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## Exploring the Lived Experience of People with Dementia Through Interpretative Phenomenological Analysis

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### Abstract

Dementia is arguably one of the biggest challenges facing society today, impacting millions of people worldwide. Nonetheless, there is only a relatively small body of research exploring what it is like to live with dementia from the perspectives of people who have this condition. This is partly because of the (implicit or explicit) belief that people with dementia lack insight into their condition and cannot talk about their experiences clearly. In this article, I argue that such beliefs are typically both erroneous and unhelpful, and that there is great value in seeking to illuminate the lived experiences of people with dementia. I present an interpretative phenomenological analysis of data from semi-structured interviews with six participants who had moderate dementia. I elicit five themes from this analytic process, and discuss the three most prominent here: awareness and understanding of dementia, clarity and confusion, and social support and relationships. I mobilise these themes to narrate the lived experiences of people with dementia, demonstrating their awareness both of the difficulties presented by dementia and of the negative perceptions of others.

### Keywords

Dementia, Interpretative Phenomenological Analysis (IPA), Lived Experience, Personhood, Stigma

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## Exploring the Lived Experience of People with Dementia Through Interpretative Phenomenological Analysis

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*Dementia is arguably one of the biggest challenges facing society today, impacting millions of people worldwide. Nonetheless, there is only a relatively small body of research exploring what it is like to live with dementia from the perspectives of people who have this condition. This is partly because of the (implicit or explicit) belief that people with dementia lack insight into their condition and cannot talk about their experiences clearly. In this article, I argue that such beliefs are typically both erroneous and unhelpful, and that there is great value in seeking to illuminate the lived experiences of people with dementia. I present an interpretative phenomenological analysis of data from semi-structured interviews with six participants who had moderate dementia. I elicit five themes from this analytic process, and discuss the three most prominent here: awareness and understanding of dementia, clarity and confusion, and social support and relationships. I mobilise these themes to narrate the lived experiences of people with dementia, demonstrating their awareness both of the difficulties presented by dementia and of the negative perceptions of others. Keywords: Dementia, Interpretative Phenomenological Analysis (IPA), Lived Experience, Personhood, Stigma*

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In this article, I discuss an interpretative phenomenological analysis of semi-structured interviews conducted with six people who have diagnoses of moderate dementia. I aim to illuminate the lived experiences of these participants, with a particular focus on how they live with and make sense of their condition, and on the impact this has on their selves and their relationships with others. I begin by outlining how dementia has been conceived within the dominant biomedical framework, before moving on to consider what we know about the *people* who live with this condition. I then introduce the current study, placing the interviews within the broader context of an arts-based, performative social science project, “I Will Tell You Something of My Own” (the title for which comes from a poem co-written by Olwyn Jones and Karen Hayes as part of a poetry writing and performance intervention with people with dementia; see Gregory, 2011; Gregory et al., 2012 a, b). The subsequent analysis of the interview data focuses on three themes that describe the research participants’ awareness of their condition and their struggle to adapt to the difficulties this presents. I conclude by considering how we, as researchers and as fellow human beings, can build on these understandings to help people with dementia live as full and happy lives as they are able to live.

### **Dementia as a Biomedical “Problem”**

The term dementia covers a group of related, but heterogeneous conditions. These have in common a pattern of progressive neurological decline, which ultimately results in severe cognitive and behavioural difficulties (Durand & Barlow, 2013; Feinstein, Duff & Tranel, 2010). Dementia affects a large and increasing number of people, with diagnoses in excess of 24.3 million cases worldwide (Ferri et al., 2005) and 66 million cases projected for 2030 (Wortmann, M. 2012). Accordingly, the former U.K. Government’s National Dementia

Strategy declares that, “Dementia is now one of the most significant challenges facing our society” (Department of Health, 2009, p. 70). The same report estimates that the condition costs the U.K. economy around £17 billion per year. Despite the many advances that have been made in understanding dementia, however, scientists still have much to learn about the aetiology, course and treatment of this condition (Luengo-Fernandez, Leal, & Gray, 2010; Ritchie & Lovestone, 2002).

At present, there is no cure for dementia and no medical treatment to reliably and significantly alter the progression of conditions like Alzheimer's disease (Durand & Barlow, 2013). As Harman and Clare (2006) illustrate, this understandably results in a lack of faith in medical interventions among some people with dementia. Nonetheless, there is an over-reliance on anti-psychotic and other medication in dementia care, with drugs being prescribed widely to manage symptoms, behaviours and emotional states (Department of Health, 2009). Depression and anxiety, in particular, are often viewed as symptoms of dementia, which can be treated in this way (e.g., Wetzels et al., 2011). There is growing evidence, however, that the distress, depression and anxiety associated with dementia are at least partly because of the social situations in which people with dementia find themselves (e.g., Baldwin et al., 2007; Mitchell, Dupuis, & Kontos, 2013).

Despite this, the social context and interpersonal needs of people with dementia are often overlooked (Albanese et al., 2007). Undoubtedly, this neglect is due partly to the limited resources available to those who care for people with dementia. It is important not to overlook, however, the impact of dementia stigma on the care and daily interactions of people who live with this condition. Tom Kitwood (1990, 1997) has written extensively on this topic. For him, dementia is more than neurological impairment alone. Instead, it can be defined according to the formula:  $D = P + B + H + NI + SP$  where dementia is viewed as a combination of an individual's *personality*, *biography*, *health*, *neuro-impairment* and *social psychology*.

### **Personhood, Disability and Voice in Dementia**

Kitwood (1997) argues for a “new culture” view of dementia, where dementia is redefined as a disability, the nature and extent of which can be largely determined by the quality of care received. This new culture perspective rejects pessimistic, deterministic models which position people with dementia as little more than disintegrating shells, and emphasizes instead their capacity to lead full and enjoyable lives in which their “personhood” is upheld and respected. Kitwood (1997) defines “personhood” as, “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (p. 8).

Kitwood's (1990, 1997) landmark work has been highly influential in the literature, and his concept of personhood has been developed further by several theorists (e.g., Baldwin et al., 2007; Bartlett & O'Connor, 2007). “Person-centred care” is now a virtually ubiquitous phrase in the care sector, with numerous care homes, organisations and practitioners citing this model as an influence. Nevertheless, for many people with dementia, the concept of personhood has yet to change the ways in which they are treated and cared for on a daily basis. Instead, fatalistic descriptions of dementia as a “slow unravelling of the self or the living death” (Beard, Knauss, & Moyer, 2009, p. 227) remain commonplace. The prevalence and impact of this dehumanising language is illustrated well by Mitchell, Dupuis, and Kontos (2013), whose insightful and disturbing paper urges the reader to challenge the “tragedy discourse of being doomed, gutted, ravaged, taken over by a beast, and turned into the living dead” (p. 2) which still dominates accounts of dementia. According to these authors, the impact of such language on people with dementia is both powerful and negative.

Indeed, as Sterin's revealing autobiographical account observes, the dementia label is still "the kiss of death" (2002, p. 8) for many social interactions. People who live with dementia often find that others speak for them, talk about them as though they are not there, or otherwise avoid engaging them in conversation (Killick & Craig, 2012). This leads to a loss of agency, identity and social connectedness, which could at least be seen to exacerbate the symptoms of dementia, and at most be viewed as an alternative explanation for these *symptoms* (Kitwood, 1997). Related to this is the commonly held view that people with dementia lack insight into their condition, being unable to recognize or articulate their own needs or desires. Autobiographical accounts such as those by Bryden (2005), Debaggio (2002), Henderson (1998) and Sterin (*ibid*), however, call such claims into question, and there is increasing recognition that people with dementia have greater awareness than they are typically credited with.

This moves the onus onto others to provide the conditions which enable people with dementia to express their thoughts, needs and desires (Killick & Craig, 2012). Such a shift in responsibility away from the individual living with dementia and toward society as a whole is reminiscent of the social model of disability. Indeed, authors like Gilliard et al. (2005), Marshall (1994, 2000) and Wilkinson (2002) have argued that this model has much to teach us about dementia. They contend that a social model of dementia has the potential to result in more attentive, personalized care, where clients' abilities are emphasised more than that which they have lost, and their personal experiences are treated as paramount. As Marshall (1994) remarks, this model also allows us to take seriously the discrimination and marginalisation which are a key feature of life for so many people with dementia.

Nonetheless, ageism, dementia, stigma and power inequalities continue to result in the voices of people with dementia going unheard (Wilkinson, 2002). For Wilkinson, this is an inequity in which researchers have the power (and obligation) to address (*cf.*, McKillop & Wilkinson, 2004). Mapping brain damage or developing indices of "problem behaviours" will not help us here. These approaches cannot tell us what issues are important to people with dementia, what challenges are most salient to them in their daily lives or how they evaluate their happiness and wellbeing. Instead, if we are to have a meaningful impact on the lives of people with dementia, we must build an understanding of how such individuals experience, and make sense of the difficulties they face; we must strive to give voice to those who live with this condition, helping them to convey their valid, meaningful experiences to others. Thus, the phenomenological accounts of people with dementia can offer valuable insight which we, as researchers, practitioners and human beings, should take seriously, rather than dismissing it as inaccurate, flawed or inconsequential.

### **Researching the Lived Experience of People with Dementia**

There is a growing literature on the lived experience of those who care for people with dementia (*e.g.*, Kindell et al., 2014). However, research that explores the experiences and understandings of people with dementia, in their own words, remains relatively sparse. Whereas close attention to carers' accounts is undoubtedly valuable, the lesser attention which is given to people with dementia themselves calls into question how fully such research is able to "explore and describe the everyday experiences of people living with . . . dementia" (Kindell et al., 2014, p. 402).

Research that has sought to investigate the lived experience of people with dementia directly, has suggested that they (at least in the early stages) continue to have a rich inner life. Furthermore, there is evidence that their subjective experiences vary in both nature and quality, depending on their interactions with others in the world. Sabat and Harré (1992), for instance, apply social constructionist ideas of the self to dementia, arguing that people living with

Alzheimer's disease maintain a sense of personal identity, but often experience threats to their subjectivity and public presentation of self when those around them restrict their autonomy, silence their voice and persist in defining their behaviour as symptomatic of dementia.

Harman and Clare's (2006) interpretative phenomenological analysis of nine participants with early-stage dementia provides some support for this theory. Their research reveals how people with dementia seek to negotiate and maintain their identities in the face of their condition and stigma from others. (cf., Beard, 2004; Pearce, Clare, & Pistrang, 2002). Clare (2003) argues that such attempts to negotiate the self in the light of dementia can easily be misinterpreted by others as representing individuals' lack of awareness into their condition. This suggests that the stigmatising and labelling effects of dementia can hinder a full understanding (and expression) of the lived experience of people with this condition.

### **Introducing "I Will Tell You Something of My Own"**

In this article, I seek to build on this small, but growing body of research with people who have mild and early-stage dementia by presenting an in-depth exploration of the lived experiences of people whose condition is further along and who have more severe symptoms. The interviews analysed in this article derive from a performative social science (or arts-based research) project, "I Will Tell You Something of My Own." (See Gergen & Jones, 2008 for an in-depth discussion of performative social science.) The title for this project comes from a poem co-written by Olwyn Jones and Karen Hayes, as part of a poetry writing and performance intervention with people with dementia (see Gregory, 2011; Gregory et al., 2012 a, b). In this project, I worked with a group of artists and people with dementia to create and exhibit poems, three dimensional collages, photographs, songs and poetry/song fusions. These artworks were used to illuminate and celebrate the lives of people with dementia, with a view to helping combat dementia stigma.

The interviews were carried out as part of creative sessions, in which I worked with people with dementia to create collages of objects that were important to them in some way. In the first interview, my interview questions focused on participants' interests, activities and identities, their feelings around dementia, and the collage object. In the second interview, I asked participants to expand on the significance of the objects, using these as the jumping off point for a more in depth, focused discussion of participants' lived experiences.

I describe the collage objects and accompanying narratives in some depth in Gregory (2014), alongside a more wide-ranging discussion of the artistic arm of this project. Accordingly, I have chosen to focus the remainder of the current article on an interpretative phenomenological analysis (IPA) of those portions of the interviews that consider participants' lived experience of dementia. In doing so, I seek to address the following research questions:

- 1.) How do people with dementia talk about their lives and selves?
- 2.) What is it like to live with dementia?

As I discuss below, IPA is well suited to an investigation of these aims, because it seeks to capture in rich detail the individual, subjective meanings and experiences associated with a given phenomenon (e.g., Eatough & Smith, 2007).

## Method

### Ethical Approval

Permission to undertake this project was received from the University of Gloucestershire Research Ethics Sub-committee. Informed consent for the research was obtained from all interviewees. Consent was also obtained from family and/or carers, as these individuals acted as gatekeepers in the process and were considered by the Ethics Sub-committee to have greater capacity than those they cared for to make informed decisions about participation. Written consent was sought from participants at three junctures: at the start of the first interview, at the start of the second interview and shortly before the first run of the exhibition. (See McKillop & Wilkinson, 2004 for a discussion of issues of consent in research with people with dementia.) Throughout this paper, I have used pseudonyms for participants, carers and other people/places implicated in participants' accounts.

### Design

This was a qualitative project, using performative social science, semi-structured interviews and interpretative phenomenological analysis to explore the lived experiences of people with dementia.

### Participants

I recruited six participants with diagnoses of moderate dementia via opportunity sampling. For the recruitment process, organisations such as The Alzheimer's Society, Age U.K. Gloucestershire and local care homes were emailed. In response to these emails, I was invited to talk to a local arts group, memory cafes and support sessions for carers run by the Alzheimer's Society, and to staff at two care homes. Three people responded to my request for participants from the Alzheimer's Society arts group, two participants were recruited from one of the care homes, and one participant was recruited via emails sent directly to members from a local Alzheimer's Society branch. In all cases, contact was initially with carers (family members or care staff) who acted as gatekeepers. This was both a pragmatic decision, since carers could be accessed more easily than participants, and an ethical decision in order to ensure that carers felt included in all stages of the study. Participants were then contacted directly and asked if they wished to participate in the project.

Participants were all in their seventies and eighties; two were male and four were female. All came from a British background and spoke English as a first language. All participants had lived with a diagnosis of dementia for at least five years and required significant support with daily living. Two participants lived in a residential care home (Ruth and Janice), two further participants (Ian and Nancy) were husband and wife and lived together with close support from their daughter (Eva), one participant (James) lived with his wife (Margaret), and the final participant (Ailsa) lived independently while being cared for by her daughter (Lucy).

It was necessary that participants be aware of their dementia diagnosis and willing to talk about this. Given the focus of this project on participants' lived experiences and subjective understandings, no enquiries were made into the exact nature of their diagnosis. Instead, the analysis was framed around participants' own understandings of their condition. (See Eatough & Smith, 2007 for this approach in connection to a phenomenological epistemology and the method of interpretative phenomenological analysis.) During the course of the interviews, four

of six participants spontaneously described their diagnosis as Alzheimer's disease; the remainder used the term "dementia" throughout.

### **Data Collection**

All of the participants were interviewed in their homes. The interview set-up varied case-by-case to ensure participants' comfort, while helping to relieve any anxieties they might have had about participating in the project. Ruth and Janice were interviewed in their rooms at the care home. Ailsa was interviewed at her flat with her daughter present. James was interviewed alone at his house, while his wife checked intermittently on us and occasionally joined in the conversation. Ian and Nancy were interviewed together with their daughter. Where family members were present, their contributions were also recorded, transcribed and analysed (with their permission). This is important, as it allows for a more full analysis of the contextual and intersubjective nature of participants' observations. (See the discussion of interpretative phenomenological analysis below for more on this.) However, my core focus remained on the participants living with dementia.

I interviewed participants over two sessions, using a semi-structured method. In the first interview, I designed the questions to glean a general understanding of participants' interests, activities and identities, as well as exploring what they felt about dementia and how the condition had impacted their life. The latter portion of these interviews focused on objects that were salient to participants, with a view to including some of these in the exhibition collage. These initial interviews lasted between approximately 50 and 75 minutes. Questions included: "What is it like to live with dementia?" and "Do you think that people treat you differently now that you have dementia?"

In the second interview, participants were asked to expand on the significance of the objects they had chosen for their collage. These second stage interviews ran for approximately 15 to 30 minutes. Questions included: "Can you tell me why you chose this object?" and "Why is it important to you?" A prompt was clearly visible to participants throughout the interviews. It read: "This is an interview about what it's like to be you, and what it's like to live with dementia and memory problems. We are making a picture frame about this for an exhibition in December."

The interviews were audio recorded and transcribed. I posted or emailed a copy of the typewritten transcript for each interview to participants and their carers within three weeks of the interview. Participants and their carers were asked if they wished to make any changes to the transcript and were reminded at this point of their right to withdraw from the study. No participants chose to withdraw and one participant made minor corrections, which were largely confined to errors with names, dates or spelling.

### **Data Analysis**

I analysed the interview transcripts using interpretative phenomenological analysis (Smith, 1996; Smith & Osborn, 2004, 2008). IPA enables researchers to explore participants' individual, subjective accounts, while recognising that these are produced in interaction with others, including researchers. The epistemological basis of IPA is phenomenological, emphasising the emotional, embodied lived experiences of participants (Eatough & Smith, 2007). Thus, this approach enables us to understand how people with dementia experience and make sense of their changing selves and bodies, giving due prominence to the role of emotional experiences within this. Furthermore, as Eatough and Smith note, IPA is a holistic approach, acknowledging the interrelationships between the individual and their social world, and between talk, thought and behaviour. This reflects my concern with the social contexts within



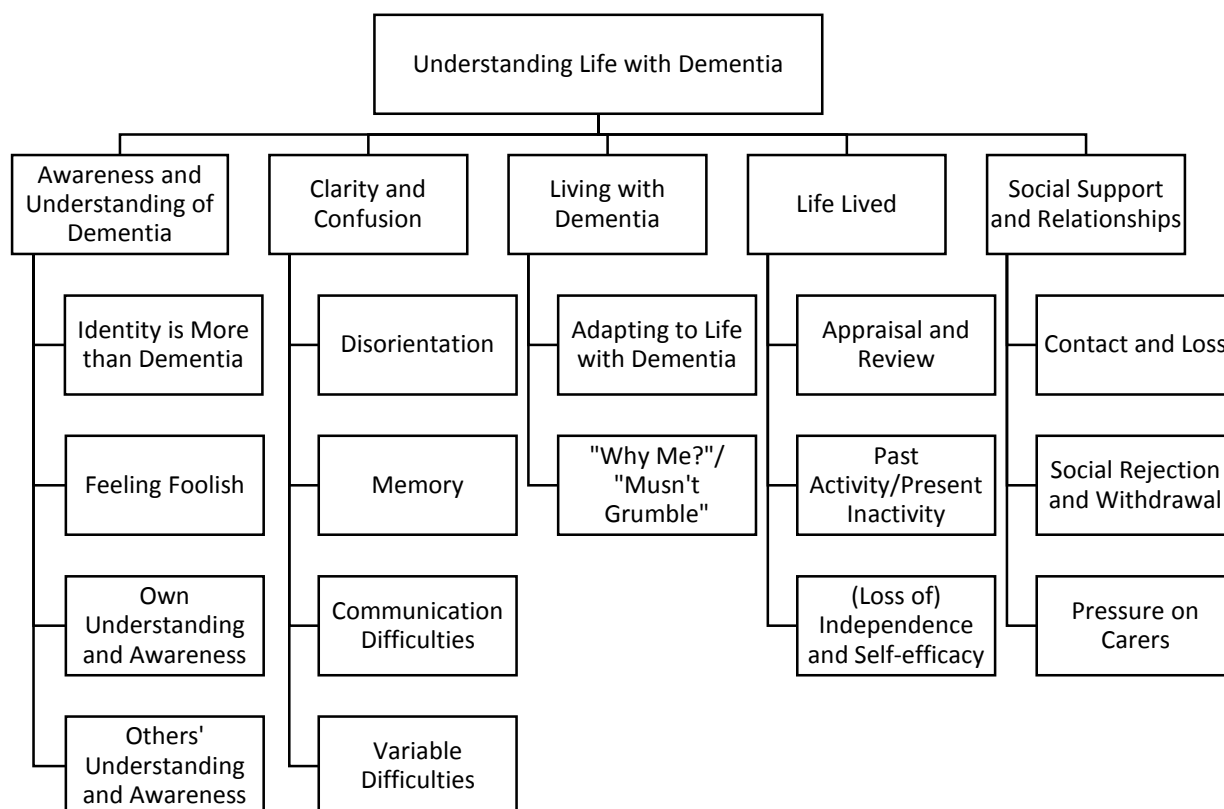
which people with dementia live, and with the very real, concrete impact that the subjective experiences and understandings of these individuals have on their daily lives. Finally, IPA's focus on participants (rather than, say, discourse or narratives) as the unit of analysis allows for a sense of individual participant's stories to come through. This reflects the approach taken within "I Will Tell You Something of My Own" as a whole, where the richness and variety of the different participants' lives is highlighted and celebrated (see Gregory, 2014).

The analytic process I followed involves an iterative process of close readings to identify salient patterns within texts. Initially, I made (relatively) unguided notes on the first participant's interview transcripts. I then sculpted the preliminary patterns elicited from these texts into proto-themes. This process was repeated for the remaining participants. Following this, I gradually refined the proto-themes through a cyclical process of reading and analysis, until I could elicit themes that resonated across the data set, without quelling important variation within it. I then coded the transcripts for the final themes and highlighted key, illustrative passages. In the analysis that follows, I present these passages from the interviews in the form of *cleaned-up* speech, which omits the hesitations, interruptions and repetition of everyday conversation in favour of producing a more lucid text. (Abbreviations and notations are explained in Appendix A.)

## Findings

I derived five themes from the analytic process: awareness and understanding of dementia, clarity and confusion, social support and relationships, living with dementia, and life lived. Together, these themes tell of the varied and challenging lived experiences of these six people, as they live their lives with dementia, struggling to come to terms both with their own cognitive difficulties and with the attitudes of others toward their condition. This account challenges the common depiction of dementia as a "living death," laying bare the continuing humanity of people who live with this condition.

To deliver as concise an account as possible, the analysis presented here focuses on the first three themes listed above. In addition, I have chosen to discuss these themes as whole, rather than breaking them down into their constituent subthemes. These themes were the most salient across all participants' accounts, and tell a powerful story about the lived experience of people with dementia. Focusing on these themes allows me to present a detailed exploration of the ways in which participants construct their identities, and of the key role of intersubjectivity within this. (The full map of themes and subthemes is shown in Figure One.)

**Figure One: Thematic Map**

### **“I’ve Got Alzheimer’s Now:” Awareness and Understanding of Dementia**

Participants discussed their own understandings of dementia, as well as how they felt dementia is perceived by others. They spoke of dementia both in general terms and in relation to their own experiences. Participants commonly associated dementia with foolishness and were keen to avoid being viewed labelled in this way because of their condition. For some, this was coupled with an awareness that they might be defined in terms of dementia; others shied away from this conclusion.

All of the participants were aware they had dementia, but the implications of this were not necessarily clear to them. As Ailsa put it: “I know I’ve got Alzheimer’s, but I don’t really know how it affects me.” Although this could be a point of confusion at times, participants sometimes seemed happier not to think about their condition. This was readily apparent with Ruth, who frequently changed the subject when asked about dementia. Indeed, in response to the question “What’s it like for you having dementia?” Ruth responded: “I don’t even think about it really.” Ruth was clearly aware of her condition, however, and apologized for her conduct during the interview saying, “My brain isn’t as good as it used [to be]. It’s getting a bit rusty now.” Furthermore, whereas all the participants were aware of their diagnosis and of some of the problems dementia presented for them, several participants minimised their difficulties by suggesting that their symptoms were less severe than those of other people. As Janice put it, “I’m very fortunate really, because Alzheimer’s is a bugger. With some people it’s very bad indeed.”

It was common for participants to associate dementia with stupidity or irrationality, and to worry that they might be labelled in this way themselves. Although participants sometimes dismissed themselves as “dozy” or “silly,” at other times they were keen to assert that dementia

did not make them stupid and that they were coping well. Thus, Ailsa stressed: "I'm quite sure if I was doing something silly one of the girls would say "Oh Mum, you don't need that" . . . but as far as I know. I'm doing alright."

Several of the participants questioned whether people other than their close family and carers would know that they had dementia. This was often accompanied by the claim that such awareness would not lead people to treat them negatively:

Int: And do you think that people treat you any differently because of having Alzheimer's?

Ailsa: No I don't think so. I don't think a lot of people know . . . I don't think they would put it against me and say, "Oh, you silly owl. Why did you do that?"

It was clear, however, that participants were often worried that their condition would lead to people viewing them as odd, foolish or something to be feared. Such concern is apparent in Ailsa's reference (above) to a possible response of "Oh, you silly owl." This association of dementia with foolishness was also clear in several similar comments made by participants, such as in this conversation with Janice:

Int: Do you think that people treat you differently because you've got Alzheimer's?

Janice: No. They don't know. You see. Because I can speak to you like I can. So they don't know, fortunately . . . they just accept me as I am.

Int: You said, "People don't know, fortunately." What do you mean?

Janice: Well they might think I'm something queer, you know.

In contrast to Ailsa and Janice, Ian and Nancy presented a more unequivocal view of the negative perceptions others might hold around dementia.

Nancy: A lot of people are afraid of it.

Ian: Yeah. That's it.

Nancy: Afraid they're going to catch it. That's what I think a lot of it is, ignorance.

James and his wife Margaret also bemoaned such negative perceptions of people with dementia. They were keen to counter these views and to emphasize that James is the same person he has always been. For them, dementia is something they must live with, rather than a part of James' identity. As James said, "I don't like to think that Alzheimer's makes me talk to people differently or feel different . . . It's not me . . . it isn't who I am. It's part of my situation."

### **"Occasionally My Brain Goes a Bit Wobbly:" Clarity and Confusion**

In contrast to the lay belief that people with dementia have no awareness of their condition, all of the participants acknowledged that they experienced confusion, as well as

cognitive difficulties like memory loss, disorientation and problems communicating with others. Participants talked about how other people might usefully adapt to these difficulties. There was a strong feeling, however, that it was up to people with dementia to manage their problems, and to help others deal with them appropriately.

Ruth described her life as confusing and slippery, saying, “My life now is very mixed up. And I mean, nothing’s solid really.” She was particularly confused over the loss of her husband, whose death she was sometimes able to accept tentatively, but whom she perceived as being alive at other times. Even when apparently accepting her bereavement, Ruth expressed confusion over this, portraying her husband’s death as inexplicable and intangible.

It was very tragic, you know, when I lost [my husband]. I still have to think of him as dead, but I still wonder if he’s out there somewhere, but my eldest son said, “Mother” he said, one day “. . . I’ve told you. Dad is dead.” And I think he was quite honest about it.

Memory loss was a common issue raised by participants. As Ruth put it, “. . .something will go immediately out of the mind and you can’t remember at all.” Indeed, for many this was a key aspect to dementia, sometimes providing the first clue that there was a problem. “Well I first sort of felt that . . . my memory (was gone), you know.” (James) At other times, memory loss was seen as defining the condition almost in its entirety. Ruth, for instance, questioned whether dementia was equivalent to problems with memory, asking, “What is dementia? Forgetting?” This equation of dementia with memory loss reflects popular understandings of the condition. Not all participants acknowledged memory problems, however. Nancy, for example, willingly spoke about Ian’s memory problems, but insisted that she experienced no such difficulties herself, citing early childhood recollections as evidence of her intact memory: “I got no problems with memory . . . I remember taking a gas mask to school.”

Most of the participants also related problems they had with navigating and orientation, particularly when they were in unfamiliar places. As Ailsa said, “I wouldn’t go out on my own for any other reason in case I got lost or took the wrong turning.” For Janice, such difficulties were a clear reminder of her dementia: “. . .at times I get myself in a bit of stew when I go somewhere strange. That’s when I feel it and remember it, because I have to ask people which way to go and that sort of thing.”

Many of the participants cited communication difficulties too; however, it was not communication across the board that they struggled with, but rather particular kinds of talk. Accordingly, Ian and Nancy highlighted problems they had communicating in specific contexts, such as on the telephone or with specific styles of communication like rapid talk.

Ian: I can get through to people if I say what I want. . . . but some of them come up to me (and say) so-and-so and so-and-so-and-so. That confuses me a bit.

Int: So you can talk to people and tell them what you want, but if someone comes to you and gives you a long list of things to do –

Ian: Yeah. I wouldn’t understand it all.

In other contexts or with other styles of communication, these difficulties were not experienced. Thus, Ian spoke of talking to other people with dementia at a local day care centre as an example of more effective communication. “In The Martins they slow down and completely (put it like) exactly what you want. And you know exactly what they want . . . They understand more. . . . They’re in the same position.”

Given this, it was important for Ian and Nancy that others spoke slowly, explained things carefully and allowed them the time to frame their responses. Margaret also emphasized the importance of such adaptations, when talking about her husband James, "... it's learning really how to talk to them, because, you know, it's frustrating for James if he can't understand what I'm talking about." Despite this, the burden of adjusting to communication difficulties was often seen as falling on people with dementia themselves. As Ian put it: "We have to try our best to get over to people what we want."

### **"I Do Feel Sometimes Alone:" Social Support and Relationships**

The support and company of others were valued highly by all of the participants. Some participants felt that they had been rejected by others because of their dementia, whereas others dismissed this possibility. Where social support was lacking, this was felt as a keen loss, whereas the presence of care and companionship was treasured. Both participants and their families were aware that this support could come at a high cost to carers, however.

Social support and relationships were very important to participants, and much of their talk focused on this. The companionship of friends and family was a source of happiness, whereas its absence was cause for great sadness, particularly when that absence was permanent, as with the death of a spouse. Ruth's story, for example, was full of love and loss, particularly around her husband, whom she described as "the love of my life." The death of her husband created deep sadness for Ruth. She was keen to emphasise, though, that she still derived happiness from the company of her sons, and felt down when they did not visit her as often as she would like. "I think my boys make me happy when they feel like it. Sometimes they make me sad, like at the moment they're not visiting me at all."

The company of others was particularly important to Ailsa and time spent alone was accompanied by keen loneliness for her: "I don't like being lonely. I don't like that, because you sit and think." Thus, Ailsa expressed happiness and even relief at the company she had (particularly that of her daughters), but she also bemoaned the lack of close friends in her life and the lonely times in between social interactions. "And it's now that I do feel sometimes alone, but don't get me wrong, I've got two good daughters."

Although participants were grateful for the care and companionship provided by family and friends, they were also keen to avoid being a burden to loved ones. Thus, Ailsa talked about avoiding certain activities that might cause anxiety for her daughters, saying, "I don't want to be a worry to them." Janice, meanwhile, spoke about going into the care home to relieve pressure from her husband. "I'm glad I've come away to give Albert a bit of a break." Carers also commented on the pressures which caring brought. They talked about the high level of work involved in looking after people with dementia, particularly when they had to manage their own problems alongside this:

I've got quite big health problems as well. So I have to be a bit careful.... It becomes a full time job, you know. One you're very happy about, and you do it from choice, and you want to do it, but it's still actually very, very tiring obviously. (Margaret)

As mentioned earlier, some participants were keen to emphasize that they had not been treated differently as a result of their condition. Ailsa insisted, "Nobody abuses me or says, 'Don't be stupid' you know." Others, on the other hand, offered a different perspective, speaking of widespread social rejection. Nancy said, "If you've got a disease or something wrong, [people] shun you." This social rejection came across particularly strongly in Margaret's account of her husband James:

I can date the day from which he started losing confidence. We were going to a funeral back at the little chapel.... And [when] we got back into the car he said, "I went to say hello to Emily, but I didn't go. She looked at me. Marge, she's frightened of me." ... She was frightened she'd say the wrong thing. She didn't know how to talk to him now. ... Even at church on a Sunday morning we can stay for coffee and there is the odd occasion when not a soul there speaks to us.

James also acknowledged this change in behaviour, seeing it as his responsibility to make others comfortable around him. "People don't know how to feel comfortable. ... You think, 'Well, [what can I do] to make them feel at ease instead of being so anxious?'" Conversely, there were some instances where participants presented social distance as deriving from their own withdrawal from, or rejection of, others. This was most notable with Ruth, who spoke of occasions where she had withdrawn from the company of others, either because their interests did not appeal to her, or because she was repulsed by something about them, as in the case of her son's new beard.

I said to him "Michael," I said, "that beard is vile, horrible." ... I said, "I just can't stand you around me with that thing." So he hasn't been near me since. I don't blame him, because I just couldn't stand him...

### **Discussion**

In this study, I sought to illuminate the lived experience of six people with diagnoses of moderate dementia. My aims were to explore how people with dementia talk about their lives and selves, and to explore what it is like to live with dementia. My interpretative phenomenological analysis of the interview transcripts elicited five themes: awareness and understanding of dementia, clarity and confusion, social support and relationships, living with dementia, and life lived. The above analysis focuses on the first three of these. These themes demonstrate that participants were well aware of many of the difficulties they experienced as a result of their condition, often struggling to adapt to these. Participants were also aware that others might respond to them differently because of their condition. They were keen to avoid this happening, and to maintain social support and companionship where they found it.

It is clear from these interviews that people with dementia can possess a level of insight into their own experiences, emotions and difficulties which defies popular understandings of dementia as "a living death or slow unravelling of the self" (Beard, Knauss, & Moyer, 2009, p. 227; see Mitchell, Dupuis, & Kontos, 2013). Participants' understandings of dementia varied. Although many expressed uncertainty around the nature of the condition and its impact on them, they also described dementia in terms that mirror both medical and popular understandings of the condition. For example, just as in Harman and Clare's (2006) study, participants often associated dementia with memory loss, and it was common to describe the condition as characterised by a decline in cognitive capacity. Furthermore, all of the participants were aware of having cognitive difficulties of some sort. This suggests that autobiographical accounts of dementia, like those of Sterin (2002) and Bryden (2005), are not the isolated musings of a few extraordinary individuals, but rather represent the kinds of understandings which "ordinary" people with dementia are able to convey if given the opportunity to do so.

Participants typically felt that it was up to them to manage the difficulties presented by dementia and to help others respond to them favourably. This involved negotiating the negative connotations around dementia, and participants were particularly wary of being considered to

be “stupid” or “foolish” because of their condition. Accordingly, some participants spoke of rejection by others because of dementia, whereas others were aware of the risk of this occurring. This parallels the accounts of participants with dementia in other studies that have observed people treating those persons differently because of their diagnosis (e.g., Harman & Clare, 2006; Mitchell, Dupuis, & Kondos, 2013). Thus, participants were all too aware of the stigma around dementia, highlighted by scholars like Killick and Craig (2012), Kitwood (1997), Sabat and Harré (1992), and by other people with dementia in accounts like those of Sterin (2002).

Although social support and companionship are likely to decline in the face of dementia (Albanese et al., 2007; Kitwood, 1997; Sterin, 2002), participants’ accounts revealed that social contact was of the utmost importance to them. Visits from others were often highlighted as key sources of happiness, whereas the perceived absence of others was accompanied by sadness and loneliness. Participants also relied on their loved ones and carers for practical support, such as fetching groceries or providing memory prompts. In contrast, however, they were often all too aware that they might be a burden to their loved ones. This was reflected in carers’ accounts of the demanding nature of looking after someone with dementia, something that past research has also highlighted (e.g., Kindell et al., 2014).

It is clear from these accounts that both participants with dementia and their carers face great pressures in adapting to life with dementia. Some of these pressures appear to be the direct result of others’ unhelpful responses to the condition, whereas others are exacerbated by such responses. This emphasizes the need for greater societal responsibility for the care and support of people who live with dementia. Accordingly, it would seem that there is much merit in the social model of disability and its application to dementia by scholars like Gilliard et al. (2005), Marshall (1994, 2000) and Wilkinson (2002).

### **Moving Forward: Study Limitations and Future Research**

There were, of course, limitations to this study. I recruited participants on the condition that they were happy to talk about their diagnosis of dementia. This necessarily excluded many people with dementia from the study, many of whom are not told, or are otherwise unaware, that they have a diagnosis of dementia (see Harman & Clare, 2006). It is possible that this skewed the findings, and that another sample of participants would not demonstrate the level of self-awareness shown here. Indeed, many people with dementia did not participate in this study on the basis that they would not be able to speak about their experiences with any clarity. It is notable, however, that this decision was typically made by carers, and not by people with dementia themselves. Accordingly, on more than one occasion, I had an involved and enlightening conversation with someone about their condition, before being told by their carer or spouse that the person concerned could not possibly exhibit the awareness necessary to participate in this study.

The individuals who did take part often spoke at a length, with a level of insight that surprised those close to them. It is at least worth considering that many of those who did not participate would have been equally fluent. This would be worth following up in further research, perhaps through observational methods or using a more informal conversational approach. It is certainly the case that people with dementia are often simply not given the opportunity to express what is important to them. As Ruth said at the close of our interview, “It’s been lovely talking to you and, because it’s on a different angle to what I’m with every day.” Wilkinson (2002) notes that giving voice to people with dementia in this way is a vital step towards countering dementia stigma, and there is a strong case to be made that such work should not be restricted to the most “accessible” participants only.

A related limitation is that the methodology adopted relied heavily on participants' ability to communicate their lived experiences with reasonable fluency. Thus, it would be difficult to use this approach with people who have more severe dementia. The analysis also relies on a certain level of transparency in a participant's talk. This meant that some of the subtleties were lost. One salient example was with James, who often replied in analogies or embedded his responses in the period of his life story that he was relating at the time. The relevance of this talk was difficult to evidence using IPA, and it was here that the more creative approach of PSS proved to be particularly fruitful (see Gregory, 2014). Nonetheless, it is notable how this methodology made it possible to learn from people whose dementia was at least moderate in nature.

### **Conclusion**

Although there is a growing body of literature aiming to illuminate the dementia experience, there is still a relatively small amount of research exploring the lived experience of people with dementia in their own words. Much of that which does exist focuses on individuals in the earlier stages of the condition. In this study, I sought to build on existing research by interviewing six participants with diagnoses of moderate dementia. The data demonstrate that living with dementia can be a challenging experience, as people struggle to come to terms with difficulties ranging from disorientation and memory loss, to loneliness and a reduced social life. The participants interviewed here show a level of personal awareness and understanding of these difficulties, which defies popular representations of the condition as a kind of "living death." All of the participants in this study were aware of cognitive limitations and were wary of others treating them differently because of their condition. Social rejection and being viewed as "foolish" were particularly prominent themes in this regard. Furthermore, although participants relied on the support of others, many felt that the burden was on them to adapt to their difficulties, making others feel less anxious around them or working harder to establish effective communication.

This study reveals that there is much to be gained from talking with and listening to people with dementia. It also demonstrates that it is "possible" to talk with such individuals in a meaningful way. This suggests that there is little justification for ignoring the voices of people who live with this condition. In contrast, we should seek out their accounts, listen to what they have to say and share the responsibility of adapting to the many challenges which dementia inevitably presents. This does not mean leaving people alone to manage and define their condition in isolation. Neither does it mean taking control of the lives of people with dementia and deciding what is best for them from our own, external perspective. Rather, it is about working together to help people with dementia live the most full and happy lives that they are able to live.



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## Appendix A: Key to Abbreviations and Transcription Notations

‘ ’	Reported speech
...	Text omitted
-	Interrupted speech
[ ]	Researcher's words
( )	Transcription doubt
Int	Interviewer

### Author Note

Helen Johnson (nee Gregory) is a social scientist, psychology lecturer and performance poet. She is interested in the study of arts and creativity, and in performative social science (or arts-based research). She has studied spoken word and poetry slam communities, educational applications of youth poetry slam, and arts-interventions in dementia care. In recent years, she has begun to combine her research with poetry and visual arts, using art as a means of data collection, analysis and dissemination. She also runs poetry events, and programs the poetry stages for Glastonbury and Larmer Tree Festivals. Helen is a Senior Psychology Lecturer at the University of Brighton. Correspondence regarding this article can be addressed directly to: [h.f.johnson@brighton.ac.uk](mailto:h.f.johnson@brighton.ac.uk).

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