration of the care relationship between the women and their spouses revealed the experience of Togetherness. This experience demonstrates that for each woman, becoming cared for is a relational phenomenon influenced by their perception of their ongoing connections with their husbands. In healthcare practice there should be continued promotion of the spousal relationship, recognising and identifying ways to prevent AD taking control of a couple's existence (Svanstrom & Dahlburg, 2004) and maintaining the importance of the woman with AD as an individual.

In this study some women struggled with the necessity of togetherness when completing tasks they had always done independently, leading to feelings of worthlessness and of becoming a burden. Harder still, for some women, was the absence of togetherness, realised by tasks being completely taken over by their spouse. This study helps to heighten healthcare professional's awareness of the differences between men and women and how they approach care. Whilst men use a task oriented approach this does not always support the needs of women being cared for and who view caring as more of an emotional task (Hong & Coogle, 2014).

To avoid this behaviour having a negative impact on the couple's relationship, healthcare professionals need to assist husbands to identify and respond to the needs of their wives (Rauer *et al*, 2014). Care plans should be developed that promote agency in women, allowing them to make choices about their continued involvement with IADL's.

To assist with this, healthcare professionals need to be aware of women's past lives and how this can affect their experiences of becoming cared for. This requires time spent listening and learning about the women's personal journeys, showing interest in their lived world prior to the AD. IADL's can be modified to emphasise what women can do, not what they are unable to do. Care plans should be tailored to the women by focusing on tasks they enjoyed throughout their lives. More specifically, an awareness of the importance a woman feels regarding her sense of place in the family is required, which should be considered when offering advice and support to carers.

There should also be awareness of the notion of malignant positioning (Sabat, 2001), which continues to occur for women living with AD and has been evidenced in this research. This highlights the importance of ensuring carers are educated regarding how their behaviour may impact on a woman with AD at a time in her life when her sense of value and her practical skills perhaps need reaffirming, not taking over.

In chapter seven I identified that becoming cared for is an experience that impacts on how women view themselves and their identity when they have AD. Some of the women were attempting to maintain their sense of self by acknowledging their illness but also by normalizing the effects whilst they tried to adjust, as previously discovered by Clare *et al* (2003) and Harman & Clare (2006). The women's experience of receiving assistance with IADL's was closely linked to how they view themselves in the present compared to their past selves, and how others treat them. This demonstrates the powerful influence carers and healthcare professionals can have on the well-being of women with AD. For some women this resulted in the negative experience of a loss of part of their identity, challenging their position in the family and their sense of womanhood.

This requires acknowledgment from healthcare professionals when assessing care needs. There is evidence to suggest that a woman's experience of this transition is influenced by the on-going social construction of traditional gender roles for women (Beagan *et al*, 2008). As this gendered view remains in society, care needs should be assessed with this in mind.

Having explored this phenomenon from a gender perspective, the findings add to the existing literature, corroborating the importance for women of their connectedness with family and their home environment (van Dijkhuizen *et al*, 2006). For some women, completing IADL's created that connectedness and without it they felt a loss of belonging. The focus for most of the women when discussing IADL's was noted to be shopping and preparing meals. This is consistent with previous research demonstrating the heavily gendered notion that these specific tasks are a woman's responsibility (Gustaffson *et al*, 2003; Johansson *et al*, 2011; Locher *et al*, 2010).



Driving a car and managing finances were also significant in some women's construction of their identity. These IADL's may be perceived as male gendered tasks and therefore ignored by healthcare professionals as being inconsequential for women. This illuminates gender as an important aspect to consider, as the socially constructed world of women is still seen to differ to that of men (Boyle, 2014). The importance for healthcare professionals is to avoid a 'one size fits all' approach to understanding care. Men and women have different backgrounds and have followed different life courses, which need to be acknowledged (Calasanti & Bowen, 2006).

In *Seeing Cobwebs* I presented the positive vision some women have of the changes they experience as part of becoming cared for, representing a transition in their identity. Seeing beauty where it had not been seen before created a new experience for some women, bringing pleasure and contentment to their lives. Becoming cared for may be viewed as a negative phenomenon by some; however this research reveals that this is not always the case. The findings suggest that some women experience becoming cared for as an evolutionary experience and this adds an alternative view to current literature, based on the voices of women with AD themselves.

No longer completing IADL's they have been responsible for may be a choice some women make as part of moving from one stage of life to another. Whilst this may be viewed by healthcare professionals as a symptom of AD, it should be considered that it may be a normalised transition in their life. The women experienced a sense of relief and liberation as they no longer took the responsibility of caring for the home or had to continue to meet standards that they had previously. This freed them of concern and created an acceptance and a contentment that helped them with the change in their lives.

In the healthcare profession, the medical model continues to provide the basis of understanding of disease and illness to drive the evidence base for caring for people with AD (Borbasi *et al*, 2012). Viewing a person as a unique human being who continues to interact with the world around them is still not considered as important. My research suggests it should not be assumed that all changes observed in women

with AD are related to AD and experienced negatively. There is a need for healthcare professionals to understand women as embodied human beings and to support carers to accept this. Aged and dementia care continue to be burdened by care that disregards the individual (Walmsley & McCormack, 2015), however this research has proved it is crucial to listen to women with AD to ensure their care is based on their individual values. The need to treat AD as a problem, when there is no problem from the perspective of the person living with it, suggests intervention should be done with caution (Hulko, 2009). There is a belief that people with impairments are disabled by society, therefore the problem does not sit with the individual (Northway, 2000) and I suggest this should be considered specifically in relation to women with AD during the transition of becoming cared for.

As highlighted in chapter one of this thesis, the Prime Ministers Dementia Challenge (2015-2020) promises people with AD the provision of meaningful care. This is in accordance with NICE quality standards (2013) that state memory clinics should be developed to increase early diagnosis and support the quality of life of people with AD. However, I maintain that meaningful care through the provision of memory clinics is a challenge, as people are seen for short periods of time, often in a clinical setting, which is not an environment that necessarily optimises a person's willingness to disclose personal, meaningful issues. Ensuring healthcare professionals are equipped and skilled in interview techniques could promote disclosure from women on subjects like becoming cared for. The development of qualitative style questioning and active listening to women with AD about their experience of becoming cared for would promote the women's feeling of humanness. It would also ensure that healthcare professionals do not depend solely on carer's interpretations of their wives' abilities or the use of instrumental scales, which are also often completed by carers (Lawton *et al*, 1969).

This study identifies the importance of the experience of becoming cared for in women's lives and should be acknowledged by healthcare professionals as a transition which requires discussion. Care plans specific to individual women's needs and contextual situations should be implemented, ensuring the women remain central to

this. Healthcare professionals should also spend time educating husband's regarding this phenomenon to develop their understanding of changes in respect to women and IADL's.

Supported by the Humanisation Theory, this research can bring about change in healthcare professional's practice, as it improves the level of understanding of living with AD and becoming cared for, and highlights the importance of human values. Positive change is generated by knowledge; therefore I aim to disseminate my findings throughout the teams of community mental health staff, ward staff and consultants within my employing NHS Trust. I will do this through presentations at specific forums such as the Nursing and Allied Healthcare Conference and Medics training sessions. I also aim to publish further work to ensure my findings are read by as many people as possible.

### **9.3 Methodological reflections**

IPA was the methodology chosen to reveal the meaning women with AD give to becoming cared for and was found to provide a suitable framework for this study. The philosophies of phenomenology, hermeneutics and idiography enabled me to explore, in-depth, the women's accounts of becoming cared for. Using IPA supported the personal, individualized analysis of each woman's experience alongside the development of more general experiences seen across cases. Importantly, this study did not require the information the women gave to be wholly accurate, as it was their experience of their daily lives and the meaning they gave to that experience that was important to capture. This was supported by the use of the double hermeneutic, which allowed the women to offer their interpretation of the experience of becoming cared for and for me to understand the meaning of that interpretation (Smith *et al*, 2009).

Despite the suggested limitations of interviewing people with AD discussed in chapter four, I was successful in gaining rich, meaningful data using semi-structured interviews advocated within IPA. All the women were recruited from an affluent part of the UK;

all were white and born in England or Scotland, which provided a relatively homogenous sample for analysis. All eight women recruited were interviewed twice, enabling a fuller understanding of the experience. This method assisted in confirming that the experiences had true meaning for the women, as stories were often repeated and similar feelings acknowledged from one interview to the next. Eight participants is a relatively large number for an IPA study according to Smith *et al* (2009). The reasons given for interviewing a larger sample were explained in chapter four (4.3.3), however these were not substantiated. Despite some interviews being shorter in length than others, all of the women were able to express their thoughts and feelings in relation to becoming cared for and demonstrated the ability to make meaning of those experiences, which produced a rich data for analysis.

It is suggested that findings cannot be generalised to the whole population when small numbers are recruited into qualitative studies such as IPA, (Bowling, 2002), however this was not my intention. From the findings of this study, healthcare professionals, who are the intended readers, will gain insight into the phenomenon of becoming cared for, which will inform and enhance their understanding. This new knowledge could impact on their subsequent practice by encouraging them to acknowledge the individual experience of becoming cared for in all women with AD.

Interpretation of the data was found to be challenging for me as a novice researcher. As with all qualitative research that uses interpretation, my involvement, particularly in relation to the notion of double hermeneutics, may have produced findings which could differ to other researchers. To reduce this risk, I used reflexivity throughout the process to ensure my knowledge and preconceptions were acknowledged.

A full reflexive account can be found in the appendices (Appendix 1), however the main considerations are worth mentioning briefly, to emphasise the role I played in this study and how this was managed.

## **9.4 Personal reflections**

Throughout the research process my view came from two differing perspectives; being a woman and being a nurse. As a younger, cognitively sound woman, I was aware that I was different to the women I was interviewing and my thoughts about becoming cared for were preconceptions related to my view of the world. I made the assumption that giving up IADL's related to the perceived 'homemaker' role would be meaningful for women and that women would be critical of how their husband's performed IADL's. Being a nurse in this situation added benefit, as my ability to develop a therapeutic relationship with each woman prompted them to share some very personal experiences. However, I also had to acknowledge that my role was not to 'provide support' for the women but to allow them to tell their stories.

I believe acknowledging the differences in me and the women I interviewed, and the preconceptions I had of the phenomenon of becoming cared for, enabled me to hear and understand the individual experiences from the women's standpoint. I also shared abstracts from the interview transcripts where possible throughout my findings chapters to evidence my ongoing commitment to hearing the voices of the women with AD as the experts of their worlds.

## **9.5 Future Studies**

During this study I chose not to interview spouses due to the desire to focus on hearing the voice of the women with AD. Interviewing husbands alongside the women with AD to gauge their experience of the phenomenon from a carer's perspective could have presented another dimension to the study. If explored, this may assist further understanding of how to support couples when one spouse has a dementia. Completing similar studies with a larger sample of women and men could also offer further insight into the phenomenon. Following completion of this research I have identified that being a woman can impact on how becoming cared for is experienced, therefore research should also be undertaken involving men with AD, in order to differentiate between men and women and support both equally.

As the women in this study were all of similar ethnicity, completing the study with women from different cultural backgrounds could produce more diverse perspectives of the experience. It would also be interesting to repeat this study in time, interviewing women who are currently younger, to present a longitudinal view. With changes in society and people's view of traditional gender roles altering, adding a generational perspective would assist in ensuring the knowledge available of the experience of becoming cared for remains current and beneficial.

## **9.6 Conclusion**

As a result of this study, I have produced findings which offer a new way of thinking about the lived experience of women with AD. It would appear that once a woman is diagnosed with AD, behaviours or symptoms observed in that woman are assumed to be part of the AD. Dementia is often labelled negatively by people, including the press (Peel, 2014), reinforcing the notion that a diagnosis of AD means inevitable change and deterioration in one's health and well-being. However this research suggests that in certain situations, the changes which occur in women could be a normal part of life. This may not be due to the AD, and having experienced change in themselves throughout their lives, some women embrace the experience of becoming cared for.

The aim of this study was to explore the lived experience of becoming cared for from the perspective of women with AD. I have shown that becoming cared for is a phenomenon which requires consideration and planning by carers and healthcare professionals to ensure women are supported appropriately during this transition in their lives. Humanisation Theory can be used as a template for healthcare professionals to assist in promoting the humanness of women with AD rather than concentrating on AD as an illness.

The interesting issues I have raised in this study are just the beginning. The overarching goal has been to give voice to women who have a diagnosis of dementia and this has been achieved by demonstrating the strength, focus and ability of women with AD to express themselves. This reinforces the conviction that women should be

actively listened to in clinical practice and involved in research, to help our continued understanding of living with the illness.

### **Postscript**

Whilst completing my research I was made aware of the fact that three of the women I interviewed have now moved into residential care. This is important to note, as it confirms that the women I interviewed were not all in the mild stages of AD and those classified with moderate AD at the time, are now requiring fulltime care. Despite the stage of the illness, all the women interviewed remained able to express themselves, providing rich data and demonstrating an ability some have argued is not possible.

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# Appendices

# Appendix 1

## Reflexivity



## **Appendix 1 - Reflexivity**

Reflexivity is an important component of Interpretative Phenomenological Analysis as described in chapter three of this thesis. The impact of my reflections and preconceived ideas on the research topic will have inevitably had an influence on how the study was conducted and how the information gathered has been analysed. The methodological reflections have been detailed in chapter nine; however I now want to offer my reflections on the phenomenon of women with AD becoming cared for and acknowledge certain issues that, despite attempting to set aside my preconceptions and pre knowledge, may have influenced the analysis of this data. I have chosen to place this piece of work in the Appendices, as although it is an important element of the research process, I did not want to detract from the goal of the main thesis, which is to hear the voices of the women who took part.

From the outset of the research journey, I made the assumption that giving up the role of carer would be meaningful for women who had spent the majority of their adult lives taking care of the home and the family. I also made an assumption that women would be critical of how their husband's performed tasks they had potentially never done before. Acknowledging these assumptions as such, prior to interviewing the women, enabled me to be open to alternative perspectives. To promote this further I continually examined my thoughts and pre conceptions throughout the research process. My view came from two differing perspectives; being a woman and being a nurse and I discuss each of these positions in turn.

### **1 Being a woman**

As a woman I share a fundamental similarity to the participants I am involved with, however I am much younger than them and I do not have AD. Throughout the recruitment and interview process I had a sense of feeling lucky to be me, whilst feeling sorry for the women. To be empathic I attempted to imagine myself in their position but this was a difficult task. I reflected on my personal view of the woman as 'homemaker' and my own position in relation to this. I was brought up seeing my grandparents and parents displaying traditional gender roles; the women taking care

of the home and child care, whilst the men provided the financial ability for us to enjoy the good things in life. Despite my mother also working full time, she was the main carer in the home and made the decisions regarding my sister and I.

As I moved into adulthood however, I did not follow this pattern and now share the responsibility of looking after the home with my partner. We both work and share the cooking, cleaning and housework equally, neither of us taking sole responsibility for being the homemaker. Therefore, I looked to the women I interviewed as not only the information providers, but as the experts in the research. I wanted to ensure my interpretations remained true to the stories I was being told, which is why when some of the women appeared to lose focus during the interviews, I did not redirect them and let them tell their own stories.

I attempted to make the process a mutual one between the women and myself by sharing small facts about me during the interviews. I also offered feedback and reassurance at the end of the visits about the information they had shared. However, this led to the point of almost colluding with the women against their husbands at times. As a woman, I felt defensive of those who I believed were unhappy with their situation. For example, I could see during both interviews with Jean that her husband could be over powering; he spoke to me and did not include Jean in the conversation and he answered for her on most occasions when he was present.

This produced feelings of irritation in me, to see Jean left out of our conversations and to hear her speaking in derogatory terms about herself. I had a great deal of empathy for her and told her so. I found it hard not to talk to her about ways she could perhaps manage her frustrations and it seems the 'nurse' took over from the 'researcher'. My irritation with Jean's husband potentially fuelled my analysis of their situation, however my awareness of this helped reduce that possibility. Being younger and cognitively sound I sensed this gave me some power in the relationship and that, at times, the women saw me as more important than themselves. Added to this was my professional position as a nurse.

## **2 Being a nurse**

As stated in chapter one of the thesis, I have cared for people with dementia for many years and believe myself confident in listening to and empathising with people older than myself. As a nurse I felt I was able to ask questions to enable me to delve further into the women's experience. I introduced myself as a nurse researcher to differentiate my role clinically, though still wanted the women to know I was a nurse. I believed this would assist me to gain trust from the women and give them confidence in my ability to understand their position. However, I was also aware that this may have put me in a position of power and could have made the women feel they were being assessed, potentially affecting the type and amount of information they were willing to share. I felt that some of the women looked to me as someone of possible influence. They often asked me for my opinion of their lives, of their level of intellect and also asked my advice about practical day to day issues because I was seen as 'the nurse'.

Following my first interview with Dorothy I documented in my reflexive journal that 'She obviously found the interview therapeutic'. She expressed a great sense of relief being able to talk to someone about her life and her problems related to her family. I made the assumption that she found the interview therapeutic and this made me feel flattered. I felt a warmth towards her, which made the interview process enjoyable for me. I found it to be a more joyful experience interviewing women who were expressing contentment, which may have created a more positive interpretation of their data. I am also aware that women experiencing contentment differed from my preconception of the phenomenon and was not what I expected, consequently increasing my interest in this particular area.

I have interviewed many people with dementia in my clinical role and believed myself more than capable of building relationships with my participants to ensure they would share their stories openly with me. Having said this, I experienced my nursing background as a hindrance at one point during the data collection, highlighted when I was interviewing Margaret. It became apparent to me that I was being very careful to

avoid asking questions that would upset or show weakness in the women. I made a judgment that the women would not want to be asked direct questions related to their day-to-day problems and once I had acknowledged what I was doing it gave me the confidence to change this.

### **3 Summary**

In this chapter I have provided the reader with a reflexive account of my views and experiences during and prior to the research process. This self-awareness has assisted me in presenting the individual accounts of the women in chapter five in a way that promotes their voices and the meaning they give to their experience.

# Appendix 2

## Ethical considerations

## **Appendix 2 - Ethical considerations**

I believe there are two predominant issues to consider when carrying out research and semi-structured interviews, with women who have a diagnosis of AD who live at home. These are issues of capacity and consent and the vulnerability of both the participant and myself, as the researcher. These issues will be discussed in detail here whilst all other considerations can be found in the table at the end of this appendix.

### **1 Capacity & Informed Consent**

People with AD are classed as a vulnerable population due to their compromised decision making capabilities (Beuscher & Grando, 2009). Determining a person's capacity to understand and consent to research is important and to achieve fully informed consent I had to be sure that each participant had capacity to consent for themselves. During my first visit with the participants I completed a written assessment of capacity used within the recruiting NHS Trust. Capacity to consent was judged on whether or not the person wanted to take part in an interview and whether they were able to understand the reason for this, not on competency in all aspects of their lives (Hellstrom *et al*, 2007). The Mental Capacity Act (2005) states that a person should be able to understand the information they are given and retain it long enough to make a decision as to the benefits and risks associated with being involved. If they can then communicate this to the researcher, they are deemed to have capacity. If a woman was believed to lack the capacity to understand the nature of this study and thus to consent, they were not included.

The approach to consent involved consideration of a number of issues, namely; for people with dementia who sometimes display fluctuating capacity, a level of flexibility was shown in the protocol, to allow for the woman with AD to be visited to discuss inclusion in the study a second time, if she were deemed to be having a "bad day" and if this was the wish of her and her spouse (McKeown *et al*, 2010). Informed consent is essentially a continuing process, especially when dealing with people with AD who may not remember who you are and why you are there (Nygard, 2006). During the interview I was constantly aware of each participant and their willingness to take part

in the conversation we were having. I was aware of both verbal and non verbal communication from the person with AD and ongoing consent/assent was taken from participants who were frequently reminded that they could withdraw from the study at anytime without giving a reason. As I was to complete two interviews I ensured that on both occasions I obtained consent; written at the first interview and verbal at the second, to ensure the rights of the women were maintained (Lloyd *et al*, 2006).

I also chose to gain assent from the spouse of each woman who took part in the study. This was not a proxy consent and was not done to detract from the primacy of the women with AD (Cowdell, 2006). By the nature of the phenomenon being explored it was felt important to have the agreement of the spouse to avoid any long term issues, which may have arisen from the discussions I had with the participants about their care relationships. I was also interviewing the women in their homes and wanted to ensure each spouse was happy for this to happen. Each spouse was also asked to assent at the outset of the second interview which reaffirmed their agreement with their wife's involvement.

## **2 Being vulnerable as a participant**

People with AD can be considered as being vulnerable due to the affects the illness has on many aspects of their lives; threatening identity and independence (Pesonen *et al*, 2011). Throughout the research process it was paramount to ensure the participants positive well-being, particularly during the data collection phase. I ensured that participants were aware of their right to withdraw at any time by including this in a statement on the consent form and by verbalising it before each interview. The reasons people take part in health research are varied and include lifting participant morale and feelings of altruism (Sabat, 2003). The experience is often found to be a positive one (Hubbard *et al*, 2003) and all the participants claimed they had enjoyed the feeling of being part of something important. However I was aware at all times of the risk to individuals being asked to discuss sometimes sensitive and upsetting subjects. I did not want to cause distress to any of the participants and ensured I monitored each woman during and after the interview for signs of tearfulness, anxiety or any exacerbation of their emotional state (Hubbard *et al*, 2003).

This close monitoring caused me to pause during the interview with my final participant who showed signs of discomfort and anxiety shortly after we began. The cause of her concern was where her husband had gone and following some discussion we brought him back into the room and he stayed with us for the rest of the interview. In this particular instance, a compromise in data collection was made in order to promote the well-being of the woman being interviewed (Pesonen *et al*, 2011). Although this meant she initially looked to him for answers to the questions I asked her, she was able to relax and became more vocal as the interview went on. She also agreed to a second interview, which was conducted with her alone. This required a sensitive and skilful approach and my nursing skills were found useful here.

I monitored the content of the discussion during the interviews and attempted to maintain the focus of the participant as much as possible without influencing their descriptions or responses. At times, information that was not relevant to the study was disclosed; however this was not used for analysis. I explained to all participants prior to interviewing, that if anything was said that I believed indicated a risk to them and/or others, I would have to report this to their named healthcare professional.

### **3 Being vulnerable as a researcher**

In IPA it is essential that the researcher work closely with participants to ensure the phenomenon being explored can be viewed from the 'insider's perspective' (Smith, 1996). This closeness to the sensitive issues being discussed placed me as the researcher, in a vulnerable position and it was important for me to be aware of my emotional well-being along with those of the participants (Pesonen *et al*, 2011). The use of my reflective journal to document any sensitive or hard to handle situations assisted me in this whilst also helping me to understand the influence this may also have on the research (Watt, 2007).

The second issue needing consideration was that of researcher safety. I conducted interviews in participant's homes; therefore the employing NHS Foundation Trust lone worker policy was followed and details of where and when I would be visiting



participants were made available to the research team. A full risk assessment is completed by healthcare professionals' during their clinical consultations with patients and prior to all the visits I undertook, the risk assessment was examined by myself to ensure I was fully aware of any threat to my safety.

<b>Ethical consideration</b>	<b>Implementation</b>
Training and suitability	<ul style="list-style-type: none"> <li>• The individual who undertook this research has been a qualified Mental Health Nurse for 19 years. Is also trained in Good Clinical Practice, Informed Consent, Data Protection and follows the NMC Code of Conduct.</li> </ul>
Consent	<ul style="list-style-type: none"> <li>• All participants involved in this study had the opportunity to consent or decline involvement.</li> <li>• Capacity was assessed using the MCAAct.</li> <li>• Fully informed consent was required from every participant prior to any study procedures.</li> <li>• It was made clear to all individuals that their participation was voluntary and if they chose not to take part in the interviews, this would not affect their future relationship with their clinical team or the research team.</li> <li>• Carer assent was gained from each spouse whose wife expressed an interest in taking part.</li> </ul>
Confidentiality	<ul style="list-style-type: none"> <li>• Patient data was accessed for screening purposes and to enable contact to be made. It was treated confidentially at all times.</li> <li>• All information disclosed during interview was used for the sole purpose of the research. It was made clear that if the researcher believed a participant to be of</li> </ul>

	<p>risk to herself or others, this would be discussed with the participant and reported to the appropriate clinical team.</p> <ul style="list-style-type: none"> <li>• No patient identifiable information was used in the research. Quotes used were anonymised to ensure confidentiality was maintained.</li> </ul>
Data storage/protection	<ul style="list-style-type: none"> <li>• No data in this study was stored with patient identifiable information.</li> <li>• Hard copies of transcribed interviews are held by the researcher and kept in a locked cabinet. Where data is stored electronically, it is stored on an encrypted memory device, to which, only the researcher has access.</li> <li>• Information gathered for this study was used only for this purpose and will be destroyed at the completion of the researcher's academic study.</li> </ul>

# Appendix 3

## Ethical approval

**NRES Committee East Midlands - Northampton**

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839425  
Facsimile: 0115 8839294

18 February 2013

Miss Gayle Borley  
Senior Research Nurse  
Northamptonshire Healthcare Foundation Trust  
Berrywood Hospital  
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Northampton  
NN5 6UD

Dear Miss Borley,

**Study title:** A phenomenological exploration of the lived experience of becoming cared for from the perspective of women with Alzheimer's disease.  
**REC reference:** 13/EM/0009  
**IRAS project ID:** 99200

Thank you for your letter of 12 February 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

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 Co-ordinator Miss Jessica Parfremment, NRESCommittee.EastMidlands-Northampton@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, subject to the conditions specified below.

**Ethical review of research sites**

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

**Conditions of the favourable opinion**

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

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		11 December 2012
Evidence of insurance or indemnity		02 August 2012
Investigator CV		28 November 2012
Letter of invitation to participant	2	03 February 2013
Other: Academic Supervisor CV: Judith Sixsmith		
Other: Academic Supervisor CV: Dr Sarah Church		
Participant Consent Form	1	15 November 2012
Participant Information Sheet	2	03 February 2013
Protocol	1	05 December 2012
REC application	99200/391985/1/948	10 December 2012
Response to Request for Further Information		12 February 2013

### **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 NRES 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 please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

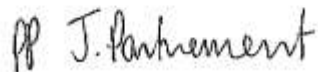
13/EM/0009

Please quote this number on all correspondence

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/>

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

Yours sincerely



**Mr John Aldridge**  
Chair

Email: NRESCommittee.EastMidlands-Northampton@nhs.net

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

*Copy to:* Sponsor – Judith Sixsmith

*R&D Contact - Mr Stephen Zingwe*

# Appendix 4

## Case study publication



<http://dem.sagepub.com/>

# How does a woman with Alzheimer's disease make sense of becoming cared for?

**Gayle Borley**

University of Northampton, UK

**Judith Sixsmith**

Public Health Improvement and Implementation, Institute of Health and Wellbeing, University of Northampton, Northampton, UK

**Sarah Church**

Centre for Family Life, Institute of Health and Wellbeing, University of Northampton, Northampton, UK

## Abstract

This case study explores the meaning one woman with Alzheimer's disease (AD) gives to receiving assistance with instrumental activities of daily living (IADLs) from her spouse. Improving the care of people living with AD is widely accepted as an important outcome in dementia services. Understanding how it feels for the person with AD to receive that care is essential to enhance their quality of life. Experiences identified using interpretative phenomenological analysis focus on a connection to past self and maintaining identity whilst also accepting change. The experience of 'Sameness and Change' identifies her feelings of discontinuity whilst 'Goodness' depicts her continued emotional expression of care presented in an attempt to remain someone of value within her family. These findings offer new insight and understanding to assist a woman's transition from carer to becoming cared for.

## Keywords

alzheimer's disease, instrumental activities of daily living, lived experience, gender, women

## Introduction

In 2013, there were an estimated 44.4 million people with dementia worldwide (Alzheimer's Disease International, 2013) and approximately 800,000 of those people live in the UK (Alzheimer's Society, 2012). Dementia is an umbrella term given to a number of diseases

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Dementia

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including Alzheimer's disease (AD), vascular dementia (VD), lewy body dementia (LBD) and many more, distinguished by specific causes. The majority of people living with the disease will be diagnosed over the age of 65, but some experience early onset AD and can suffer at a much younger age.

Internationally dementia is recognised as a global disease putting the elderly population at risk and placing extreme economic pressures on all countries (Pan European Networks, 2014). The G8 community met at the end of 2013 to focus on raising the profile of the disease. This was led by UK Prime Minister David Cameron who launched the Prime Minister's challenge on dementia 2015 (Department of Health (DoH), 2012), promising improvements in health and care, dementia friendly communities and better research. The G8 announced a shared goal to improve the quality of life of people with dementia, develop treatments and a cure by 2025.

To gain further knowledge of dementia and to develop more effective treatments and services require research involving those people who are living with the disease. Whilst finding a cure is imperative, understanding the lived experience of those already diagnosed is also essential to achieving the goal of improved quality of life. Current UK statistics report that two-thirds of people with dementia live in the community and two-thirds of people diagnosed are women, with the most prevalent diagnosis being AD (Alzheimer's Society, 2012). It is predominantly women across the western world who are viewed as the caregivers in a family and with recognised gender traits such as understanding, caring and nurturing, women identify with this role (Kramer, 2005). This indicates that women with AD are a large group of people who could benefit from further study exploring the meaning they give to the transition from caregiver to becoming cared for.

This case study used interpretative phenomenological analysis (IPA) to explore the lived experience of becoming cared for from the perspective of a woman with AD. IPA is a qualitative approach to enquiry and is concerned with understanding people's experiences of life events which are of significance to them. Using IPA enabled the phenomena to be described and interpreted as it is experienced by the woman with AD, recognising the role of the researcher who is trying to make sense of the participant trying to make sense of what is happening to them (Smith, Flowers, & Larkin, 2009).

## Understanding the lived experience of AD

AD is a type of dementia distinguished, by its gradual progression (Jacques & Jackson, 2000). In the mild stage, symptoms including decline in short-term memory, reasoning and language difficulties such as decreased word fluency are usually evident. As the illness progresses through the mild to moderate stages it also begins to affect an individual's ability to function independently and the need for care and support with daily activities increases. In the severe or advanced stages of AD, individuals will become completely dependent on others for all their care needs, such as washing, eating and toileting and often require a move from the community into a long term care facility (Graham & Warner, 2009) in order to receive specialised care.

Living and coping with AD has been the focus of a growing number of studies undertaken over the past 20 years (Steeman, Godderis, Grypdonck, De Bal, & Dierckx de Casterle, 2007; Wolverson, Clarke, & Moniz-Cook, 2010). When people are diagnosed with AD, they show signs of trying to adjust (Clare, 2002, 2003). They develop coping strategies in the early stages in the form of self-protective strategies such as sticking to a routine to provide a sense

of normality, hiding the fact that memory problems exist and relying on others. Alternatively, some people will attempt to understand the illness, talk about it openly with others and demonstrate a fighting spirit (Clare, 2002). Similar themes of self-maintaining or self-adjusting behaviours have been described by people with AD when managing threats to self, such as normalizing the effects of the illness or acknowledging the illness and its difficulties and creating a new sense of self (Clare, 2003). MacQuarrie (2004) terms the lived experience of AD as a dialectical tension between agency and objectification. Agency refers to the autonomous individual who demonstrates independence and a determination to take control of life, whilst the objectified self reflects a disempowerment the same person may feel as they are redefined as 'patient' due to their need for assistance with daily activities.

Understanding how people attempt to cope with distressing symptoms of AD whilst striving to retain their sense of self in the face of objectification by others and change in themselves provides insight for both carers and healthcare professionals when supporting people living with AD. Past studies on the lived experience of AD have indicated that there is a common strategy used by people with AD to help them cope with the illness. This strategy involves a reliance on family and spouses for support. For many people with AD, care is interpreted as practical support, such as remembering appointments and being an advocate (Preston, Marshall, & Bucks, 2006) and emotional support in the maintenance of relationships (Wolverson et al., 2010). However, some acts of care, although well meant, can be interpreted by men and women with AD as a diminishment of their personhood (MacQuarrie, 2004).

As AD progresses it is known that certain functions will become more difficult for the person, for example, once previously taken for granted thoughts and activities can become effortful. This highlights a clear 'slowing down' when completing tasks and holding conversations as described from the perspective of the person with dementia (Phinney & Chesla, 2003). Instrumental activities of daily living (IADLs) such as housework, preparing meals and shopping, along with managing money and using the telephone are not as essential as basic activities of daily living such as washing, dressing and eating, but they are a required aspect of life (Graham & Warner, 2009). There is limited qualitative research on IADLs and dementia particularly focusing on the perspective of the person with dementia when receiving care and living with a spouse. This case study extends our understanding of the lived experience of AD in the context of IADL since IADL form an intersection between the person, their needs and their social world. This needs to be carefully negotiated in order to enable care to be provided appropriately from both healthcare professionals and family carers. This case study offers a female gendered viewpoint and has been specifically chosen in order to explore the notion of traditional gender roles and a woman's sense of self and identity.

### Gender perspective

Across the developed and developing world, women are viewed as nurturers (Bamford & Walker, 2012) and the needs of others, whether they are children, partners or ageing parents, are often given priority in women's lives (McKie, Gregory, & Bowlby, 2002). There is an assumption that women are the people who will take on the role of carer and that this is perceived as natural and freely given (Ward-Griffin, Bol, & Oudshoorn, 2006). Family care has been described as a euphemism for female care and conformity to specific gender roles due to societal pressures has meant women have assumed the role of 'carer' (Bamford & Walker, 2012). Women are, in part, the way they are because of the way they are thought to be (Oakley, 2005) and IADLs have traditionally been seen as feminine tasks and thus a woman's responsibility (Beagan, Chapman, D'Sylva, & Bassett, 2008). This can be related to socially constructed feminine characteristics such as gentleness and sensitivity and the traditional belief that men work and women take care of the home.

Research conducted in 1974 involved interviewing women about their experience of being a housewife (Oakley, 1974). For them, housework was viewed as work. Some aspects of the work they enjoyed but other aspects they found monotonous and socially isolating. The women interviewed in this research are people who would now be over the age of 65 and potentially living with AD. They described men as 'real' men if they went out to work, they also stated they were better at understanding their children and taking care of them than men, so pre conceived ideas about their own gender impacted on how they viewed themselves and their responsibility.

The importance of housework to women, the amount of time spent on it and the meaning women give to it, has been little explored since 2005. Women may not enjoy the role of housewife necessarily (Oakley, 2005), however when that responsibility is taken away, arguably so too is their role and identity. There has been a shift in attitudes to gender roles over the past 30 years. In the mid-eighties, 43% of people supported a gendered separation of roles believing a man's job was to earn money and a woman's to look after the home and family (NatCen, 2013). However, despite less support for restrictive gender roles research shows that women continue to undertake the majority of the housework and caring tasks for family members (Yee Kan, Sullivan, & Gershuny, 2011). The support for gender specific roles reduced to 13% in 2012 (NatCen, 2013) indicating a change in people's views, however the backing for a traditional division of labour remains much more pronounced in older people.

The reality of caring relationships now is somewhat different to those anticipated from a traditional standpoint. In the UK, men aged over 75 are now more likely than women to be caring for their spouse (Office of National Statistics, 2005). Current national statistics report that two-thirds of people with dementia are women (Alzheimer's Society, 2012); women are more commonly diagnosed with AD than men (Graham and Warner, 2009) and therefore require some level of care from their spouse.

### Becoming cared for

The majority of provision of care for people in the mild to moderate stages of AD living at home is reported to come from family members (DoH, 2009). Past AD research has emphasised the lived experience of being cared for from the caregiver's perspective (Paun, 2003; Persson & Zingmark, 2006; Siriopoulos, Brown, & Wright, 1999; Walters, Oyebode, & Riley, 2010). This body of research points to the sense of obligation and strength of belief in marriage vows which underpins the caring relationship in many caregiver's accounts (Paun, 2003; Siriopoulos et al., 1999).

Becoming cared for and needing assistance with IADLs have been a focus in cancer research and Locher et al. (2010) describe those diagnosed and their carers experiencing distress surrounding food preparation and mealtime activities. More specifically, the distress was expressed by women who could not participate fully in these activities, which they felt were central to their self identity. Older women in the same study found it uncomfortable to relinquish cooking tasks they had been undertaking all their lives, to their husbands. This sense of frustration however is not seen in a study by Crist (2005) who interviewed elderly participants about receiving assistance from their families. Receiving help had positive meaning for these participants within the context of ongoing family relationships and receiving help in this context helped them maintain a sense of control in allowing tasks to be completed for them.

The experience of people with dementia needing assistance with IADL's of shopping and cooking has been an area studied by Johansson, Christensson, & Sidenvall (2011) who interviewed 5 men and 10 women about their experience of managing mealtime tasks. Findings show people use different strategies to enable them to maintain their independence, such as reducing the complexity of meals, accepting meals-on-wheels and being supported by partners or significant others with tasks of cooking and shopping. Being unable to complete mealtime tasks led to feelings of emptiness in some informants. More women than men were interviewed in this study, which could suggest the results are more indicative of women's views. There was little distinction made however, between the experience of men and women other than some women with dementia maintaining responsibility for managing meal times believing husbands would not be able to manage these tasks. This view could be an accurate perspective on the situation or could be an attempt to help preserve the image of the woman as independent (Haak, Fange, Iwarsson, & Ivanoff, 2007).

There is limited research on becoming cared for from the sole perspective of women with AD, who are still perceived to hold the role of homemaker and carer. However, the relationship between mothers with AD and their daughters exploring the experience of receiving and providing aspects of care has been examined (Ward-Griffin et al., 2006). The findings suggest that women with AD suppress their own needs due to their daughters having families of their own to worry about. They accept help but only under certain circumstances such as shopping and banking, which did not restrict the independence of their daughters and were considered "normal" daily chores for adult daughters to perform. Identifying specific tasks to be assisted with enables some control to be maintained by the mothers and supports the findings of Crist (2005). The expectation that a daughter would complete these normal daily chores demonstrates the traditional belief that these tasks are a normal part of a woman's role. It also suggests the care would not create a burden for the daughter, enabling the mother to maintain a positive sense of self (Svanstrom & Dahlberg, 2004). Many people care for others out of affection, love and empathy or a moral duty to do so (Engster, 2005). This case study focuses on how a woman with AD makes sense of changes in herself and her care relationship with her spouse due to AD and loss of instrumental abilities. Understanding the meaning of becoming cared for from the perspective of women with AD increases care providers understanding of the lived experience and enables more effective care delivery.

## Method

This case study draws on data collected during two interviews with a woman living with AD. The interviews were part of a larger IPA study in which nine women were interviewed at two time points to explore the phenomenon of becoming cared for in women with mild to moderate AD. IPA is a qualitative approach to enquiry and is concerned with understanding people's experiences of life events which are of significance to them (Smith et al., 2009). IPA is underpinned by phenomenology and hermeneutics and is idiographic in nature. It is particularly apt here as the main aim is to describe and interpret the lived experience from the perspective of the person with AD. There is very little research available on this and currently understandings of gender suggest that a gendered perspective would be necessary (as argued earlier). Accordingly, this study focuses specifically on the experience of becoming cared for as a woman with AD in relation to IADLs which are often located within the female role.

IPA follows the core principles of phenomenology through paying particular attention to a person's individual experience and by encouraging stories to be told in the individual's own words (Bryman, 2004). When engaging in analysis of a participant's experience, it requires a process of interpretation from the researcher which ties IPA to a hermeneutic perspective (Smith, 2011).

As a person with AD begins to decline, their capacity to grasp a situation and understand enough to create meaning from it may also appear to others to decline (Jacques & Jackson, 2000). A distinction can be made however, between the cognitive self, which is affected by memory and the experiencing, feeling self which is much less impaired. This necessitates a level of interpretation by the researcher in order for the meaning of the experience to become visible to others. Idiography is the exploration of the particular (Smith et al., 2009) and can provide us with a personally unique perspective on the phenomena of interest. This has value in enhancing our understanding of the lived experience of people with AD (Hellstrom, Nolan, & Lundh, 2005). This case study follows this principle and presents an in-depth picture of one woman's experience of becoming cared for, recognising her wholeness and uniqueness as a person (Malim, Birch, & Wadeley, 1992).

## Recruitment

The participant was recruited through a process of screening from a 'research interested' database held within the researcher's employing NHS Trust. The 'research interested database' lists individuals with a diagnosis of dementia who have expressed an interest in hearing about research. Referrals are received from members of Community Mental Health Teams and memory clinics across the Trust and consent is gained from each individual referred and their carer, via telephone, to hold their information and contact them if a study is suitable for them to participate in. For the purpose of this study, the criteria of women recruited included a diagnosis of AD, a Mini Mental State Examination indicating mild to moderate AD (26-11, Folstein & Folstein, 1975) within the past six months, living in the community with their husband and requiring assistance with IADLs. Information sheets were sent out to participants who were given up to one week to read these before being contacted via phone. Barbara (name changed to ensure anonymity) and her husband expressed an interest and were the first couple to be visited by the researcher. All questions related to the study were answered by the researcher and Barbara agreed to take part. Ethical approval for this research was given by the local Research Ethics Committee.

## Data collection

Data was gathered using two semi-structured interviews. IPA requires rich data, obtained by offering participants the opportunity to speak freely and develop their ideas at length (Smith et al., 2009). Taking into consideration the unpredictable nature of dementia on communicative capacities (Hubbard, Downs, & Tester, 2002) and the requirement of the researcher to enter into the participant's lifeworld, the researcher conducted the two interviews with Barbara a week apart. The aim of this was to develop rapport and empathy with Barbara and promote disclosure of meaningful experience (Nygard, 2006). Previous studies using IPA have found this an extremely useful method of gaining an in-depth understanding of the lived experience of people with dementia (Clare, 2002, 2003; McIntyre & Reynolds, 2012) whilst maintaining a safe, supportive environment for the participants (Pratt, 2002).

The first interview was undertaken to enable Barbara to talk about her life and her experience related to her diagnosis of AD. Topics explored included Barbara's experience of daily life following her diagnosis, how she feels about her ability to manage tasks now compared to when she was younger and how this impacts on her relationship with her husband and her family. The second interview was undertaken a week later to allow for further exploration and clarification of the experiences discussed during the first interview. The second interview consisted of open ended questions related to the discussions had during the initial meeting and this way a more in-depth analysis of the topic was achieved. During the second interview Barbara was able to recall the majority of what she said during the first interview however, to ensure accuracy, confirmation was sought on previous answers whilst developing further insight into her experience.



## Data analysis

IPA provides a set of flexible guidelines which can be adapted by individual researchers to analyse data. Smith states that IPA guidelines do not offer a recipe for data interpretation and researchers are advised to think creatively in their analysis (Pietkiewicz & Smith, 2012). IPA involves a 'double hermeneutic' in that the researcher must attempt to make sense of the participant, who is making sense of their lived experience (Smith et al., 2009).

Acknowledgement is paid to the fact that the researcher only has access to the woman's experience through the description she has given and this has been interpreted through the researcher's own experiential lens. As a novice researcher, the steps for analysis offered by Smith, Flowers, and Larkin (2009) were useful to follow, however the terms 'emergent themes' and 'super-ordinate themes' were found to be unhelpful in focusing the researchers' connection with the overall human experience. Therefore, the simple terms 'experiences' and 'key experiences' were chosen to assist the researcher and the reader to retain the link to individuals.

Firstly, the researcher read and reread the data collected from individual interviews, making initial notes, which were descriptive, linguistic and conceptual. Experiences related to the phenomenon were discussed within the research team and challenged until all agreed with the developing analysis. The next step was to explore connections across the experiences and suggest interpretations which stood out as key for the woman and which the research team agreed upon. Whilst doing this, divergences within the data were also explored. All names and places have been changed to ensure anonymity. Anonymised transcripts/records of analysis of data can be obtained from the corresponding author on request.

## Barbara's perspectives of becoming cared for

Barbara is an 83 year old woman with a current Mini Mental State Examination score of 24/30, which indicates she is in the mild stage of dementia (Folstein & Folstein, 1975). She was diagnosed with AD in 2012 but does not believe she has any problems with her memory. She lives with her husband and agreed to take part in the research interviews to explore her lived experience of AD in relation to her need for help with IADLs, acknowledging that she is not as able as she has been in the past.

Barbara was born in the UK in the 1930s, she met and married her husband in the early 1950s and they had two children. Barbara took on the traditional role of housewife and looked after her two children and her home, whilst her husband went out to work. She also took her mother in to live with them when her father died; this was followed by the death of their eldest child a number of years ago. They now have two working age grandchildren and four great grandchildren, all of school age, who live locally. One of their great grandchildren is physically disabled and requires a lot of care.

Barbara herself experiences poor mobility due to arthritis in her knees; she walks with a frame and only manages short distances now. She has poor short-term memory and during screening for participants for this study it was noted that her husband had reported noticing a reduction in her ability to do tasks around the home over the past 12 months, stating she was very organised in the past but this is now changing. Her husband now does the majority of the housework, the shopping, food preparation and the cooking.

## Understanding the experience of becoming cared for

The key experiences identified from the interviews with Barbara focus on her connection to her past self and maintaining that identity whilst also coming to terms with change. The experience of 'Sameness and Change' identifies the discontinuity between feeling the same as a person and living through a change in her life. The experience of 'Goodness' depicts an interdependence within the family throughout Barbara's life. Firstly, discussion will be had in relation to Barbara's diagnosis of AD and her experience of this, as this drives her view of self and subsequently the meaning she gives to the phenomenon of becoming cared for.

## Experiencing a diagnosis of AD

Receiving a diagnosis of AD is a subjective experience; some people show acceptance immediately and some will come to a gradual realization over time (Vernooij-Dassen, Derksen, Scheltema, & Moniz-Cook, 2006). Others are unable to recognise cognitive deficits despite being given a diagnosis (Barrett, 2006). Living and coping with AD has already been discussed in an earlier part of this article, relating to those people who have an awareness of their diagnosis. Awareness in people with dementia, or lack of it, is a subject which has been debated for some time. This concept has been described in a number of ways; unawareness (Lamar, Lasarev, & Libon, 2002), denial (Sevush & Leve, 1993), impaired insight (Mangone et al., 1991) and determining an overall meaning have been difficult (Markova, Clare, Wang, Romero, & Kenny, 2005). In Barbara's case, she appears unaware of any real change.

*Barbara: I suppose I didn't feel any change, cause to me I could still sort of remember things, sometimes it took a bit longer, but really I mean I can't say that there was much change, urh and [my husband] helps me a lot*

Barbara talks in the past tense when describing her diagnosis and the problems with her memory suggesting this is something that happened long ago. By compartmentalising this, she may be protecting her sense of self (Preston et al., 2007). She claims she felt no change at the time of diagnosis, however acknowledges some differences speaking in the present tense and talking about the help she receives from her husband. This demonstrates an awareness of the need for a certain degree of help which she describes as 'a lot'. Despite this acknowledgement, Barbara denies having concerns about her diagnosis,

*Barbara: I don't think about it . . . It doesn't really worry me. In fact I don't think, you know, I don't think I've got it . . . cause they (doctor's) are not always right are they? . . . mind you when they ask me lots of questions about who's the Prime Minister, I answered um all . . . So, I mean, you can't really tell can ya?*

Barbara goes on to identify that she was able to remember the name of the prime minister which indicates to her that there cannot be anything wrong with her memory. She feels able to challenge the expertise of the doctor due to her ability to answer all of his questions. As Clare (2002) argues, a diagnosis of AD can only be given as a probable or possible diagnosis and so without the certainty it can be understood that people may adopt other explanatory models. The use of denial can allow a person time to adjust to the diagnosis of AD and identify ways to cope (Snyder, 2001).

Barbara attributes deterioration in her physical health rather than dementia for her lack of ability to complete activities she use to such as the housework and cooking and her need for assistance. She may hold the belief that physical deterioration does not have such a negative social connotation as AD. The risk of social stigma has been identified by people with dementia, believing they will be treated differently when given a diagnosis and that they will be seen as incompetent (Husband, 1999). Barbara may also feel that she is able to recover from a physical problem whereas having dementia does not hold such hope. Past documentation of AD has portrayed the illness as severely debilitating and often describes only the moderate to late stages of the illness, therefore it is not unreasonable for Barbara who still functions at a relatively high level to question the validity of the diagnosis and attribute her lack of ability to other things (Snyder, 2001).

MacQuarrie (2004) identifies that people in the early stages of AD minimize their problems with their memory and resist knowing or accepting a change in themselves. This reluctance to believe the diagnosis Barbara has been given influences how she experiences life and helps her maintain a positive sense of self and value (Steeman et al., 2007). The following theme of Sameness and Change explores Barbara's sense of self further and the impact this has on her life.



## Sameness and Change

Barbara's denial of her memory problems has a huge impact on how she portrays her life. She describes herself as a woman who is the same as she has always been.

*Barbara: I still feel the same. I don't think there is anything wrong with me. It is interesting to note that there is a distinction to be made between 'feeling' and 'being' in her statement. Despite the physical and mental deterioration that has occurred, she does not see this as changing who she is as a person.*

A study exploring the experiences of ageing concluded that people over the age of 65 do not feel old unless describing circumstances that were troublesome to them (Cremin, 1992). 'Troublesome' was not a term expressed by Barbara and her statement that she still feels the same demonstrates that her sense of self is intact despite being told she has AD, which could be interpreted as troublesome for some. Even people who are accepting their diagnosis of AD have stated they feel no major change in themselves as a whole (Caddell & Clare, 2011). Barbara appears accepting of the physical decline she has, as there is the possibility of recovery to her former self. She views herself as determined and the short term view she adopts relating to her problems means she is able to believe she could go back to doing the things she used to enjoy.

*Barbara: I used to go aerobics, line dancing, I hope to go back to line dancing, um, I'm pretty active, shopping and all that sort of thing.*

This belief maintains her present feeling of connection with the life she had prior to her diagnosis of AD. She talks about the things she perceives she can do, rather than dwelling on discussions of the things she can no longer do, which supports her view of herself as being unchanged. This is reinforced for her when discussing how her family see her now.

*Barbara: I don't think they think anything has changed. I suppose to my family I'm still the same one, you know, I mean I can still sort of, have a good conversation and that with um,*

The ability to converse with her family is identified as an important activity for Barbara and one that links to her past self. The theory of symbolic interactionism describes how a person's view of themselves is determined by an awareness of how others see us (Blumer, 1992). Following this theory, Barbara is implying that whilst her family continue to hold conversations with her, she remains the same person and continues to hold the same value in the family.

Barbara also talked keenly about the caring role she once held in the family.

*Barbara: I used to look after em, urm, play with em, have em to dinner, well they all come to dinner Sunday, and of course my daughters two boys, urm, I use to look after them when they were little and urh, yeah, we used to have some good times together. I used to have em all on the mat, you know playin' and [pause] yeah, yeah, I sort of bought em up when my daughter weren't well and their dad went to work and I looked after em, you know, when they come home from school, used to have some fun together . . .*

This description she gives of the important role she played in the wider family reinforces her perception of her own usefulness and value. She portrays a competent and caring woman who was in control and a central figure in her family's life. Barbara strives to maintain this connection with her family when she talks about her ongoing relationship with her grandchildren and great grandchildren.

*Barbara: I play with grandchildren when they come down or great grandchildren [chuckles] . . . well they come and um, we talk to each other and I can't lift em up like I used to but um, they sit on my lap sometimes*

Barbara's main role throughout her life has been to look after the family; she went out shopping, cooked and cleaned whilst also at times socialised with friends at groups such as line dancing and aerobics. The notion of 'sameness' for Barbara can be defined as continued feeling of being involved in the responsibility of caring for her home and her family. Becoming cared for in the IADL domain is perhaps not all encompassing in every part of her life. The transition from carer to cared for is a process which is still occurring and whilst reflecting on her life, Barbara begins to see change but still displays caring in other forms such as play.

Reflecting on her life Barbara acknowledges that things have changed and in contrast to a previous statement she recognises here her inability to do the shopping but attributes this solely to her physical deterioration.

*Barbara: I used to go up that hill and get all the shopping in the trolley and come back again, you know, I used to go up there, sometimes twice a day, all round the shops, yeah . . . if I go up there I have to go in a wheelchair (now), cause I definitely couldn't walk up that road.*

The acceptance of getting old and problems associated with the normal ageing process are the coping mechanism found to help a person with dementia adjust to their new situation (Robinson, Clare, & Evans, 2005) and the age related mobility problems may be easier for Barbara to accept than her diagnosis of dementia. Conversely, it may be that the physical changes Barbara is experiencing are more of a frustration to her than problems brought about by the AD. However, Barbara maintains the ability to reflect on her life in a positive way. Barbara is aware of the change in her ability and acknowledges that this was difficult to accept initially; however, she demonstrates the maintenance of self as described by Clare (2003) when she reflects on her past abilities.

*Barbara: It's one of them things and [chuckles] I am getting old. I just feel thankful that I could do all these things up to now.*

Although she asserts there is nothing wrong with her, she knows she needs reminding of things now, she can no longer do the shopping or cooking like she used to, or look after her family when they come to visit. This is indicated by Barbara here,

R: So what did you used to do when your family visited that you don't do now?

*Barbara: A lot of things, I mean I used to look after em (the family), go and get them cups of tea urh, do the dinner, dish it up, wash up, wipe up; [husband] does all that now . . . I'm sorry that I can't do it but [husband] is quite capable . . . it's nice, you know, that someone else would do it. I used to feel sorry that I couldn't do it anymore . . . I've got used to it now, it used to get to me at first, but it's one of them things, it's no good worrying about it is it?*

The role Barbara held in the family reflects that of the traditional gender view of being the person to look after everyone and she appears to have found this difficult to give up. However, her statement that her husband is quite capable and the recognition that it is nice that someone else will do it, perhaps indicates that she feels she has done her share and deserves to be cared for at this stage in her life. The acceptance of the change also comes from a confidence and reassurance that her husband is there and that the tasks will get done and so will not negatively affect her family. This will be discussed further in the next section which explores the notion of goodness and how Barbara ascribes 'goodness' to care activities performed within her family.

## Goodness

Barbara's relationship with her family over the years has been one of shared responsibilities and the sense of reciprocity was clear. She indicates a reliance on her husband that is a natural expectation and one she believes he is capable of providing.

*Barbara: We got on well together . . . we used to do things together . . . I feel you know that it, I'm sorry that I can't do it (cooking and cleaning) but we always have a good dinner anyway, and he cooks nice . . . he's a good husband . . . they (family) all love him to bits*

Research suggests early changes in cognitive decline have a great impact on the relationship between a husband and wife if one spouse has a diagnosis of dementia (Prakke, 2012). Barbara, however, makes the effort to sustain the quality and closeness of her relationship with her husband highlighting his capability and the feelings the whole family have for him. Being a good husband in Barbara's view relates to his ability to provide for her and the rest of the family as he has done in the past. Barbara also talks about the past and remembers a time when the work in the house was shared. She uses the term 'good' again here to describe her mother.

*Barbara: She [mother] was pretty good. In the end she, we had to let her go into a home, cause you know, but um, she was good, really good. She used to do things, I mean when I used to go out to work, that was long, long ago, if she was here, she used to do the dinner and things, you know, and, if my daughter come to visit her they used to have dinner together. And so you know, it was good.*

The experience of someone else's goodness promotes a sense of wellbeing and togetherness for Barbara. Her positive wellbeing is promoted by individual psychological characteristics and also by the quality of her environment (McNulty & Fincham, 2012). The relationships across Barbara's family and the caring she has witnessed over the years enable her to view her current situation in a way that defines her and her family.

The change that has occurred in Barbara's ability appears to be something she has accepted, however the word 'good' is used here to describe her experience of change.

*R: So can you tell me a little bit more about how you feel when you see [your husband] doing all the jobs around the house?*

*Barbara: Well, I don't feel very good but I mean, it's one of them things, I can't do it and that's it . . .*

*R: Can you tell me more about how it actually feels?*

*Barbara: Horrible really . . . to think that I used to do all that and now I can't . . . you know, it's horrible not being able to do it but it don't make me feel [pause] un useful*

In this excerpt 'good' is used with a negative connotation, as it relates to her inability to provide the care she once did. She states this does not make her feel 'un useful', however she is very aware that there has been a change in her circumstances and goes on to use the word 'horrible' to express her feelings. Despite all the explanation she gives and acceptance of change she appears to demonstrate, it must be acknowledged that feeling horrible about needing to be cared for is part of her lived experience. For Barbara, someone being good means someone who helps others, who perhaps goes beyond expectations and who holds a family together and her ability to do this is now limited.

She needs to preserve her sense of wellbeing by looking at what is good and maintaining a level of care she is still able to. The way Barbara manages this and maintains that caring role in the family is conveyed in the continued concern she shows for her family, especially her husband.

*Barbara: I mean he's 84 and I don't want him to push me up that hill all the time . . . I mean, I wouldn't want [husband] to take me up there cause, in the wheelchair, cause that's ever such a hill. I mean he's 84 and he's got arthritis and that, so that's a job to get up that hill with me every week.*

The experience of becoming cared for is not one Barbara feels she is going through alone and therefore understanding this cannot be explored in isolation (Kitwood, 1997). She is part of a family system which shares a common bond and centres on relationships and values (Beeber, 2008). The interdependence shared by this family over the years has impacted on how Barbara views herself now. She is accustomed to her family supporting each other and she continues to offer the support she can by avoiding certain activities she feels will put her husband at risk, further reinforcing the caring and useful person she still is. Overall, the perceived transition from independence to dependence that is evident when hearing about changes in Barbara's ability may not be felt as strongly by her as one may expect at this stage of her illness.

## Conclusion

This case study offers an insight into the experience of one woman living with AD in the UK, who now requires assistance with IADLs. The study supports the findings of Steeman, Godderis, Grypdonck, De Bal, and Dierckx de Casterle (2007) who found a person's feelings of value were linked to having done things of value for others during their life, being autonomous and being loved and cared for by others. Although Barbara is less able to do the things she used to do, she remains positive about what she has done in the past and maximises what she can do in the present. Despite the growing need for assistance, she believes this does not change who she is as a person. Nevertheless, she describes the feeling of relying on others as horrible and she is actively taking steps to ensure she does not become a burden on her husband demonstrated by her reluctance to allow her husband to push her wheelchair up the hill. This shows an awareness of the potential to become a burden.

Through interpretation it could be concluded that Barbara has experienced a number of life events which could have impacted on how she copes today; her changing role from wife to mother to grandmother, the role of carer for her mother and her grandchildren and the death of her daughter. Although Barbara did not highlight these events as impacting on her life in any way, it could be argued that the transition from caring to becoming cared for is no more challenging to accept than any life event she has experienced thus far. Along with her belief that she does not have AD, Barbara is able to maintain that she continues to care for her husband and her family through playing with the great grandchildren and expressing concern for her husband. The reduction in her ability to complete IADL does not appear to impact on her life as a whole. Barbara gave a picture of her life that demonstrates a close family who support each other. She also maintains that if she can continue to do some things around the home she will be happy. This positive story Barbara tells of her life now gives value to the self but could also be her attempt to remain someone of value in her family (Steeman et al., 2007).

Research indicates that a life event that changes a person's self-concept, beliefs or expectations is a turning point (Hutchison, 2010). It could be argued that Barbara has experienced a major life event when being diagnosed with AD in 2012, as others may perceive this to mean she has undergone a substantial change in her life, however at this point Barbara is still in the mild stage of the illness and sees very little change in herself. Her positivity and reluctance to believe she has AD suggests her subjective assessment of her life is very different. This is demonstrated throughout her interviews when she discusses her lived experience.

People with AD are often described by healthcare professionals as 'suffering from AD', indicating a belief that the person with the illness is enduring a major change in their life, however in Barbara's case this cannot be said and the view of healthcare professionals should be questioned. Barbara clearly needs assistance in her life now and despite the acknowledgement that relying on others feels horrible, she appears accepting of this based on her experience of reciprocity within her family. The quality of her relationship with her husband in good and difficult times shows a commitment to the relationship over years, potentially making it easier to deal with changes than if they had lived separate lives with little commitment to each other (Prakke, 2012). She feels valued and worthy of help; therefore her sense of self remains positive. This is important, as her level of impairment from AD is minimal at present and her physical health impairs her more. In conclusion, it could be suggested that as the AD progresses and she requires more assistance, her sense of self and value within the family need to be maintained to promote a continuation of her current quality of life.

A key challenge discussed during the G8 dementia summit (2013) was to improve quality of life for people living with dementia worldwide. The concept of quality of life is defined as an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations and standards (WHOQOL Group, 1998). This can be affected by a person's environment, relationships, physical and psychological state. This case study offers an in-depth interpretation of one woman's experience of becoming cared for, acknowledging her view of quality of life and how this could be maintained as her illness progresses.

Further research from an international perspective would also enable identification and promotion of cultural differences in women; their view of themselves and their place in society. Although AD is a global issue, continued research exploring the individual and unique lived experiences of people with AD and dementia across all countries is required in order for true quality of life for all to be achieved.

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Gayle Borley is a qualified RMN and is currently working as a Senior Clinical Research Nurse for the NIHR Clinical Research Network; East Midlands. Her clinical career thus far has involved working predominantly with people over the age of 65 diagnosed with both functional and organic mental health disorders. Her research interests focus on understanding the lived experience of dementia. She is currently undertaking her doctorate of professional practice exploring women's experience of living with Alzheimer's disease.

Judith Sixsmith is Professor of Public Health Improvement and Implementation at the University of Northampton, UK and Professor of Public Policy at Simon Fraser University, Vancouver, Canada. Her research interests lie in the areas of public health and social care where she explores the ways in which people living in deprived communities experience processes of marginalisation within our social systems. Often working within collaborative, gendered, participatory and multi-disciplinary approaches, Judith has directed several research projects on issues of healthy ageing, dementia and well-being and social inclusion. An expert in qualitative methodologies, Judith prioritises the involvement of participants in the design, implementation and interpretation phases of her research. She has published widely in the fields of ageing, health and community/ environmental psychology, alongside publications concerning the use of visual methodologies and participatory processes.

Sarah Church is an academic midwife and Deputy Lead, Centre of Family Life in the Institute of Health and Wellbeing. Her work on midwives and identity was the focus of her doctoral studies. Specific research interests include reproductive ethics, the sociology of reproduction and, more recently, transcultural aspects of care and caring. Her present research focuses on the experiences of pregnancy and early parenthood of Polish mothers and fathers. Dr Church is a qualitative researcher, experienced in Phenomenology and reflexive autobiography.

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# Appendix 5

## Interview schedule v1

## **Appendix 5 - Interview Schedule v1**

*These questions are a guide for the researcher. They can be asked but not necessarily in this order and are dependent on the participant and what they want to talk about*

Tell me about yourself?

How long have you and your husband been together?

Tell me about who did what in the household when you first got married.

Did you enjoy your role in the house when you were first married?

Which jobs were yours and which were your husband's? Did you have different roles in the house?

Do you have a family? Tell me about them and how they help you.

Tell me what happened when you were diagnosed with AD.

Tell me what has changed in you since your diagnosis.

What do you think your husband and your family think has changed?

How does that make you feel?

What do you need help with now? What does it feel like to need help with activities you have done yourself in the past?

What role do you have in the family and how has that changed since the diagnosis?

How do you feel about the help you get?

Do you think the need for help has changed how you think of yourself? In what way?

# Appendix 6

## Interview schedule v2

## Appendix 6 - Interview Schedule v2

*These questions are a guide for the researcher. They can be asked but not necessarily in this order and are dependent on the participant and what they want to talk about*

Tell me about yourself? What do you remember about your life?

*How long have you and your husband been together?*

Tell me about a day in your life when you were first married

*Tell me if you had separate roles/jobs in the house when you and your husband were younger? Who did the housework, shopping, cleaning etc?*

What did you enjoy in your role in the house when you were first married?

*What differences can you think of between what you did then and what you do now?*

Do you have a family? Tell me about them and how they help you.

*Tell me what happened when you were diagnosed with AD.*

Tell me what has changed in your life since your diagnosis.

*What do you think your husband (and your family) think has changed?*

How does that make you feel?

*What do you need help with now?*

What does it feel like to need help with activities you have done yourself in the past?

*What do you see your role as in the family and how has that changed since the diagnosis?*

How do you feel about the help you get?

*Do you think the need for help has changed how you think of yourself? In what way?*

Prompts:

Why?

How?

Can you tell me more about that?

Tell me what you were thinking?

How did you feel?

# Appendix 7

## Interview schedule 2 (example)

## Appendix 7 - Interview Schedule 2 (example)

What did you do yesterday? What have you done this morning?

*You enjoyed helping others in the past, how do you still help people now?*

You told me you don't feel capable anymore because your husband does things around the home. Do you think he is doing this to help you? How does it feel?

*How does your husband care for you?*

You said you don't say anything to your husband because it might turn into an argument – do you argue about things in the house? Why is that?

*You've always been a caring woman, tell me how it feels to be cared for?*

Do you think it changes you as a woman not being able to do the jobs around the house? How?

*Do you think it's the woman's role to do the housework and keep the house? In what way?*

Do you think you played a traditional role in the family as you and your husband have grown older together?

*How have you changed? How does that feel?*

Why is it important to you as a woman to be able to continue doing things you do around the house?

*How do you see your future? How does that make you feel?*

Do you think it's important to keep your independence?

Prompts:

Why?

How?

Can you tell me more about that?


Tell me what you were thinking?

How did you feel?

# Appendix 8

## Invitation letter



Gayle Borley  
Senior Research Nurse  
Thames Valley DeNDRoN  
Berrywood Hospital  
Berrywood Drive  
Northampton  
NN5 6UD  
 (01604) 685527

Date:

Participant address:

**An exploration of the lived experience of becoming cared for from the perspective of women with Alzheimer's disease.**

Dear

I am writing to ask if you would be interested in taking part in a study exploring the lived experience of women with Alzheimer's disease. This will give you an opportunity to talk about your experience of the disease and if it has had an impact on your life in relation to your ability to manage day to day activities and what help you receive from your husband and family.

Dementia care and research are an important focus for government policy development at the moment. To truly understand Alzheimer's disease I believe those living with the disease are the best people to talk to about their needs and feelings.

I have enclosed a copy of the Patient Information Sheet which offers further information regarding the study and what would happen to you, should you take part. If you do take part in the study, you will be free to withdraw at any time without this having any affect on your normal care. If you do not wish to take part your normal care will also not be affected.

If you are interested in this study and would like further information, please telephone me on 01604 685527 or 07668 151214.

Yours sincerely

Gayle Borley  
Senior Research Nurse

# Appendix 9

## Participant information sheet

**TITLE: An exploration of the lived experience of becoming cared for from the perspective of women with Alzheimer's disease.**

## **Patient Information Sheet**

**Study Sponsor: University of Northampton  
Park Campus  
Boughton Green Road  
Northampton**

**Chief Investigator/  
Researcher: Gayle Borley  
Senior Research Nurse  
Thames Valley DeNDRoN  
Berrywood Hospital,  
Northampton  
NN5 6UD**

### **Introduction**

I would like to invite you to take part in a research study which is looking at what it means to you to be cared for. Before you decide whether you would like to take part you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. You can talk to your family, memory clinic nurse/consultant as well. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### **What is the purpose of the study?**

This study is being undertaken as part of my university doctoral degree. I have chosen to look at care that women with Alzheimer's disease receive from their husbands when

living at home. The main aim is to understand how you feel about needing help and how that impacts on you as a woman and your relationship with your husband and your family. The purpose of this is to help healthcare professionals understand what

living with Alzheimer's disease is like for you and others, to enable them to provide the most effective and appropriate support.

Dementia care and research are also an important focus for government policy development at the moment. To truly understand Alzheimer's disease I believe those living with the disease are the best people to talk to about their needs and feelings.

This is a non-interventional study. Your treatment and medical care will not change because you are participating in this study. You and your doctor will continue to make all decisions regarding your ongoing treatment and care.

### **What will happen to you if you take part?**

It is up to you to decide if you would like to take part or not. If you are interested, I will meet with you to describe the study and go through this information sheet. I will give you the opportunity to ask any questions you have regarding the study. I will then ask you to sign a consent form to show you agree to take part. I will also ask your husband to agree to your involvement. Please remember, you are free to change your mind and withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

You will be interviewed by me on two separate occasions. I am not part of your care team. The interviews will take place at a convenient time and place for you and will be a week apart. You will be asked a series of questions about your experiences of being cared for and receiving help from your husband in relation to needs such as preparing meals, doing the housework and taking your medication.

I will ask you how your role in life has changed since you were diagnosed with Alzheimer's disease and how this makes you feel. The interviews will take about 1½ hours. I will record what you say on a digital voice recorder. This is to make sure that I have an accurate record of the things you say.

I will arrange the second interview with you after the first has been completed and as long as you are happy for me to do so. The second interview will take place within a week from the first interview and will be an opportunity for us to talk about any experiences you did not have the chance to discuss during the first interview or any new thoughts or feelings you have had regarding being cared for. If you take part in the first interview, there is no obligation for you to take part in the second interview.

The information you tell me during the interviews will be used by me and my supervisors to look at the similarities and differences of your experiences. This will be done alongside interview data from other women who have Alzheimer's disease. I hope it will enable me to present a meaningful picture of what it feels like to be cared for from a woman's perspective.

**What are the possible risks and benefits of participating in this study?**

We think the risks of taking part in this study are very low. If for any reason it upsets you to be asked about your views and experiences I will remind you we can stop at any time and give you information about where to get support.

There are no direct benefits from participating for you as an individual. However, I hope that the results from the study will help providers of dementia care services better understand the feelings and needs of women living with Alzheimer's disease and consider this in future care, policies and treatments.

**Expenses and payments**

You and your husband will not receive any payment or other benefits for taking part in this study. Your participation in the study is entirely voluntary.

**Who is organizing and paying for the research?**

There is no funding required for this study, as it is part of a Professional Doctorate Degree course run by the University of Northampton.

**Will your taking part in this study be kept confidential?**

All information I use for this study will be anonymised. Any information about you will have your name removed and replaced by a pseudonym so that it cannot be recognised. The data will be used only for this study and only I and my two supervisors from the University of Northampton will have access to it.

Your information will be kept in a locked cabinet within the University of Northampton, which only I will have access to and after the study is complete it will be destroyed.

I will use direct quotes/descriptions from the interviews. All these will be anonymised, as will any other names used or place names.

If you tell me something that makes me believe that you or someone else is at risk then it is my duty to report this and I would have to break confidentiality. I would always discuss this with you first.

The information that you share with me will be stored in paper form and electronically until the study ends in 2015. Electronic data will be protected by a password. The answers you give me will not be stored with any of your personal details.

By signing the consent form for this study, you will give permission for the use of the information you give during the interviews. If you do not want to allow this, you should not participate in this study.

### **What will happen if you don't want to carry on with the study?**

You may withdraw from the study at any time by notifying me. Should you appear distressed during the course of this study, the interview will be paused and you will be asked if you would like a break. You will be reminded that you can withdraw from the interview process at any time.

You will be given the opportunity to end the interview or continue. You will be directed to your memory clinic nurse or consultant if you require support with matters arising from taking part in this study.

### **What will happen to the results of the study?**

I will produce a report about the findings of the study and intend to publish this.

I will also produce a short report for those people who have participated in the study and you may have a copy of this if you would like one. You will not be identifiable in any report or publication.

### **Who has reviewed the study?**

All research is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been

reviewed and given a favourable opinion by East Midlands Research Ethics Committee.

### **How can you get more information?**

You may ask questions at any time about this study. If you have questions you should contact:

Chief Investigator:	Gayle Borley
Telephone number(s):	01604 685527 07668 151214

### **What if I have a complaint?**

If you have any concerns or complaints about the research during or after I have interviewed you, you should contact,

Professor Judith Sixsmith (University supervisor), Tel: 01604 893698  
University of Northampton. Boughton Green Road, Kingsthorpe, Northampton

And if you any have questions about your rights as a research participant, you may contact:

Northampton Patient Advice & Liaison, Tel: 01536 494130 or  
Northampton Research and Development, Tel: 01536 840300

This copy of the information sheet is yours to keep.

# Appendix 10


## Mini Mental State Examination



## Mini-Mental State Examination (MMSE)

Patient's Name: \_\_\_\_\_ Date: \_\_\_\_\_

**Instructions: Score one point for each correct response within each question or activity.**

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.)  
30		TOTAL

# Appendix 11

## Instrumental Activities of Daily Living Scale

**INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADL)**  
**M.P. Lawton & E.M. Brody**

**A. Ability to use telephone**

- |                                                                           |   |
|---------------------------------------------------------------------------|---|
| 1. Operates telephone on own initiative; looks up and dials numbers, etc. | 1 |
| 2. Dials a few well-known numbers                                         | 1 |
| 3. Answers telephone but does not dial                                    | 1 |
| 4. Does not use telephone at all.                                         | 0 |

**B. Shopping**

- |                                                   |   |
|---------------------------------------------------|---|
| 1. Takes care of all shopping needs independently | 1 |
| 2. Shops independently for small purchases        | 0 |
| 3. Needs to be accompanied on any shopping trip.  | 0 |
| 4. Completely unable to shop.                     | 0 |

**C. Food Preparation**

- |                                                                                            |   |
|--------------------------------------------------------------------------------------------|---|
| 1. Plans, prepares and serves adequate meals independently                                 | 1 |
| 2. Prepares adequate meals if supplied with ingredients                                    | 0 |
| 3. Heats, serves and prepares meals or prepares meals but does not maintain adequate diet. | 0 |
| 4. Needs to have meals prepared and served.                                                | 0 |

**D. Housekeeping**

- |                                                                                          |   |
|------------------------------------------------------------------------------------------|---|
| 1. Maintains house alone or with occasional assistance (e.g. "heavy work domestic help") | 1 |
| 2. Performs light daily tasks such as dish-washing, bed making                           | 1 |
| 3. Performs light daily tasks but cannot maintain acceptable level of cleanliness.       | 1 |
| 4. Needs help with all home maintenance tasks.                                           | 1 |
| 5. Does not participate in any housekeeping tasks.                                       | 0 |

**E. Laundry**

- |                                                 |   |
|-------------------------------------------------|---|
| 1. Does personal laundry completely             | 1 |
| 2. Launders small items; rinses stockings, etc. | 1 |
| 3. All laundry must be done by others.          | 0 |

**F. Mode of Transportation**

- |                                                                                    |   |
|------------------------------------------------------------------------------------|---|
| 1. Travels independently on public transportation or drives own car.               | 1 |
| 2. Arranges own travel via taxi, but does not otherwise use public transportation. | 1 |
| 3. Travels on public transportation when accompanied by another.                   | 1 |
| 4. Travel limited to taxi or automobile with assistance of another.                | 0 |
| 5. Does not travel at all.                                                         | 0 |

**G. Responsibility for own medications**

- |                                                                                  |   |
|----------------------------------------------------------------------------------|---|
| 1. Is responsible for taking medication in correct dosages at correct time.      | 1 |
| 2. Takes responsibility if medication is prepared in advance in separate dosage. | 0 |
| 3. Is not capable of dispensing own medication.                                  | 0 |

**H. Ability to Handle Finances**

- |                                                                                                                                         |   |
|-----------------------------------------------------------------------------------------------------------------------------------------|---|
| 1. Manages financial matters independently (budgets, writes checks, pays rent, bills goes to bank), collects and keeps track of income. | 1 |
| 2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.                                                     | 1 |
| 3. Incapable if handling money.                                                                                                         | 0 |

Source: Lawton, M.P., and Brody, E.M. "Assessment of older people: Self-maintaining and instrumental activities of daily living." *Gerontologist* 9:179-186, (1969).

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# Appendix 12

## Informed consent form

TITLE: An exploration of the lived experience of becoming  
cared for from the perspective of women with Alzheimer's  
disease.

Participant Consent Form

Please initial box

1. I confirm that I have read and that I understand the Information Sheet dated..... version..., for the above study and have had the opportunity to consider the information, ask questions, and have had such questions answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.
3. I understand what the research study is all about and I am happy to talk to the researcher about my thoughts and feelings about living with dementia
4. I understand that my name will not be used in the report, and I will be given a copy of the report if I wish
5. I understand that the interview will be recorded using a digital voice recorder, and will then be typed out.
6. I understand that direct quotes and descriptions from my interview may be used in the report but that I will not be able to be identified from these.
7. I agree to take part in two interviews for the above study.

\_\_\_\_\_  
Printed Name of Participant

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Researcher

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

# Appendix 13

## Sample transcript & IPA process

## IPA Process (sample transcript)

Emerging Themes	Transcript Interview 1 (Edith) 20.05.13	Notes (Description, <u>Language</u> , interpretation)
Being = doing	<p>G: tell me a little bit about yourself. What do you remember about your life?            Edith: well I think I had a good life, i had a happy childhood, with urm, you know, at home and that, with my brother and sister and we were a happy family. Unfortunately we lost mum quite early so we urm, we became you know..</p> <p>G: how old were you when you lost your mum?            Edith: in my teens</p> <p>G: were you, gosh, so that was obviously, had quite an impact            Edith: yes but we urm, we all pulled through it together, you know and we had you know urm, relations that were very good and that.</p> <p>G: were you the eldest?            Edith: no, my sister and my brother is the youngest. But urm, I'll just tell you this for no reason, but, my mother, I felt well we felt, as a family she was always <u>doing</u> for other people. And I remember saying this, <u>mum died running around after doing for other people and I see that it doesn't happen to me</u>. I remember saying that and I wasn't very you know, i was only in my teens and urm, but urm...</p> <p>G: was that running around doing things for other people in the family or...            Edith: well, if anybody wanted anything or that they used to knock our door and things like that</p> <p>G: right, so it was friends and people that lived nearby?            Edith: well it was neighbours and you know and we were you know, well, you know, everyone used to know mum, she was a willing person and that and urm, you know you urh, you do, you urh, <u>you feel well you know it won't happen to me but I don't like to say this but I've been the same</u>.</p> <p>G: in what way?            Edith: well if anybody's wanted anything or you know or wanted anything to do you know, they, [husband] and I were always prepared to help, yes but urm, we've got some lovely friends you know that we go and visit and I think the</p>	<p>Mum died when she was young.</p> <p>Doing. This word is used to describe her mum who was always being asked by others to help them. This is what she believes caused her mother's death and she didn't want the same thing to happen to her.</p> <p><i>'I don't like to say this' Doesn't like to admit she has fallen into the same pattern as her mum? Doesn't want to judge herself?</i></p> <p>Her and her husband have always been helpful when they can.</p>

	<p>saddest thing of all is that we've met some wonderful people that urh, that live at, not close you know, that we have since [daughters] terrible accident, and that's the saddest part of it all. I'm not saying, i mean i think a lot of them we would never have met but through that we've met some wonderful people. We all keep in touch, they ring and we ring you know to see how they are and it's nice and I think I've been blessed with a wonderful man (gets tearful). I mustn't get like this, it's stupid</p> <p>G: it's not. It's urh, I think it shows the tough life you've had doesn't it.</p> <p>Edith: well, not a, not tough like some people we've been very fortunate</p> <p>G: well that's good of you to say</p> <p>Edith: very fortunate, this, the worst part has been not being able to have a family (tearful)</p> <p>G: and what about when your mum died. Did you get on well with your father?</p> <p>Edith: oh yes, my dad, he was, yeah he was always up here, he loved comin up ere, [husband] and him got on fine and he loved my dad</p> <p>G: so did he look after you when your mum passed away, your dad?</p> <p>Edith: no, we urm, we, I can't remember exactly what it was, I can't honestly remember</p> <p>G: no, but obviously you had a good relationship with your dad.</p> <p>Edith: yeah, my dad, yeah, well he used to come up, he used to love comin up ere, he got on well with [husband] and you know.</p> <p>G: so when did you meet your husband?</p> <p>Edith: when did I meet [husband?] donkey's years ago. I didn't get married until I was, I was in my late twenties when I married, yes, I urm, I had other friends and that but I never, I had one boyfriend that was really urm, not worried about money, but urm and yeah, it was upsetting but I knew he wasn't right and I didn't wanna , in the back of my mind i thought well, he's got yeah, he'd lavish anybody, he bought me some lovely jewellery and all that you know but money doesn't make you love somebody but I mean I loved him but only in a different way, i didn't, marriage wasn't, he was a bit older than me but only a few years but urh, there you are, I'm glad to say that he did marry so that wasn't quite so bad, yeah.</p> <p>G: so where did you meet your husband?</p> <p>Edith: I think we were dancing, we used to go to the same place dancing</p> <p>G: oh lovely</p> <p>Edith: yeah, i think we were, i can't really remember yeah we used to go, i can't remember where, we used to go different places dancing and i think we met in,</p>	<p>She and her husband had a good relationship with her dad.</p> <p>Talks about money.</p> <p>Her view of love was not about being lavished upon. Money can't buy you love.</p> <p>She met her husband when they were dancing.</p>
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View of gender	<p>he might remember I'll ask him in a minute. I can't remember where it was but I can see it, it used to be two or three of us all together and that yeah</p> <p>G: and where did you live when you first married?</p> <p>Edith: when we first married, oh dear we moved up here i think [name of street]we lived, not here</p> <p>G: [] I know it well</p> <p>Edith: do you?</p> <p>G: yes, I've been a [] girl all my life</p> <p>Edith: oh have you? Yeah and I worked at the hospital [name of hospital]</p> <p>G: ah ok, which is no longer there sadly</p> <p>Edith: no, built on init?</p> <p>G: well half and half.</p> <p>Edith: yeah, that used to be ideal, I just used to have to run up the road</p> <p>G: yeah, definitely</p> <p>Edith: I loved that, you know we used to have the doctors there; we used to have some of the first you know, in...you know, they weren't called interns but first um, youngsters you know and I wouldn't, you were given the opportunity to have an injection against you know, and I couldn't stand needles, couldn't stand them and I wouldn't have it see and some of these young interns they got to know and urm our urm, office was at the, not in the main building, you had to go up to it and if I go up there , they'd watsit, scuse my language but the buggers would be there looking for me you know</p> <p>G: with a needle ready?</p> <p>Edith: yeah (laughs) I mean it was only, it wasn't meant but you know you'd think oh no..</p> <p>G: well they were obviously concerned for you weren't they, that's why they did it</p> <p>104: yeah but they were, we had some oh yeah, we had some wonderful laughs and that cause they were only youngsters, I wasn't as old as them quite but they were, I was in my teens but they were a bit older than me but I used to</p> <p>G: so what was your role, what did you do there?</p> <p>Edith: secretarial. I always done secretarial, so I was urh, yeah.</p> <p>G: so tell me then, tell me about a day in your life when you and your husband were first married?</p> <p>Edith: oh, I can't remember it's too long ago. [husband] used to have to go to work <u>obviously</u> but urm we had quite a nice circle of friends who we met through sort of going to different places, going out in the evenings and that you know, [husband] can probably tell you more about you know, I can't really</p>	<p>Talks about her old job at the hospital.</p> <p><i>Social construction. It is right that the husband goes to work?</i></p>
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Caring role	<p>remember but we used to be in sort of, not a crowd but we used to meet up with people and that.</p> <p>G: can you remember what you did? Did you stay at home when your husband was a work? What did you do?</p> <p>Edith: during the day I was still working I think. Oh no, I was the sick visitor, yeah, for the village</p> <p>G: ok, what did that entail?</p> <p>Edith: anybody that was poorly or that, I'd go and visit. That was when we came here you know,</p> <p>G: so that was some time later was it?</p> <p>Edith: yeah, yeah, but I was the sick visitor for the WI</p>	<p>Talks of her role as the 'Sick visitor', which is a role she played later in life with the WI.</p>
Unspoken control	<p>G: did you have, sort of separate roles in the house you and your husband?</p> <p>Edith: well I had, we had 4, 5 dogs so I always walked the dogs. {husband} did sometimes but I you know, I was brought up with dogs so I couldn't be without them when I got married but he won't, urm, when we said goodbye to the last one he wouldn't have another one and quite honestly I miss that more than anything cause I know if I had a dog I'd get out and go for a little walk every day instead of sitting here. [husband] is not one for walking so urm,</p>	<p>Talks about her love for dogs. Has always had dogs in her family.</p> <p><i>Husband is in charge?</i> He won't allow another dog so she accepts that decision but moans about it.</p>
Feeling taken over	<p>G: and you wouldn't go for a walk without dogs?</p> <p>Edith: well I wouldn't cause if I went anywhere I'd like to do what i used to do, walk up to the forest and back you know, but I wouldn't do it on my own not these days, no. But there you are, that's life so I sit ere all day, he's {husband} doesn't discuss anything, as I say, <u>he's taken over and never been mentioned you know, oh I'll get the meals, nothing, he's just got, taken over.</u></p>	<p>Taken over. No discussion that she can remember, <i>she feels her whole life has been taken over because he is now doing the cooking?</i></p>
Normality	<p>G: you said to me that he's taken over which to my mind means that one of your jobs in your married life was to take care of the home, is that right? You did all the cooking and cleaning and things like that did you?</p> <p>Edith: oh yeah, yeah. Cause well [husband] was working you see, so that was it you see, but nowadays he's urm....</p> <p>G: did you enjoy taking care of the house?</p> <p>Edith: oh yes, I mean it was like you, <u>it's normal init?</u> It's something that you do in life you know, yeah and as I say, I had several dogs that I walked so um, we used to meet, you know, I miss other people that used to walk their dogs and that, so you know, we used to meet other people un I loved it, yeah.</p>	<p>Traditional relationship where husband worked and her role was to 'keep house' although she also worked.</p> <p><u>Normal.</u> <i>Socially constructed view. If you do the housework as a woman you are normal, if not are you abnormal?</i></p>
Making decisions/choices	<p>G: so it doesn't feel quite the same anymore?</p> <p>Edith: oh, it's not the same anymore, I mean I don't , as I say, [husband] has taken over, he doesn't like the cleaning but I don't like, I don't, I give it a clean when I, but I don't make an effort like I used to.</p>	<p>Describes her life as different now because he has taken over. He doesn't like doing the cleaning so she does that occasionally but she doesn't make the effort anymore.</p>

Treated like a child – behave like a child	<p>G: why do you think that is?  Edith: I can't be bothered. I think, well he's taken, he's done everything else, he's taken away doing the shopping and all that and everything else so he can do the cleaning as well. It's a terrible attitude to take but <u>I'm not ere just to clean</u>. That's it.</p>	<p><i>Reaction to takenoverness is stubbornness, childishness? She <u>'can't be bothered'</u> to clean if that is all he expects her to do now. He can't choose to take over the good bits and leave the rest to her – in her mind there are some jobs in the home which hold more importance/responsibility. Sense of pride in her.</i></p>
View of self through others eyes	<p>G: so do you go shopping with him?  Edith: yes, oh yes, he pays for everything, I don't have to put my hand in my pocket at all, which again is <u>a bit embarrassing to me</u>  G: is that something you used to do then, did you used to share the finances.  104: I used to do the shopping and that yeah. I mean if we went to a big store he'd perhaps, but no I used to do that. But I wouldn't now; I don't think I'd know what to do with money (laughs)</p>	<p><i>Why? Demeaning? View others have of her?</i></p> <p><i>Loss of skills because this role has been taken over.</i></p>
Change in behaviour of others Feeling lost	<p>G: really?  Edith: I, no, I have me own pension but if I wanted anything I've got, you know a bit that I can use yeah and I think if I asked him for anything he'd probably, I don't know I can't really understand him anymore, perhaps it's me, it might be me I don't know (pause) I mean he goes, as I say he'll urm, I don't know where he is now even,  G: he's just gone to sit in the kitchen, he was going to make a telephone call to [] about the funeral arrangements  Edith: oh yeah, oh he urh, I don't know it's so different to what it used to be, urm, funny how life changes init?</p>	<p><i>Questioning herself <u>'it might be me, it could be me'</u> and her relationship <u>'I can't understand him anymore'</u>. She struggles to understand what is happening to herself and it is the change in her husband's behaviour which makes her look at herself.</i></p>
Being active	<p>G: it is  Edith: (pause) yeah but it used to be lovely when we had the dogs  G: so the dogs were obviously quite important to you  Edith: oh they were, well they got me out every day, I mean when you've got 4 or 5 dogs you don't mind walking up to the forest and that but you wouldn't go up to the forest on your own, well I wouldn't not these days no Its a, I'm not going to say anything would happen but you it's not like it used to be donkey's years ago when you could let your children out to go for a little walk, it's not like that now is it?</p>	<p><i>She recognises change but has little explanation for it. <u>'So different'</u></i></p> <p><i>Talks of her dogs again. Dogs are symbolic of something else? Maybe this is not about the dogs but about a time when she had more in her life; it represents a time when she had a social life, work, her daughter was still alive. She was active/doing</i></p>
Reasoning	<p>G: no it isn't  Edith: I wouldn't want to walk up to the, I wouldn't walk in the forest on me own in any case without [husband] or that or something yeah when you feel safe  G: how is your mobility?  Edith: pardon, oh ok, yeah. I get about fine ya know, we use the car a lot obviously cause of where we live now. We've got a bus pass but ya know</p>	<p><i>Talks of the change in society and being safer years ago. This impacts on her ability to do things she wants to do now. Able to construct a reason why she isn't doing what she used to; change in society, no dogs.</i></p>

<p>Being in control</p>	<p>[husband] is quite happy to use the car, well in actual fact we've got somebody, I don't know I might have told you this, if I have, say I have, but we've got somebody [name] somebody that I used to work with many many years ago and her, ya know we became friends and that and it's her son [name] and he comes over if we want to go anywhere or that. {husband] gives him a tinkle and he'll come over and take us if we want to do if [husband] doesn't feel like ya know, feels yeah, will take ya or so its very handy ya know, having somebody like that, he's a lovely fella he's not married, I don't know why, he's a, he lives with his mum, so he's just nice [name], yeah.</p> <p>G: So you said about [husband] not being so keen on driving anymore and obviously you used to drive</p> <p>Edith: oh <u>I loved it but he won't let me</u>, wouldn't let it stop, and <u>wouldn't let me</u>.</p> <p>G: why do you think that is?</p> <p>Edith: I don't know why, no idea but I've not driven for some time now and what the roads are like I don't think I'd really want to.</p> <p>G: how does it make you feel?</p> <p>Edith: what, <u>incapable</u></p> <p>G: does it?</p>	<p>Explains how she and her husband get out now. A friend's son drives them to places if needed.</p> <p><i>Sense of dominance. What he says goes, although I think she has always been an independent lady, has he always had the last word?</i></p> <p><i>Again, reasons why she is no longer driving. Takes back some of the control over the decision – not her husband's but hers because of the changes in society and more cars now on the road.</i></p>
<p>Feeling useless Loss of role/ purpose</p>	<p>Edith: mm. Mm. I mean you know, I feel useless, that's how I feel. [husbands] taken away doin the shopping and everything, as I say from choice and I just feel useless I just feel at times I'm just sitting in this chair waiting to die, that's a dreadful thing to say but I'm so bored and miserable. If I had a little dog, I'd at least, it would make, ya know, I'd have to make the effort to get up and go for a little walk with it. But it's just not worth the, the ya know, what it would (pause) it's just not worth it now, I'll just sit here now and wait.</p> <p>G: Do you try and talk to [husband] about how you feel?</p> <p>Edith: no. I don't think he would understand.</p> <p>G: so when he goes shopping what do you do?</p> <p>Edith: I sometimes go with him</p> <p>G: do you?</p> <p>Edith: yeah. <u>I just push the trolley</u></p> <p>G: right. So you don't get involved in picking what you're going to buy?</p> <p>Edith: no, no. He might say oh, ya know, d'ya fancy this or that, I should give that to him but apart from that I don't, I don't have anything to do with the money or anything, apart from my pension.</p> <p>G: what about around the house, what about the cooking, the meals?</p>	<p><i>A dog in her life would give her purpose/a role.</i></p> <p><u>I just feel useless, I just feel at times I'm just sitting in this chair waiting to die..... If I had a little dog, I'd at least, it would make, ya know, I'd have to make the effort to get up and go for a little walk with it..... But it's just not worth the, the ya know, what it would (pause) it's just not worth it now, I'll just sit here now and wait</u></p> <p><i>Waiting for death? She has given up the fight.</i> Questions her relationship again believing he will not understand how she feels.</p>
<p>Being active Being responsible</p>	<p>G: so when he goes shopping what do you do?</p> <p>Edith: I sometimes go with him</p> <p>G: do you?</p> <p>Edith: yeah. <u>I just push the trolley</u></p> <p>G: right. So you don't get involved in picking what you're going to buy?</p> <p>Edith: no, no. He might say oh, ya know, d'ya fancy this or that, I should give that to him but apart from that I don't, I don't have anything to do with the money or anything, apart from my pension.</p> <p>G: what about around the house, what about the cooking, the meals?</p>	<p><i>Demeaning task, she no longer makes decisions about what they buy. No sense of responsibility.</i></p> <p><i>Money is a symbol of responsibility.</i> Even though she does seem to get involved in choosing items, she no longer pays for things.</p>
<p>Being in control Making choices</p>	<p>G: what about around the house, what about the cooking, the meals?</p>	<p><i>It was his choice to start doing the cooking, he didn't have to do it? but she expresses her own choice by saying she wouldn't want to do it now anyway. Taking control of herself. She is coping with becoming cared for – not an</i></p>

<p>Being taken over</p>	<p>Edith: oh he does, he does, he, and from choice he does it but I wouldn't want to be cooking again now, it's so long since I've done it, it'd be like starting again and I don't wanna, doin it my age, 80, I'm getting on, what am I? 80? No, I don't think I'd wanna start cooking again, I think <u>it would be like starting again</u>.  G: so how does that make you feel? Because cooking was....  Edith: incapable  G: .....obviously something you enjoyed doing?  Edith: oh I did yeah.  G: how did it happen that you stopped doing it?  Edith: [husband] just took over. (pause)  G: how did he take over?  Edith: he just started doin it.  G: did you question him at the time, why he was doing that?  Edith: I don't remember now, it was such a long time ago, it seems like such a long while ago  G: is it? Is it a long time?  Edith: yeah, (pause). No he started doin it, and doin the shopping, ya know, I go with him to do the shopping but he never used to, I mean he just started, he just stopped givin me any housekeeping and took it all over. Whether he thought I was extravagant or that I don't know but I never ask, I never ever asked him for any more money cause if I was a bit short I'd always got my own.  So, unless it was something big but I mean there was never anything like that, no (pause)  G: And what about his cooking – is it ok?  Edith: yeah, yeah I think it, I think if he had the chance we'd have ready meals, a lot of ready meals but I don't touch those, no  G: right, you like fresh food?  Edith: yes. I was brought up on fresh food but um, no I wouldn't touch ready meals, I don't know what you think about them but  G: well, I think they've got their place  Edith: they're alright, yeah that's right. If you're in a rush or something you'd use it wouldn't ya but from choice... fresh food which is nice. (pause) I don't know where he is now?  G: He's in the kitchen, he took the paper in the kitchen, he's gonna make some telephone calls  Edith: oh right.  G: so, all the changes that you feel have happened as you've got a bit older, how do they make you feel?</p>	<p><i>easy transition but one she is having to rationalise whilst maintaining some control over what is happening to her.</i>  <i>? it would be like starting again Acknowledging the difficulty of the skill of cooking, once lost, it would be hard to get back. A skill makes a person worthwhile?</i></p> <p><i>Expression of 'took over' suggests it was her job preciously</i></p>
<p>Change in behaviour of others</p>	<p>Edith: yeah, (pause). No he started doin it, and doin the shopping, ya know, I go with him to do the shopping but he never used to, I mean he just started, he just stopped givin me any housekeeping and took it all over. Whether he thought I was extravagant or that I don't know but I never ask, I never ever asked him for any more money cause if I was a bit short I'd always got my own.  So, unless it was something big but I mean there was never anything like that, no (pause)  G: And what about his cooking – is it ok?  Edith: yeah, yeah I think it, I think if he had the chance we'd have ready meals, a lot of ready meals but I don't touch those, no  G: right, you like fresh food?  Edith: yes. I was brought up on fresh food but um, no I wouldn't touch ready meals, I don't know what you think about them but  G: well, I think they've got their place  Edith: they're alright, yeah that's right. If you're in a rush or something you'd use it wouldn't ya but from choice... fresh food which is nice. (pause) I don't know where he is now?  G: He's in the kitchen, he took the paper in the kitchen, he's gonna make some telephone calls  Edith: oh right.  G: so, all the changes that you feel have happened as you've got a bit older, how do they make you feel?</p>	<p><i>Trying to make sense of the change in her husband's behaviour. Was it something she did? She sees the change as negative, not caring. A slight on her as a person – she was always able to manage the budget she was given, prides herself in not asking for more money but still this role has been taken away. Trust?</i></p>
<p>Standards</p>	<p>Edith: yeah, yeah I think it, I think if he had the chance we'd have ready meals, a lot of ready meals but I don't touch those, no  G: right, you like fresh food?  Edith: yes. I was brought up on fresh food but um, no I wouldn't touch ready meals, I don't know what you think about them but  G: well, I think they've got their place  Edith: they're alright, yeah that's right. If you're in a rush or something you'd use it wouldn't ya but from choice... fresh food which is nice. (pause) I don't know where he is now?  G: He's in the kitchen, he took the paper in the kitchen, he's gonna make some telephone calls  Edith: oh right.  G: so, all the changes that you feel have happened as you've got a bit older, how do they make you feel?</p>	<p><i>She believes he would do things the easiest way possible if able? Not meeting her standard.</i></p>
<p>Trustworthiness</p>	<p>Edith: yeah, yeah I think it, I think if he had the chance we'd have ready meals, a lot of ready meals but I don't touch those, no  G: right, you like fresh food?  Edith: yes. I was brought up on fresh food but um, no I wouldn't touch ready meals, I don't know what you think about them but  G: well, I think they've got their place  Edith: they're alright, yeah that's right. If you're in a rush or something you'd use it wouldn't ya but from choice... fresh food which is nice. (pause) I don't know where he is now?  G: He's in the kitchen, he took the paper in the kitchen, he's gonna make some telephone calls  Edith: oh right.  G: so, all the changes that you feel have happened as you've got a bit older, how do they make you feel?</p>	<p><i>She asks where he has gone, unsure of his whereabouts – trust?</i></p>

<p>No going back</p>	<p>Edith: useless.  G: do they?  Edith: makes me feel I'm not capable of anything now.  G: do you think if you got up and went into the kitchen and tried to do some cooking that you'd be able to?  Edith: I'm sure I would but I don't, I think now its not worth the (pause) hassle.  G: what hassle would you get do you think?  Edith: well like [husband] would say, no, no, probably, I'll do it, go on, you go and sit down. I think, well I might as well sit ere as go out and urh, because I wouldn't want to be out there with him, him saying oh you peel the potatoes and things like that. If I was in the kitchen I'd like to be doing it all myself.  G: right. You like to be in control?  Edith: oh yes, yes. Well, I think most women would, would you? You know if you were in the kitchen getting a, and that, instead of having somebody at the side of you, I'll do these, will you do that, ya know.  G: everyone has their little ways don't they?  Edith: oh yeah, yes. But um, what I find you know, I still can't find why, why he suddenly started doin it (pause)  G: do you think it was anything to do with.....  Edith: well I think he thought that it ya know, he's the type of bloke whose very thoughtful and he probably thought oh ya know I'll um, I'll do it for [name] but I didn't expect it to be permanent. But I wouldn't say that to him now cause if I did it might cause an upset and it wouldn't be worth it.  G: right</p>	<p><i>Trying to take her role back would be a hassle? Relationship.  Even if she tried to 'do' now she would not be independent in her actions despite the fact that she hates being inactive and not 'doing'  Does she hate being inactive?</i></p>
<p>Being judged</p>	<p>.....</p>	<p><i>Doesn't want to be watched. Social construction of a woman's role.  Her domain is the house, this is where she holds the control in the relationship.</i></p>
<p>Making sense of his behaviour</p>	<p>.....</p>	<p>She cannot understand why he has started doing things around the house.</p> <p>Acknowledges that he is helpful and thoughtful and may have enjoyed a break from the responsibility of looking after the home but not a permanent change.</p> <p><i>Keeping the peace is more important than how she feels in herself? Keeping him happy?</i></p> <p><i>Part of her likes having everything done for her?</i></p>

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