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

## Abstract

This case study explores the meaning one woman with Alzheimer's disease gives to receiving assistance with instrumental activities of daily living (IADL) 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

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

## 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 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 (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 requires 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 that 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, 2009).

## **Understanding the lived experience of AD**

Alzheimer's disease 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 (Warner & Graham, 2012) in order to receive specialised care.

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). When people are diagnosed with AD, they show signs of trying to adjust (Clare 2002, Clare 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 et al, 2006) 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, 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 (Warner & Graham, 2012). 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 et al, 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 et al, 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 instrumental activities of daily living have traditionally been seen as feminine tasks and thus a woman's responsibility (Beagan et al, 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 research shows that women continue to undertake the majority of the housework and caring for family members than men (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 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 (Warner & Graham, 2012) 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 (Siriopoulos et al, 1998; Paun 2003; Perrson & Zingmark, 2006; Walters et al, 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 (Siriopoulos et al, 1998; Paun 2003).

Becoming cared for and needing assistance with IADLs has 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 positive family relationships and maintaining 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 et al (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 attempt to help preserve the image of the woman as independent (Haak et al, 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. 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 woman, enabling the mother to maintain a positive sense of self (Svanstom & 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 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 Alzheimer’s disease (AD). The interviews were part of a larger Interpretative Phenomenological Analysis (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, 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 IADL activities 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, 200). 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 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 et al, 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, 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 instrumental activities of daily living.

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, 2009). Taking into consideration the unpredictable nature of dementia on communicative capacities (Hubbard et al, 2003) 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; Clare, 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 (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 Alzheimer's disease 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 Alzheimer's disease in relation to her need for help with instrumental activities of daily living, acknowledging that she is not as able as she has been in the past.

Barbara was born in the UK in the 1930's, she met and married her husband in the early 1950's 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 et al, 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 paper relating to those people who have an awareness of their diagnosis (page 1). 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 et al, 2002), denial (Sevush & Leve, 1993), impaired insight (Mangone et al, 1991) and determining an overall meaning has been difficult (Markova et al, 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 can't 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 (2005) 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 of 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 recognizes 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 is a coping mechanism found to help a person with dementia adjust to their new situation (Robinson et al, 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's 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 enables 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 IADL's. The study supports the findings of Steeman et al (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 (World Health Organisation, 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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