

Living With Semantic Dementia: A Case Study of One Family's Experience

Qualitative Health Research
2014, Vol. 24(3) 401–411
© The Author(s) 2014
Reprints and permissions:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1049732314521900
qhr.sagepub.com


Jacqueline Kindell¹, Karen Sage¹, Ray Wilkinson², and John Keady¹

Abstract

Semantic dementia is a variant of frontotemporal dementia and is a recently recognized diagnostic condition. There has been some research quantitatively examining care partner stress and burden in frontotemporal dementia. There are, however, few studies exploring the subjective experiences of family members caring for those with frontotemporal dementia. Increased knowledge of such experiences would allow service providers to tailor intervention, support, and information better. We used a case study design, with thematic narrative analysis applied to interview data, to describe the experiences of a wife and son caring for a husband/father with semantic dementia. Using this approach, we identified four themes: (a) living with routines, (b) policing and protecting, (c) making connections, and (d) being adaptive and flexible. Each of these themes were shared and extended, with the importance of routines in everyday life highlighted. The implications for policy, practice, and research are discussed.

Keywords

case studies; dementia; families, caregiving; interviews, semistructured; narrative inquiry

Dementia is not one condition but a set of symptoms caused by a number of brain illnesses that affect a range of cognitive functions and behaviors, thus impacting on abilities required for everyday activities (Dua, Nichols, & Setoya, 2012). It is estimated that 36 million people worldwide are living with dementia, with a projected increase to 66 million by 2030 (Alzheimer's Disease International, 2012). Such present and predicted demographics require a significant increase in public health attention and investment in dementia (Dua et al.).

One less-well-known type of dementia is frontotemporal dementia, which covers a spectrum of conditions that particularly affect behavior and language (Neary et al., 1998). A recent report published by the World Health Organization used figures from the Islington study (Stevens et al., 2002) and gave the rate of frontotemporal dementia within dementia in general as 3% of all cases (Dua et al., 2012). Frontotemporal dementia is a common illness causing dementia in the under-65 age group, particularly in men (Dua et al.). Knopman and Roberts (2011) estimated the prevalence of frontotemporal dementia in people under the age of 65 to be 15 to 22 per 100,000 in the United States, leading to at least 20,000 to 30,000 Americans living with this condition.

Semantic dementia, also termed the semantic variant of primary progressive aphasia, is one type of frontotemporal dementia (Gorno-Tempini et al., 2011; Neary et al., 1998). Other types of frontotemporal dementia include behavioral variant frontotemporal dementia and

nonfluent primary progressive aphasia (see Snowden, Neary, & Mann, 2002, for a review of classification). The profile of skills and difficulties in semantic dementia is different from that evident in more common dementias, such as Alzheimer's disease, in which the experience of problems with recent memory, for example, is often an early and striking symptom. In contrast, in semantic dementia, recent day-to-day memories and visuospatial function are relatively well preserved. This means people with semantic dementia are often able to recall recent events and can go out and about alone within their locality without getting lost for some time into their condition (Hodges & Patterson, 2007; Kertesz, Jesso, Harciarek, Blair, & McMonagle, 2010; Neary et al.).

There are, however, prominent changes in communication skills, personality, and behavior in semantic dementia. Loss of semantic knowledge leads to difficulties in finding words when talking, including the names of people, places, and objects, along with significant difficulties in understanding the speech of others. The semantic loss is a broad conceptual loss that extends

¹University of Manchester, Manchester, United Kingdom

²University of Sheffield, Sheffield, United Kingdom

Corresponding Author:

Jacqueline Kindell, Floor 6, School of Nursing, Midwifery and Social Work, University of Manchester, Oxford Road, Manchester, M13 9PL, United Kingdom.

Email: jacqueline.kindell@postgrad.manchester.ac.uk

beyond language skills to affect nonverbal understanding of the world. This leads to problems recognizing and understanding words, objects, faces, sounds, smells, touch, and tastes, and creates challenges with activities of daily living (Hodges & Patterson, 2007; Kertesz et al., 2010). Changes in personality and behavior are also common in semantic dementia (Hodges & Patterson), with behavioral features sharing much in common with the behavioral variant of frontotemporal dementia in the later stages of the condition (Kertesz et al.).

Perhaps understandably, a major part of the research agenda in semantic dementia has been to explore the biomedical and quantitative differences between this condition and other dementias to achieve a more accurate clinical description and differential diagnosis (Hodges & Patterson, 2007; Kertesz et al., 2010). There has been some interest in the quantitative analysis of care partner burden in frontotemporal dementia and whether care partners experience greater levels of stress, burden, and need than in other types of dementia, such as Alzheimer's disease (see Nunnemann, Kurz, Leucht, & Diehl-Schmid, 2012, for a review of the literature in this area). Much of this work arises from the hypothesis that higher stress levels are caused by the particular challenges of behavior and personality change evident in frontotemporal dementia. Indeed, Nunnemann et al. have called for more research to unravel the complexities of care partner experience within frontotemporal dementia.

In some respects, such developments mirror the general literature on dementia during the 1980s and 1990s, when care partner stress and burden were studied extensively (Zarit & Zarit, 2008). Since that time, however, it has become clear that the experience of care partners in cases of dementia is multidimensional and includes many factors relevant to the culture, context, and dynamic in each individual relationship, such as the support structures available within the family and the community, personal coping resources, and the meaning that individuals ascribe to their experiences (Hayes, Boylstein, & Zimmerman, 2009; Hibberd, Keady, Reed, & Lemmer, 2009; Lin, Macmillan, & Brown, 2012; Zarit & Zarit). In addition, many care partners also report positive emotions, including satisfaction with how they perform their role and personal growth arising from their caring experiences (Robertson, Zarit, Duncan, Rovine, & Femia, 2007).

Various tailored interventions have been advocated for the care partners of those with dementia, including group and individual psychoeducation, peer support, and psychological therapy, delivered following a full assessment of the care partner's particular needs and situation (Elvish, Lever, Johnstone, Cawley, & Keady, 2012; National Institute for Health and Clinical Excellence, 2006). Although these findings are an important step forward,

they are generic to dementia studies and to caregiving as a whole and, as we have identified, living with semantic dementia presents different challenges for the person with the condition as well as for his or her care partner.

There is a small number of qualitative studies examining the impact on families in cases of behavioral variant frontotemporal dementia (Kumamoto et al., 2004; Oyebode, Bradley, & Allen, 2013). However, after searching the qualitative and quantitative literature using systematic methods, we could not find any studies that explored such experiences in semantic dementia. Therefore, to develop and deliver tailored support and information for the families of people with semantic dementia, we need a better understanding of their caregiving experience and to explore the challenges and satisfactions inherent in such care provision.

To inform this dialogue, in this article we focus on one family living with semantic dementia, using a qualitative design and narrative analysis to interpret human experience (Reissman, 2008). We present a thematic narrative analysis of interviews conducted with a wife and son living with a husband/father with semantic dementia and discuss the everyday issues that they encountered. Pseudonyms are used for all members of the family presented in this case study. In addition, other circumstantial details have been altered to protect the participants' anonymity and adhere to ethical approval requirements.

Method and Analytic Strategy

This study was part of a project to explore and describe the everyday experiences of people living with semantic dementia (Kindell, 2011). Our chosen unit of analysis for this study was one family living with this condition. Case study design allowed us to work with the family to achieve our aim of developing a rich data set, exploring issues and experiences from different perspectives using our chosen research methods (Yin, 2009). These methods included standardized assessment of communication difficulties, conversation analysis, and narrative analysis, alongside triangulation of data strands.

The data we present here are from the narratives of the care partners and describe the everyday experiences of this family in caring for a person with semantic dementia. We chose narrative analysis to explore this area because narrative inquiry is grounded in the study of the particular (Radley & Chamberlain, 2001) and thus enables exploration of in-depth experiences within a given case (Yin, 2009). Specifically, we used thematic narrative analysis to gain insight into the stories told by each participant about his or her life with semantic dementia and how this shaped their understanding of their experiences, while at the same time maintaining their autobiographical frame of reference (Sandelowski, 1991).

The first author, Jacqueline Kindell, is a speech and language therapist with 21 years' experience specializing in dementia care, including working with those with frontotemporal dementia. The impetus for the project came from this author's clinical observations and experience, in particular, the need to develop a more complete understanding about people with semantic dementia and their care partners and what interventions could help in each situation. The fourth author, John Keady, is a community mental health nurse who holds a joint appointment between his base in the National Health Service (NHS) and the University of Manchester; he has worked in dementia care for more than 25 years. Both authors work from a relationship-centered approach to dementia care that highlights the importance of balancing all positions and perspectives when making decisions on supportive care and intervention (Nolan, Davies, Brown, Keady, & Nolan, 2004).

An ethics committee registered with the NHS in the United Kingdom approved the study. Research governance approval was provided by the local NHS Trust in which the person with semantic dementia used the services of one of the community mental health teams. The family learned about the research from workers within this team. We had given a basic outline of the study to staff, explaining that we were looking for one family to take part in a research project examining everyday life with semantic dementia. Members of staff were asked to notify eligible families about the research. Inclusion criteria comprised a confirmed diagnosis of semantic dementia from a specialist center, and the condition needed to be having an impact on communication within everyday life, as observed by mental health staff during visits to the home. The family described in this article was the first to request information about the study and, following a full explanation of the project from the research team, they consented to participate.

The data we present here are taken from 3 hours 20 minutes of interview data with a wife (Karina) and son (Stuart) caring for their husband and father (Doug), who had semantic dementia. The interviewer (Kindell) had visited the house on four extended visits (each of 2 to 3 hours) prior to these interviews to facilitate consent, carry out other research tasks, and become familiar with the family situation and their story. These visits allowed the family to develop an informal relationship with the researcher and learn about her background, including her professional work and identity. The two participants were offered a choice of venues for the interviews; the wife chose to be interviewed at home whereas the son chose to be interviewed in a private room at a local mental health resource center. They were each seen separately and alone.

We used semistructured interviews that covered a range of topics, including the challenges the semantic dementia presented to them individually and as a family, changes in communication and behavior, how they managed the situation on a day-to-day basis, their lives before the onset of dementia, and the changes that occurred following the diagnosis of semantic dementia. The participants were encouraged to expand on their initial responses, taking the interview into territory each felt relevant for them and their lives (Reissman, 2008).

The interviewer had prior experience of working with families with semantic dementia and frontotemporal dementia, and this sensitizing experience served as a resource for facilitating their stories, as is appropriate in thematic narrative analysis (Reissman, 2008). Establishing a good relationship with participants prior to interview and encouraging small talk, humor, and time within the interview helped to create an informal and trusting atmosphere that, in turn, led to a naturalistic conversation about the topic area rather than a forced and formal interview.

The interviews were recorded and then Kindell transcribed each recording verbatim, including elements spoken by both interviewer and participant. Aspects of stress and intonation that were important for meaning were typed using capital letters and punctuation (e.g., words that were spoken with emphasis in terms of loudness or intonation were typed in capital letters, exclamation marks were used for humor or signs of exclamation, and so on). The final transcripts were extensive, consisting of 107 pages of (single-spaced) text. The data were complex and highly individual in nature, with information covering the present and spanning back across the years of the relationship, which was not always a positive marital and domestic story.

Two members of the research team (Kindell and Keady) read through all transcripts on a number of occasions, followed by a process of exploring them line by line and then hand coding. Codes referred to particular sequences within the text, with sequences varying in length but referring, in each case, to a salient story, incident, or issue. This process was repeated until no additional coding emerged from the data. Working separately, we progressively compared and grouped themes hierarchically (Charmaz, 2006). During two meetings, the two researchers compared the resulting themes and discussed the data at length, ensuring that themes accounted for the coded data. A third meeting allowed for agreement on a structure and flow that best represented the data under scrutiny.

Consensus was reached with codes highly consistent between the researchers, a process that added to the validity and trustworthiness of the findings. Analysis of the interview data revealed four distinct and recurring themes

within the caring experience: (a) living with routines, (b) policing and protecting, (c) making connections, and (d) being adaptive and flexible. Before these themes are explored in detail, we briefly outline the family context.

The Family

Doug, a retired lecturer of engineering, had been married to Karina for 45 years. They were both 71 years of age and had two grown-up children. Karina ran her own graphic design business using an office at home and also visited clients in their place of work. She was keen to keep her work going, although combining this with caring for Doug proved a challenge. Karina and Doug had regular contact with their son, Stuart, who lived close by. Stuart had recently been living with his parents while building renovations were carried out on his own house. The couple's daughter lived abroad and visited occasionally.

Doug had been diagnosed with semantic dementia in 2006 although, with hindsight, the family felt symptoms had been occurring for some years before this. Doug's concerns revolved around difficulty in finding the names of people, places, and objects. He found this very frustrating. At the time of diagnosis, Doug had no difficulty with day-to-day practical tasks at home and he was still driving and taking part in his favored hobbies. By the time this research took place in January 2011, Doug had given up driving and most of his hobbies. He also needed Karina or Stuart to help him to organize and carry out most activities of daily living. This was done with verbal or physical prompts. Doug still enjoyed going to the local shop alone, or for a walk around his neighborhood, and enjoyed watching specific programs on television.

Findings

Living With Routines

Karina and Stuart reported that Doug had developed a number of complex routines since the start of his semantic dementia and, as a result, living with routines formed a considerable part of their lives. For Doug, these routines included regular trips to the same shop to buy particular items; always wanting to eat carbohydrate foods including cake, bread, and pie; rubbing his hands, the soles of his shoes, and other objects including crockery and glasses; touching and sorting through the trash (rubbish bins); constantly watching the same television programs; tapping his feet as though dancing or skipping; and wearing the same set of clothes. These repetitive actions and ruminations were poignantly summarized by Stuart:

The neighbors over the road had put their bins out [a day early] for the collection . . . They were obviously away for

the weekend . . . So he was going, "The men, the men are coming, they're here!" and it was panic. He was absolutely panicked. That's obviously one of his obsessions, the bins.

Over time, Karina and Stuart had become accustomed to these routines and rather than try to change Doug's behavior, their caring now took account of them. Karina shared, "I've only got two changes of clothes that he is happy with and so one comes off, it goes in the wash, and it's ready to put back on the next time."

In contrast, some of the practical routines were more problematic for the family. For instance, Karina found Doug's habit of rubbing the soles of his shoes and then objects in the house, including cutlery and the rims of glasses, particularly disconcerting. Moreover, although the family were keen to maintain Doug's routine of going to the shop alone, Karina and Stuart were both concerned about their husband's/father's safety during these outings.

The family also described routines in Doug's conversation, in that he now talked about a reduced range of topics and primarily focused on the Second World War and a local walk that he took. He also had repeated patterns of conversational habits, including overuse of certain words and phrases. As Karina relayed, "He's obsessed by the war thing, he NEVER used to mention it at one time but I know, I can hear the train of thought going and I can think he's going back to the war thing." It was evident from Karina and Stuart's conversation that routines had been imposed on their lives and that as a consequence, spontaneity had largely been removed from it.

Policing and Protecting

Karina and Stuart reported a need to monitor, or "police," Doug's behavior, constantly having to be vigilant and keep an eye on what he was doing. As Karina explained, "There are lots of things I won't let him do, like things to do with the rubbish bins, the washing up, things like that, partly now because he will rub his hands on anything." Thus, the act of policing and protecting aimed to protect Doug, his family, and others from the consequences of Doug's behavior and actions. In addition, Karina and Stuart disclosed that Doug used to do a number of jobs in the house and garden, but as his semantic dementia progressed it led to problems for him in understanding how things worked. This exposed Doug to numerous dangerous and risk-laden situations; for example, when he attempted to cut live electricity cables when changing a plug. As a result, Karina and Stuart had limited the activities that Doug was allowed to do.

It was clear from Karina's perspective that policing Doug's behavior was a constant physical and psychological task that needed to be carried out throughout the day.

This was both stressful and frustrating, as illustrated by Karina (K) in this interaction with the interviewer (I):

K: I have to think about what, what he's doing and watch what he's doing. . . . The other day he cleaned the drain out and the moss and stuff with his hands.

I: With his bare hands?

K: Oh yes, YES! So you see I'm constantly thinking, "What's he gonna do? What's he going to be doing?"

Policing and protecting also extended to outside the home, especially to Doug's interactions with others. Karina and Stuart both worried about the recent change in Doug's behavior in that he would stop to talk to strangers and his words could be interpreted as being overfamiliar. Although Doug generally did not make offensive remarks, he now swore more often and there had been the odd occasion of swearing in public, causing embarrassment. This predicament was neatly described by Karina when she described a recent shopping trip with Doug:

He says what I think are inappropriate things to people in supermarkets. They're not offensive, just a bit weird. People in the bank yesterday, I didn't know he said something to one of the bank people, 'cos she came across and said, "Oh is it alright?" But I don't know what he had said. We went to get him a pair of shoes and he says things that are, well, just not really appropriate, and then the staff get a bit concerned or worried and I keep saying, "No, no just leave it." You know, if I can ignore it all, I do.

Karina worried that Doug was not as physically active as he used to be and she continually searched for safe activities that would keep him occupied. As a consequence, policing and protecting often brought tension between Doug and Karina because Doug did not understand why he was being stopped from doing things he wanted to do.

Making Connections

In spite of Doug's significant communication difficulties, Karina and Stuart often talked about their repeated attempts to keep Doug stimulated, and they did this by making connections between their social worlds. However, Doug rarely initiated a conversation and his responses once a conversation started were often minimal, consisting of expressions such as "Mmm" or "Oh." Karina also suggested that once started, conversation had a mechanized quality to it:

Sometimes I think when I'm talking to him it's almost like a shutter, and he thinks I have to look as though I am listening. . . . I think he's not taking this in at all, whether that's because he can't be a good listener now.

Similarly, Stuart indicated that his father no longer inquired after his well-being: "He'll never say, 'Oh how are you Stuart?'" In such a situation, making connections felt like a one-sided endeavor and Stuart talked about no longer being able to have a meaningful conversation with his father, especially about their family history.

There was, therefore, a sense that the deeper, more emotional levels of making connections were missing. Despite this, both Karina and Stuart continued to make attempts to include Doug in conversation and encourage him to talk. They both noticed that Doug had retained some verbal skills and he had developed a habit of using his hands much more when talking; this was more pronounced than before the onset of his semantic dementia. As Stuart shared, "You start getting the hand gestures and he'll be almost . . . instead of using the word, he'll be describing the action of what he'd be doing, if he was doing that thing."

Both Karina and Stuart reported various routines they used to compensate for Doug's difficulties and encourage talking. Karina, especially, manufactured opportunities to make connections during mealtimes:

I suppose I've got into a routine now. . . . If we sit to have a meal, I'll make sure there is conversation, or if he's watching television I will comment on it. Even if it's commenting on the adverts [advertisements] to see what he will say about them. For example, there's a silly car advert . . . and I do it every time.

In contrast, Stuart mainly talked to his father about practical tasks and jobs around the house: "I probably don't really introduce any new topics; I mean I always chat to him about what I'm doing on the house. I tell him what I'm doing on the house."

Doug's interests had also changed and he had developed a number of favorite topics to talk about, such as the Second World War. Karina and Stuart reported that once Doug started talking about one of these topics, he often became extremely animated and it could be hard for them to join in the conversation. Unfortunately, such topics did not seem to be of any real interest to Karina and Stuart, and this challenged the family in making connections a meaningful enterprise.

Being Adaptive and Flexible

As Doug's semantic dementia progressed, Karina and Stuart reported that there had been a number of changes to Doug's personality and the things he liked and disliked. As a result, the family had found that being adaptive and flexible was an important coping and planning resource. For example, in his earlier years and prior to his diagnosis, Doug used to play rugby and was an avid

football (soccer) fan. He was also described as liking more serious programs on the television, such as political programs, and he liked to keep up with the news. Karina and Stuart reported that Doug no longer showed any interest in these issues. This moving testimony by Karina illustrates this point:

We actually moved up here because of United [football team], and he used to go on a very, very regular basis and now he's not interested in that AT ALL either. . . . Stuart will come in and say, "Oh, football's on." You see he doesn't erm, with his son, watch football, which you think there would be that kind of link between the two males, but no, he doesn't want to see it.

Karina and Stuart both discussed how Doug now liked to watch murder mysteries, dance, and quiz shows on television. Stuart vividly captured this total change in his father's viewing habits: "Ten years ago he would have hated that program [ballroom dancing competition]. He'd walk in and walk back out again. Now he couldn't stop talking about it; he would get really excited by it."

Thus, Karina and Stuart had to adapt gradually to new and changing circumstances. They also reported that Doug's personality had changed and, again, they had to adapt to this "new Doug." Before the onset of semantic dementia, Doug was described as a serious, private, and reserved individual who rarely spoke to strangers or to the neighbors; for example, Doug used to dislike the noise made by babies and animals, and actively avoided such encounters.

Karina and Stuart now felt, however, that Doug was more jovial and sociable than he was prior to his diagnosis, and he regularly stopped to talk to mothers and their babies, people walking their dogs, and all his neighbors. Karina noted, "This lady was coming up [the street] with a dog and he said, 'Oh lovely.' He doesn't like dogs or children." Stuart also discussed a change in the way Doug interacted with the neighbors and how they had also adapted to Doug's friendly demeanor:

He'll be more chatty, even though he can't really chat, but neighbors and stuff, where he wouldn't have had the time of day for them fifteen years ago, now he'll say "hello" or he'll try to engage them a bit in conversation. But they're nice enough to sort of understand, you know, his situation, and so they'll engage a little bit.

These narratives indicated that there had been a change in Doug's personality, his style of talking, the people and situations he engaged with, his interests, and the topics he talked about. In this respect, there had been a discontinuity between Doug's past and previous identity and his present and evolving characteristics. To maintain a caring and family identity, Karina and Stuart had to be flexible

and adapt to these changes while still preserving Doug's roles as husband and father.

Discussion

In this article, we have presented the themes within the care partner experience for one family living with semantic dementia, namely: (a) living with routines, (b) policing and protecting, (c) making connections, and (d) being adaptive and flexible. Narrative analysis of the interview data has therefore allowed for an understanding of this family's experiences and the processes and meanings they ascribed to care practices in semantic dementia.

As revealed in this article, there is a paucity of research examining the subjective experiences of care partners in semantic dementia and, as such, it is not possible to ascertain if the themes shared here are consistent with other qualitative work in this area. There is, however, some overlap in our themes with the work of Oyeboode et al. (2013) in behavioral frontotemporal dementia, particularly around changes in communication, loss of inhibition leading to socially embarrassing behaviors, promoting quality of life, and loss of the person and relationship.

The narratives of care partners in more common dementias, such as Alzheimer's disease, have been recorded for many years and these help families and health and social care professionals in their discussions and processing of experience (Davies, 2011; Hellström, Nolan, & Lundh, 2007; Hibberd et al., 2009; Keady & Nolan, 2003; Lin et al., 2012; O'Connor, 2007). It would appear from this case study that the narrative descriptions of family members in semantic dementia provide insight into the practical and emotional challenges and the strategies they employ on a daily basis. This research also indicates that generalizing the experience of care partners in dementia without considering the type of dementia, or assuming that dementia is always synonymous with Alzheimer's disease, might mask some of the particular experiences that arise from living with a given condition. This could be particularly important when considering and delivering supportive interventions for care partners.

In this case study, living with routines, both physical and verbal, constituted a considerable part of the family members' daily lives. They viewed the development of such routines as complex symptoms of the dementia that required toleration and adjustment within their family caring practices. Developing a routine is often advocated as a strategy for care partners in dementia (Hibberd et al., 2009). Yet, in this case study, living with routines had a different meaning and perspective. It was not a strategy chosen by the care partners that helped them cope, but a challenge thrust on the family and, as a result, they had to assimilate this experience within their everyday lives.

Arguably, this forms a distinctive part of living with semantic dementia because Karina and Stuart were aware that Doug was not actively being difficult with respect to these routines and, for him, there was security in staying within what he knew and understood. As a consequence, they did not describe him as being difficult. Rather it was explained that he was happier within his routines; for example,

He's happier if I say "Oh, [detective program] is on." . . . "I've only got two changes of clothes that he is happy with." . . . I think sometimes he's happy with a phrase. . . . He can say that phrase.

In the same way that care partners of those with Alzheimer's disease come to understand that difficulties with memory underlie many behaviors, rather than the person being awkward or difficult, in this case, the family had come to understand that Doug's eroding semantic memory and reliance on routines underlay much of his behavior. It has been suggested that such cognitive reframing of behaviors by care partners might be important for their mental health (Vernooij-Dassen, Draskovic, McCleery, & Downs, 2011). In addition, reframing this within appropriate lay terms such as "he's happy with . . ." and so forth, rather than diagnostic terms such as mental rigidity and inflexibility (Neary et al., 1998), helped to explain the behavior in understandable and everyday language. This is evident for both care partners and professionals because it helps to convey a need rather than a problem, and is therefore more person-centered (Kitwood, 1997). It would seem that additional work exploring such care partner discourse would be valuable.

The constant mental and physical vigilance required in policing and protecting, and the moment-to-moment issues with communication described in making connections, clearly identify the ongoing practical and emotional challenges. It is clear that such daily encounters were a source of stress, frustration, and regret, and that discussion and management around such emotional challenges could form an important part of any intervention program for care partners.

Karina in particular described the constant thought and vigilance required within the theme of policing and protecting, as well as various tensions in terms of risk assessment and management. Both Karina and Stuart described some of the challenges that occurred outside the home with respect to interaction and behavior. This caused them both to worry about Doug, even when they were not with him; for example, they worried about Doug taking large amounts of money when he went to the shop and this, coupled with his over-familiar interaction style, raised other issues of risk. Karina did not let Doug go out alone when the older school children were coming out

from school. She worried that he would talk to them and they might laugh at him, and she wished to protect him from this.

Clarke et al. (2010) noted that going out is often a "contested territory" between care partners and the person with dementia, and that discussion of risk requires negotiation between the person with dementia, the care partner, and any professional practitioners, with a clear consideration of the meaning of the particular risk for each party involved. For this family, therefore, although Doug was somewhat vulnerable, going out and about was clearly very important to him, was tied to his sense of identity, and provided a source of activity and stimulation. Karina and Stuart reported that Doug regarded those who worked in the local shop as almost friends. Thus, policing and protecting also represented the family assessing and negotiating risks outside of the home that involved the wider community and, for them, this included particular issues of interactional behavior.

There has been recent interest in making communities more "dementia friendly" (Duggan, Blackman, Martyr, & Van Schaik, 2008; Mitchell et al., 2003). This family was less worried about the built environment or that Doug would get lost (often the concern in Alzheimer's disease); their worries were more about the need for the wider community to be understanding with respect to Doug's interactional needs. Given the prominent changes in communication in this condition, this might well be an important issue for other families living with semantic dementia.

This point also has broader implications for staff involved in the delivery of services, for example, community dementia workers, who need creative and individualized methods to assess and understand an individual's situation and to negotiate issues of risk. The juxtaposition of abilities and disabilities are striking in semantic dementia, and thus staff can be perplexed as to why a complex process, such as finding one's way around the locality, can be achieved, but the individual fails with seemingly easier tasks such as recognizing a comb (Snowden, Kindell, & Neary, 2006). Doug, for example, could find his way to the local shop and buy certain items, yet needed help with many basic self-care tasks.

Snowden et al. (2006) noted that one of the greatest obstacles in the care of people with semantic dementia is with respect to service providers' prior conceptions and expectations of dementia, generally derived from Alzheimer's disease. In Alzheimer's disease, memory impairment, in terms of recent memory and orientation, is seen as the principal feature of the condition (World Health Organisation, 2010). This often leads to a public narrative (Somers, 1994) of dementia derived from this focus, including concerns about retaining recent events, confusion, and getting lost when out and about. The

personal accounts in this case study and the symptoms of semantic dementia point to some distinct narratives for this condition. The private stories of other families and the challenges they face within their everyday experiences are required to develop a better understanding of the particular issues faced in semantic dementia.

The theme of making connections represented Karina and Stuart's attempts to keep Doug in contact with the social world. A key aspect to natural communication is that it is a complex collaborative endeavor, and this has been explored in family conversations with people with dementia (Perkins, Whitworth, & Lesser, 1998). In this case study, despite their best attempts, there was a clear sense that communication was, at least at times, effortful and lacking in a sense of shared and reciprocal purpose. The link between care partner burden and communication has previously been identified and the need for communication-enhancement strategies has been suggested (Savundranayagam, Hummert, & Montgomery, 2005). This can involve practical management strategies, such as aiding understanding, facilitating word recall, and developing ways to stimulate talking.

It was clear, however, from Karina and Stuart, that this was only part of their story. Therefore, enabling care partners to explore the emotional aspects to communication, the meanings they ascribe within communication, and making connections might also prove helpful. O'Shaughnessy, Lee, and Lintern (2010) reported a similar theme of connectedness and separateness in their interviews with care partners of people with dementia; such feelings arising out of a loss of shared activities, understanding, and emotional connectedness. The effect of reduced emotional reciprocity was noted for wives caring for their husbands (Hayes et al., 2009) and for young people who had a father with dementia (Allen, Oyeboode, & Allen, 2009). Both Karina and Stuart discussed specific routines they had to stimulate conversation and make a connection, and this brought us back again to living with routines.

The final theme of being adaptive and flexible represented the family's journey with accepting a change or difference in Doug, and presented a complex picture in which discontinuity with the past was part of their experience. In some instances, the description was one of change rather than loss, and the change in Doug's personality had been significant. For example, despite severe communication difficulties, in some respects, when he was out in his neighborhood, Doug talked to a wider range of people than he did previously; it appeared that this was because of changes to his personality. This brought with it both positive aspects in terms of stimulation and its own set of practical and emotional challenges for the family. An important part of caring had involved

coming to terms, practically and emotionally, with these identity changes in Doug.

In terms of therapeutic work, it is common in dementia to use an individual's past experiences to stimulate interests and conversations and help understand the person and their behavior. This continuity with the past forms an integral aspect to person-centered approaches including life-story work (McKeown, Clarke, Ingleton, Ryan, & Pepper, 2010) and reminiscence (Woods, Spector, Jones, Orrell, & Davies, 2009), which are currently advocated in the field of dementia care. Again, in this case study of semantic dementia, the picture is somewhat more complex in that past interests and activities did not always clearly lead to positive reactions from Doug, and changes in personality were seen as prominent by the family.

In the case study, exploration of both past and present interests was important, and Doug was often animated when talking about current interests and recent events in his life. The clinical implication, for the use of life-story work and reminiscence, was that a careful consideration of current interests and events was as important as, and in some instances more important than, locating interests and discussions solely in the past.

Other studies have examined the importance for care partners of maintaining continuity with the past and how this influences relationships and a shared identity (Montenko, 1989; O'Shaughnessy et al., 2010; Perry & O'Connor, 2002). Karina and Stuart felt in many ways that Doug was still "Doug," but also, at the same time, strikingly different in terms of his personality and his interests. This situation led to some complex issues for the family in terms of both continuity and discontinuity with the past, and this was something they had to understand and adapt to within their everyday life.

Being adaptive and flexible has the potential to be an underpinning dynamic in the caregiving experience for semantic dementia. For example, Karina and Stuart had adapted family life to take account of Doug's routines, they developed strategies to police Doug's behavior and interactions, and they had made changes to everyday communication to keep connected. However, additional studies are required to explore and theoretically refine such an assertion.

Overall, across the four themes, it was clear that the family had amassed considerable expertise about semantic dementia and Doug's particular needs that could aid others, should Doug require care from others beyond the family. Additional work on the expert knowledge and skills held by care partners of people with semantic dementia would greatly add to the literature, understanding, and practice.

Conclusion and Implications for Practice

In this article, we present the unique experiences of one family living with semantic dementia, and in this respect the generalizability of findings is limited, although qualitative research makes no assumptions about this phenomenon. Given the lack of research in this area, the experiences presented here might be theoretically and clinically relevant to those working in this field and could be used as a starting point for exploration. This case indicates that there is a challenge for dementia services in providing assessment and individualized intervention for a condition that presents and progresses in a manner that is different from the standard blueprint of dementia.

Living with routines illustrated how practical and verbal routines had become part of this family's life and how they had come to accept and work around this, as a symptom of the condition. To provide effective care packages, services must also learn about, accept, and understand the importance of such routines to the person with semantic dementia.

Policing and protecting raised a number of practical issues, including assessment and negotiation of risks that are less often discussed in dementia care, including inappropriate verbal behavior. Some of the risks were idiosyncratic and were tied to Doug's particular current concerns and routines, such as his obsession with sorting through the trash (rubbish). Thus, in terms of practice, effective risk assessment and negotiation for this condition requires working beyond standard dementia models or questions about risk. Instead, it is important to take the time to identify the unique challenges and worries faced by the family concerned, perhaps through more open-ended questions, alongside a clear understanding of how the individual with semantic dementia wishes to spend his or her time.

Making connections shed light on the constant challenges the family faced and the strategies they used to keep connected to Doug. To provide realistic advice about communication in this condition, a vital part of the assessment process should be to gain a clear picture of the particular everyday communication challenges and strategies used, as we have done here. Relying on formal assessment of communication gives only part of the story. Service providers should be mindful that communication within the family is not a technical endeavor, but is first and foremost about emotional connections and relationships.

Finally, being adaptive and flexible showed how the family had come to accept marked changes in their husband's/father's personality, behavior, and interests. This has clear clinical implications for life-story work, reminiscence, and identity, in particular how the recent past

contributes to such issues in semantic dementia, in contrast to more common dementias such as Alzheimer's disease. Models for person-centered practice, arising predominantly from types of dementia in which recent memory is a prominent problem, are likely to need adapting for semantic dementia.

There is a lack of accessible information about semantic dementia, particularly about personal experiences and long-term management. This, coupled with the relative rarity of the condition, can often make families feel isolated. Meeting other care partners of those with more common dementias, such as Alzheimer's disease, might be helpful; for example in psychoeducation groups or peer support. Services should also be aware, however, that this could highlight differences in experience and therefore the need for additional, condition-specific, information. Some services, particularly those in specialist centers, have explored education and support groups specifically for frontotemporal dementia (Damianakis, Climans, & Marziaki, 2008; Weintraub & Morhardt, 2005). Additional research is needed to explore the focus and effectiveness of such provision, alongside practical issues within delivery of such services, such as the geographical spread of families living with rarer dementias.

Both care partners and professional staff need to understand the conflicting profile of skills and difficulties in semantic dementia and use the skills available to build person-centered therapeutic strategies that contribute to quality of life for all concerned. We hope that this article stimulates debate and research about the lives of those living with semantic dementia and contributes to developing more effectively tailored clinical practice.

Authors' Note

Portions of this article were contained in a poster presentation to *The Eighth International Conference on Frontotemporal Dementia*, Manchester, United Kingdom, September 5–7, 2012.

Acknowledgments

We thank the family involved in this study for taking part.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and or publication of this article: Grants from The Dunhill Medical Trust (grant number RTF33/1111) and The National Institute for Health Research, United Kingdom (Masters in Clinical Research Program).

References

- Allen, J., Oyebode, J. R., & Allen, J. (2009). Having a father with young onset dementia. *Dementia, 8*, 455–480. doi:10.1177/1471301209349106
- Alzheimer's Disease International. (2012). *World Alzheimer Report: Overcoming the stigma of dementia*. London: Author.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage.
- Clarke, C. L., Keady, J., Wilkinson, H., Gibb, C., Luce, A., Cook, A., & Williams, L. (2010). Dementia and risk: Contested territories of everyday life. *Journal of Nursing and Healthcare of Chronic Illness, 2*, 102–112. doi:10.1111/j.1752-9824.2010.01040.x
- Damianakis, T., Climans, R., & Marziaki, E. (2008). Social workers' experiences of virtual psychotherapeutic caregivers groups for Alzheimer's, Parkinson's, stroke, frontotemporal dementia and traumatic brain injury. *Social Work with Groups, 31*, 99–116. doi:10.1080/01609510801960833
- Davies, J. C. (2011). Preserving the "us identity" through marriage commitment while living with early-stage dementia. *Dementia, 10*, 217–234. doi:10.1177/1471301211398991
- Dua, T., Nichols, P., & Setoya, Y. (Eds.). (2012). *Dementia: A public health priority*. Geneva: World Health Organization.
- Duggan, S., Blackman, T., Martyr, A., & Van Schaik, P. (2008). The impact of dementia on outdoor life: A "shrinking world." *Dementia, 7*, 191–204. doi:10.1177/1471301208091158
- Elvish, R., Lever, S., Johnstone, J., Cawley, R., & Keady, J. (2012). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research, 13*, 106–125. doi:10.1080/14733145.2012.739632
- Gorno-Tempini, M. L., Hillis, A. E., Weintraub, S., Kertesz, A., Mendez, M., Cappa, S. F., . . . Grossman, M. (2011). Classification of primary progressive aphasia and its variants. *Neurology, 76*, 1006–1014. doi:10.1212/WNL.0b013e31821103e6
- Hayes, J., Boylstein, C., & Zimmerman, M. K. (2009). Living and loving with dementia: Negotiating spousal and caregiver identity through narrative. *Journal of Aging Studies, 23*, 48–59. doi:10.1016/j.jaging.2007.09.002
- Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining "couplehood": Spouses' strategies for living positively with dementia. *Dementia, 6*, 383–409. doi:10.1177/1471301207081571
- Hibberd, P., Keady, J., Reed, J., & Lemmer, B. (2009). Using photographs and narratives to contextualise and map the experience of caring for a person with dementia. *Journal of Nursing and Healthcare of Chronic Illness, 1*, 215–228. doi:10.1111/j.1752-9824.2009.01024.x
- Hodges, J. R., & Patterson, K. (2007). Semantic dementia: A unique clinicopathological syndrome. *Lancet Neurology, 6*, 1004–1014. doi:10.1016/S1474-4422(07)70266-1
- Keady, J., & Nolan, M. (2003). *The dynamics of dementia: Working together, working separately, or working alone?* In M. Nolan, U. Lundh, G. Grant, & J. Keady (Eds.), *Partnerships in family care: Understanding the caregiving career* (pp. 15–32). Maidenhead, United Kingdom: Open University Press.
- Kertesz, A., Jesso, S., Harciarek, M., Blair, M., & McMonagle, P. (2010). What is semantic dementia? A cohort study of diagnostic and clinical boundaries. *Archives of Neurology, 67*, 483–489. doi:10.1001/archneurol.2010.55
- Kindell, J. A. (2011). *Sustaining conversation at home in semantic dementia: A case study* (master's thesis). University of Manchester, United Kingdom.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, United Kingdom: Open University Press.
- Knopman, D. S., & Roberts, R. O. (2011). Estimating the numbers of persons with frontotemporal lobar degeneration in the US population. *Journal of Molecular Neuroscience, 45*, 330–335. doi:10.1007/s12031-011-9538-y
- Kumamoto, K., Arai, Y., Hashimoto, N., Ikeda, M., Mizuno, Y., & Washio, M. (2004). Problems family caregivers encounter in home care of patients with frontotemporal lobar degeneration. *Psychogeriatrics, 4*, 33–39. doi:10.1111/j.1479-8301.2004.00064.x
- Lin, M., Macmillan, M., & Brown, N. (2012). A grounded theory longitudinal study of carers' experiences of caring for people with dementia. *Dementia, 11*, 181–197. doi:10.1177/1471301211421362
- McKeown, J., Clarke, A., Ingleton, C., Ryan, T., & Pepper, J. (2010). The use of life story work with people with dementia to enhance person centred care. *International Journal of Older People's Nursing, 5*, 148–158. doi:10.1111/j.1748-3743.2010.00219.x
- Mitchell, L., Burton, E., Raman, S., Blackman, T., Jenks, M., & Williams, K. (2003). Making the outside world dementia friendly: Design issues and considerations. *Environment and Planning B: Planning and Design, 30*, 605–632. doi:10.1068/b29100
- Montenko, A. K. (1989). The frustrations, gratifications, and well-being of dementia caregivers. *Gerontologist, 29*, 166–172. doi:10.1093/geront/29.2.166
- National Institute for Health and Clinical Excellence. (2006). *Dementia: Supporting people with dementia and their carers in health and social care* (NICE Clinical Guideline 42). London: Author.
- Neary, D., Snowden, J. S., Gustafson, L., Passant, U., Stuss, D., Black, S., . . . Benson, D. F. (1998). Frontotemporal lobar degeneration: A consensus on clinical diagnostic criteria. *Neurology, 51*, 1546–1554. doi:10.1212/WNL.51.6.1546
- Nolan, M., Davies, S., Brown, J. M., Keady, J., & Nolan, J. (2004). Beyond "person-centred" care: A new vision for gerontological nursing. *Journal of Clinical Nursing, 13*, 45–53. doi:10.1111/j.1365-2702.2004.00926.x
- Nunnemann, S., Kurz, A., Leucht, S., & Diehl-Schmid, J. (2012). Caregivers of patients with frontotemporal lobar degeneration: A review of burden, problems, needs, and interventions. *International Psychogeriatrics, 24*, 1368–1386. doi:10.1017/S104161021200035X
- O'Connor, D. L. (2007). Self-identifying as a caregiver: Exploring the positioning process. *Journal of Aging Studies, 21*, 165–174. doi:10.1016/j.jaging.2006.06.002

- O'Shaughnessy, M. O., Lee, K., & Lintern, T. (2010). Changes in the couple relationship in dementia care. *Dementia, 9*, 237–258. doi:10.1177/1471301209354021
- Oyebode, J. R., Bradley, P., & Allen, J. L. (2013). Relatives' experience of frontal-variant frontotemporal dementia. *Qualitative Health Research, 23*, 156–166. doi:10.1177/1049732312466294
- Perkins, L., Whitworth, A., & Lesser, R. (1998). Conversing in dementia: A conversation analytic approach. *Journal of Neurolinguistics, 11*, 33–55. doi:10.1016/S0911-6044(98)00004-9
- Perry, J., & O'Connor, D. (2002). Preserving personhood: (Re)membering the spouse with dementia. *Family Relations, 50*, 55–62. doi:10.1111/j.1741-3729.2002.00055.x
- Radley, A., & Chamberlain, K. (2001). Health psychology and the study of the case: From method to analytic concern. *Social Science & Medicine, 53*, 321–332. doi:10.1016/S0277-9536(00)00320-8
- Reissman, C. K. (2008). *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage.
- Robertson, S. M., Zarit, S. H., Duncan, L. G., Rovine, M. J., & Femia, E. E. (2007). Family caregivers' patterns of positive and negative affect. *Family Relations, 56*, 12–23. doi:10.1111/j.1741-3729.2007.00436.x
- Sandelowski, M. (1991). Telling stories: Narrative approaches in qualitative research. *Journal of Nursing Scholarship, 23*, 161–166. doi:10.1111/j.1547-5069.1991.tb00662.x
- Savundranayagam, M. Y., Hummert, M. L., & Montgomery, R. J. V. (2005). Investigating the effects of communication problems on caregiver burden. *Journal of Gerontology, 60B*(1), S48–S55. doi:10.1093/geronb/60.1.S48
- Snowden, J. S., Kindell, J., & Neary, D. (2006). *Semantic dementia*. In K. Bryan & J. Maxim (Eds.), *Communication disability in the dementias* (pp. 125–141). Chichester, United Kingdom: Whurr.
- Snowden, J. S., Neary, D., & Mann, D. M. A. (2002). Frontotemporal dementia. *British Journal of Psychiatry, 180*, 140–143. doi:10.1192/bjp.180.2.140
- Somers, M. R. (1994). The narrative constitution of identity: A relational and network approach. *Theory and Society, 23*, 605–649.
- Stevens, T., Livingston, G., Kitchen, G., Manela, M., Walker, Z., & Katona, C. (2002). Islington study of dementia subtypes in the community. *British Journal of Psychiatry, 180*, 270–276. doi:10.1192/bjp.180.3.270
- Vernooij-Dassen, M., Draskovic, I., McCleery, J., & Downs, M. (2011). Cognitive reframing for carers of people with dementia. *Cochrane Database of Systematic Reviews* (Issue 11. Art. No.: CD005318). doi:10.1002/14651858.CD005318.pub2
- Weintraub, S., & Morhardt, D. (2005). Treatment, education and resources for non Alzheimer dementia: One size does not fit all. *Alzheimer's Care Quarterly, 6*, 201–214.
- Woods, B., Spector, A. E., Jones, C. A., Orrell, M., & Davies, S. P. (2009). Reminiscence therapy for dementia (review). *Cochrane Database of Systematic Reviews* (Issue 2. Art. No.: CD001120). doi:10.1002/14651858.CD001120.pub2
- World Health Organisation. (2010). *The ICD-10 classification of mental and behavioral disorders: Clinical descriptions and diagnostic guidelines* (10th ed.). Geneva: Author.
- Yin, R. K. (2009). *Case study research: Design and methods* (4th ed.). Thousand Oaks, CA: Sage.
- Zarit, S. H., & Zarit, J. M. (2008). Flexibility and change: The fundamentals for families coping with dementia. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care* (pp. 85–102). Maidenhead, United Kingdom: Open University Press.

Author Biographies

Jacqueline Kindell, BSc, MCLinRes, HPC Reg, is a clinical research fellow in the School of Nursing, Midwifery and Social Work at the University of Manchester, Manchester, United Kingdom.

Karen Sage, Dip in Human Communication, PhD, HPC Reg, is a senior clinical lecturer in the School of Psychological Sciences at the University of Manchester, Manchester, United Kingdom.

Ray Wilkinson, MA, PhD, HPC Reg, is a professor of human communication in the Department of Human Communication Sciences at the University of Sheffield, Sheffield, United Kingdom.

John Keady, PhD, RMN, RNT, is a professor of older people's mental health nursing in the School of Nursing, Midwifery and Social Work at the University of Manchester, United Kingdom.