

**Knowledge of Dementia: do family members understand dementia as a terminal condition?**

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S Andrews, A Robinson, C Toye and C Parkinson designed the study. S Andrews was responsible for data collection and analysis. A Robinson, F McInerney and C Toye, contributed critical review to the data analysis. S Andrews wrote the paper and A Robinson, F McInerney, C Toye and C Parkinson provided critical review.

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## **Abstract**

Current research identifies advanced dementia to be the terminal phase of this progressive and incurable condition. However, there has been relatively little investigation into how family members of people with advanced dementia understand their relative's condition. In this article, we report on semi-structured interviews with 10 family members of people with advanced dementia, in a residential aged care facility. Using a qualitative, descriptive design, we explored family members' understandings of dementia, whether they were aware that it was a terminal condition, and the ways they developed their understandings. Findings revealed that the majority of family members could not recognize the terminal nature of dementia. Relying on predominantly lay understandings, they had little access to formal information and most failed to conceptualize a connection between dementia and death. Moreover, family members engaged in limited dialogue with aged care staff about such issues, despite their relatives being in an advanced stage of the disease. Findings from our study suggest that how family members understand their relative's condition requires greater attention. The development of staff/family partnerships that promote shared communication about dementia and dying may enhance family members' understandings of the dementia trajectory and the types of decisions they may be faced with during the more advanced stages of the disease.

## **Introduction**

Internationally, the number of people living with dementia is increasing. A Report by Alzheimer's Disease International (2009) estimates that by 2050 115.4 million people will have dementia, an increase from 35.6 million when the report was released. Likewise, the number of people in Australia with dementia is estimated to increase from 266,574 in 2011 to 942,624 by 2050 (Deloitte Access Economics, 2011). In Australia over half (52%) of the people living in Residential Aged Care Facilities (RACFs) (also referred to as Nursing Homes) have a diagnosis of dementia (Australian Institute of Health and Welfare [AIHW], 2011a). People with dementia have significantly higher care needs related to activities of daily living and behavior management compared to any other residents (AIHW, 2011b). Similar circumstances are reported internationally (Chi, 2004; Magaziner et al. 2000; Matthews & Dening, 2002; Alzheimer's Disease International 2013).

Dementia is caused by progressive, incurable neurodegenerative disease processes, for which there is currently no effective treatment, with Alzheimer's disease recognised as the leading cause (Draper, 2011). Within academic, research and other professional literature advanced dementia is recognised a terminal condition (Mitchell, Kiely & Hamel, 2004; Mitchell et al. 2009; Robinson et al. 2005; Volicer & Hurley 1998; Dempsey et al. 2015; Hughes et al. 2005; Alzheimer's Society & Marie Curie 2015; Arcand 2015). Indeed, recent data released by the Australian Bureau of Statistics has escalated dementia to the second leading cause of death in Australia (ABS 2015). However, the recognition of dementia as a cause of death by health care professionals has been and continues to be problematic in Australia and overseas (Covinsky, Eng, Lui, Sands & Yaffe, 2003; Palliative Care Australia, 2010; author, 2014). Studies of death certificates which have demonstrated that dementia is often overlooked as a cause of death by medical professionals (Kammoun, Bouras,

Giannakopoulos, McGee, Hermann & Michel, 2000). Dementia is not readily understood as a cause or even a contributor to death by health care professionals for a number of reasons. The dementia trajectory is unique to the individual. It is comprised of a complex interplay of personal and social dimensions (Baars Dohmen, Grenier & Phillipson 2014) and it often occurs in conjunction with other co-morbid health conditions which can complicate the clinical picture (Dempsey et al 2015; Hughes et al. 2015). Additionally, survival times are highly variable and the disease trajectory characteristically lacks a clearly defined dying phase making prognostication extremely challenging (Covinsky, Eng, Lui, Sands & Yaffe, 2003; Volicer, 2001; Sachs, Shega & Cox-Hayley, 2004; Murtagh, Preson & Higginson, 2004). However, the failure to identify dementia as a terminal condition has negative implications for end of life care. Mitchell et al. (2004) highlight that people dying from advanced dementia are at much greater risk of futile interventions compared to people with no cognitive impairment. Moreover, people with dementia are also less likely to receive adequate pain management (Horgas & Tsai 1998).

Due to the progressive cognitive decline that people experience as dementia advances, family members often become key decision makers and advocates for the person with dementia in the more advanced stages of the condition (High & Rowles, 1995). Hence, their understandings of dementia have implications for care and decision making. Family members are often in possession of intimate knowledge about the person with dementia, their care preferences and care needs (Woods, Keady & Seddon, 2008). Therefore, their involvement and collaboration with health care professionals to plan individualised approaches to care in advanced stages of dementia is crucial (Australian Department of Health and Ageing [ADOHA], 2006), especially given the low prevalence of advance care directives or other documents limiting futile treatment

for people with dementia (Gessert, Moiser, Brown & Frey, 2000; Mitchell et al. 2004), However, there is evidence to suggest that family members people with advance dementia in long term care settings find it difficult to engage in discussions about end of life care for a variety of reasons. Research suggests that family members feel unsupported and under-prepared to engage in sensitive and potentially confronting discussions related to end of life (Givens, Kiely, Carey & Mitchell, 2009; Stokes, Combes & Stokes 2015; Forbes, Bern-Klug, M & Gessert 2000). Moreover, problems with relationship development between family and staff (Bauer 2006; Hertzberg & Ekman 2000) can also undermine the development of collaborative partnerships

Advance care planning for someone with advanced dementia can be understood as a communication process that occurs over time, wherein family members and health care providers discuss care and treatment preferences (Meller & Caplan, 2009). Plans of care can be developed for the person with advanced dementia that prioritise comfort care and limit treatments for common end-stage complications such as infections and swallowing difficulties that may cause additional suffering or discomfort (Hughes, Jolley, Jordan & Sampson, 2007). In the Australian-developed *Guidelines for a Palliative Approach in Residential Aged Care* (ADoHA, 2006), the involvement of family members in advance care planning for people with dementia is recognised as a crucial component of the delivery of a best-practice palliative approach. A palliative approach is considered appropriate for people with dementia as it focuses on enhancing quality of life for those experiencing life-limiting conditions within a proactive and needs based framework (ADoHA, 2006). The Palliative Approach Toolkit (University of Queensland, 2012), a resource which supports the implementation of a palliative approach to care in residential aged care settings, has advance care planning as one of its three key processes.

However, operationalising advance care planning in advanced dementia is highly complex.

The process relies on family members and aged care staff developing collaborative partnerships and reaching mutual understandings of goals and preferences for the future care of the person with dementia. Hence, an important part this reciprocal engagement is predicated on family members and health care professionals having shared and accurate understandings about the progressive and terminal nature of dementia (ADoHA, 2006). We have previously (author, 2014, p. 163) argued that knowledge of family caregivers and aged care staff about dementia, as a life limiting health condition, may serve as a ‘foundation for and mediator of conversations about ...care planning and the achievement of evidence based outcomes.’ In support of this contention, Mitchell and colleagues (2009) report that people with advanced dementia in US nursing homes were less likely to be subjected to unnecessary, burdensome interventions during the last 3 months of life if their family members understood the poor prognosis and clinical complications of advanced dementia. Hence, family members’ knowledge about dementia can have important implications for the type of care that people receive, particularly at the end of life.

To date, only a small body of research has investigated family members’ knowledge about dementia. Findings from cross-sectional survey studies suggest that family carers do not understand the causes of dementia, associated life expectancy, and other clinical issues (Rosa et al., 2010; Werner, 2001). Findings from our research (Author, 2014) also highlight that family members of people with dementia in residential aged care settings lack knowledge about the life-limiting nature of dementia and the presence of physical symptoms associated with disease progression. Moreover, on interviewing family members of people living with dementia in the community, Chung (2000, p. 371) reported that participants held ‘lay understandings’ of

dementia that were ‘based on personal experiences, observations and beliefs’, rather than understanding of the disease process. Stokes et al. (2014) explored how family carers of people with dementia made sense of and understood diagnostic information. This study reported that participants’ knowledge of dementia was largely based in personal understandings, due to their difficulty accessing information and a lack of available and useful resources outlining the disease process. Interestingly, the same study (Stokes et al. 2014) also reported that caregivers referred to dementia as a terminal condition, yet how family members understood its progressive and terminal nature was not further explored.

Other research has investigated how family members engaged in decision making at the end of life for people with advanced dementia in long-term care. These studies also reveal that participants are unaware of the common features of advancing dementia (such as dysphagia, pneumonia and other infections) and fail to recognise the dying trajectory (Caron, Griffith & Arcand, 2005; Forbes, Bern-Klug & Gessert, 2000; Gessert, Forbes & Bern-Klug, 2000-2001). Shanley, Russell, Middleton & Simpson-Young (2011) report that family members did not recognise their relatives’ dying and were shocked when it occurred. This literature raises a number of concerns about whether family members have sufficient knowledge about the condition to engage effectively in advance care planning discussions and associated decision making.

Little has been published around how family members access information about dementia and the ways that this might impact on their understandings of the condition (Bourgeois, Schulz & Burgio, 1996; Chung, 2000). Even though Shanley and colleagues (2011) report that family members of people with end stage dementia benefit from practical information and support from carer support groups, the type of information they access and whether this assists with their



understandings of the dementia trajectory has not been explored. Nevertheless, it has been argued that a lack of a consistent communication with a health care provider who can assist family members to understand changes as the dementia progresses can be a key factor in their not recognising the terminal trajectory of dementia (Forbes et al. 2000; Gessert et al. 2000-2001). Poor communication in general between aged care staff (including General Practitioners) and family members in institutional care settings has also been identified as impacting on their knowledge of dementia and associated care (Hennings, Froggatt & Keady, 2010; Kaarbø, 2011).

To provide care for people with advanced dementia that promotes quality of life and limits burdensome interventions, family collaboration and involvement in decision-making, namely advance care planning, is advocated as best practice (ADoHA, 2006). Such engagement is complex and multi-faceted, and relies at least in part on family members having an accurate understanding of the terminal nature of the dementia trajectory. Given the limited body of literature investigating what family members understand about dementia, the purpose of this study was to address the following research questions: (i) how do family members understand the condition of dementia; (ii) what are family members' understandings about the terminal nature of dementia; and (iii) how have family members developed their understandings about dementia?

## **Method**

### *Design*

This qualitative descriptive study was conducted as part of a preliminary investigation within a larger mixed methods project that explored the possibilities for providing a palliative approach to care for people with advanced dementia. Sandelowski (2000, p.335) explains that qualitative description should provide a comprehensive understanding of the phenomena under investigation in “everyday language”. This approach enables analysis and interpretation of data within a

naturalistic paradigm so that findings remain “data-near” (Sandelwoski 2010, p.79). In this sense the data is not subject to more theoretical transformations, as may be the case with other methodologies. Given that data would be fed back to other participants (such as nurses and care staff) in a larger study, the descriptive exploratory design enabled a high degree of accessibility and usability of the data by others, while also being a suitable approach to explicating this under-researched issue.

### *Participants and Setting*

The participants in this study were family members of people with dementia resident in a Dementia Specific Unit (DSU) in Tasmania, Australia. The DSU accommodated between 30 and 40 people with dementia. Residents of the unit had significant cognitive impairment and complex care needs (including behavioral disturbances) that were difficult to manage in a more traditional nursing home setting. To be eligible to participate in an interview, family carers had to be aged 18 years or above and documented as the ‘person responsible’ for making health and medical decisions for the person with dementia. To avoid any undue distress for the family member, the person with dementia had to be resident on the DSU for a minimum of 3 months, as research suggests that transfer to an aged care facility is a particularly stressful event for both family members and residents (Woods et al. 2008). Given that we were specifically interested in the knowledge of family members of people with advanced dementia, we recruited only from the DSU. Hence, a purposive sample of family members was obtained. The primary goal of purposeful sampling is to obtain information-rich data to learn about ‘select cases’ (Lofland, Snow, Anderson & Lofland, 2006, p. 91); in this study it was appropriate as we had a desire to learn specifically about the understandings of family members of people with advanced dementia. Residents who were clearly documented as having advanced dementia were identified by a

registered nurse who worked regularly on the DSU. Such documentation was either in the form of a formal diagnosis or clinical opinion within the resident's medical notes entered by their treating doctor. The level of cognitive impairment of those residents was independently verified by the researcher undertaking a retrospective audit of resident documentation, using the criteria of the Global Deterioration Scale (GDS) (Reisberg, Ferris, De Leon & Crook, 1982). All residents were classified as either at Stage 6 (severe cognitive decline) or Stage 7 (very severe cognitive decline) of the GDS – and thus considered to have advanced dementia (See Table 1). No neuropsychological assessments were undertaken in order to avoid burdening residents.

<Insert Table 1>

Ethical approval for the study was obtained from the Southern Tasmania Social Sciences Human Research Ethics Committee (Tasmania), University of Tasmania (Ethics ref: H0008633). A third-party staff member (pastoral care worker at the facility), who was not involved in personal or nursing care for the residents on the DSU, approached the identified resident's family members and provided them with information about the study. The third party staff member sought the family member's permission for them to be contacted by the first author.

When agreement was received, the family member's details were provided to the first author who made contact and organised a meeting with the potential participant, away from the DSU, to discuss the study. Information was provided about the study and how confidentiality and anonymity would be maintained; written consent to participate in an interview was obtained. None of the family members who were approached declined the opportunity to participate.

### *Data Collection*

Data were collected using semi-structured, audio-recorded individual interviews lasting between 45 and 80 minutes. Data collection was undertaken by the first author (SA). Recruitment of

family members was discontinued after 10 participants had been interviewed as data saturation around key themes was reached at this point, with no new information being added to these themes. At their request, two of the interviewees were accompanied by their spouses, who were also closely involved in the care of the person with dementia. It was apparent that these dyads had shared experiences and understandings of their relatives' condition and therefore were included in the data collection. Table 1 also outlines the relationship of the 10 family members (pseudonyms used) to the resident as well as the resident's length of stay on the DSU.

The semi-structured format of the interviews is particularly useful for descriptive/exploratory work which aims to elicit how people understand certain things and the processes by which they come to such understandings (Payne, 2007). An interview schedule was developed through a review of the literature and discussions with experts in the research team. Table 2 (below) lists the key questions and prompt questions. The semi-structured schedule enabled a discursive process with flexibility to explore emerging themes but also addressed specific topics important to the wider research project. The opening question provided family members with an opportunity to share background information about their relative and their current condition. This question also functioned as an "icebreaker" to encourage family members to share their stories. The interview questions and probing questions were open-ended, enabling participants to share their stories and experiences (Hansen, 2006). The probing questions were used to explore emerging themes as the interviews progressed.

<Insert Table 2>

### *Data analysis*

Interviews were transcribed verbatim by a third party and checked by the first author (SA). Data analysis, undertaken by SA was simultaneous and continuous with data collection. Transcripts

underwent iterative/thematic analysis (Hansen, 2006), using NVivo© qualitative software to facilitate data management. The analytic process of identifying, coding and categorising patterns emerging from the data was undertaken by SA in consultation with AR. This process involved repeated immersion in the data; that is, reading and re-reading of the transcripts (Hansen, 2006) and constant comparison of themes. The soundness of qualitative research is assessed by Lincoln and Gubba's (1985) criteria of credibility, dependability, confirmability and transferability. Credibility and dependability were established through SA testing the emerging themes with the participants as the research progressed to ensure that these interpretations were reflective of participants' experiences. Credibility was also enhanced by SA engaging in regular peer debriefing with another experienced member of the research team (AR) to explore rival explanations, probe biases, and clarify bases of interpretation (Ezzy, 2002). Confirmability was enhanced by documenting participant accounts verbatim to support interpretations and conclusions reached and these were regularly scrutinised by other members of the research team who had both clinical and research expertise in the care of people with dementia and their family members. Finally the issue of transferability rests with the user of the findings, whereby they make a judgment as to whether the findings have meaning to other similar situations, to support this process a description of the study setting has been provided (Lincoln & Guba, 1985).

## **Findings**

Four key themes emerged from the family member interviews:

1. Lay understandings of dementia;
2. Developing lay understandings: opportunistic strategies;
3. Lack of dialogue with aged care staff; and
4. Disconnections between dementia and death

### *1. Lay Understandings of Dementia*

Across all of the interviews, family members' responses illustrated predominantly lay understandings of dementia. Marion described her mother's dementia using the metaphor of a circuit board:

. . . it's [the dementia] like a cloud going over short circuiting every bit of movement, every bit of, um, memory. It's sort of corroding it [the brain] or short circuiting it . . . what goes on in the brain [of her mother] has nothing to do with reality.

Another participant, Peter, indicated that his understandings of dementia were informed by observations of his father's condition. He asserted that he understood the "basics" about dementia stating:

. . . [dad] hasn't got a memory, he hasn't really got a mind . . . he's strapped in [a chair] most of the time . . . he's stuffed [sic] in my eyes . . . he's not there, he never will be.

There was no explicit acknowledgment by the respondents that dementia was caused by a disease process. Indeed, some family members were resistant to considering dementia in this way. For example, Carol stated:

I don't know if it'd [dementia] be an illness . . . I personally think it [dementia] was because of mum being so isolated and lonely . . . she needed more company and to be more active . . . to keep her mind ticking over, which she didn't have.

Robert recounted that prior to his father's admission to the DSU, he had observed his father's loss of short-term memory over a number of years. He too did not attribute his father's dementia to a disease process but suggested that it was associated with ageing when he stated: "... people with dementia are just worn down memory people . . ." Allie, whose father-in-law was on the DSU, explained that she was uncertain about how to understand dementia in relation to other terminology. She stated "dad's got dementia" and following this posed the question: "that's what Alzheimer's is, isn't it?". Despite knowing the word "Alzheimer's" and its association with the brain, Allie explained that she had 'guessed' about the link between it and dementia. Illustrative of family caregivers' lack of formalised knowledge about dementia, Marion explained that following her mother's admission to the DSU three years earlier she had independently come to the conclusion that her mother's dementia was not Alzheimer's disease. Illustrating her (erroneous) understanding, she explained:

. . . [the] difference between Alzheimer's and dementia is Alzheimer's patients get physically and verbally aggressive and Mum doesn't, so she's got dementia. I figured that out for myself.

Like other family members, Marion's understandings of dementia were informed by what could be understood as lay knowledge, which might or might not be valid.

## *2. Developing lay understandings: opportunistic strategies*

Most family members spoke about using opportunistic strategies to learn about dementia, regardless of whether the person with dementia had received a formal diagnosis. It was through these processes that family members developed their lay understanding. Few family members spoke about receiving formal information or support from health care professionals, such as General Practitioners (GP) or geriatric/psychogeriatric specialists (prior to or after their relative's

admission to the DSU). Peter explained that before his father's admission to the DSU he had been in a psychogeriatric unit and at that time was diagnosed with dementia. However, Peter asserted that he did not receive any information either from his father's GP or the psychogeriatrician at that time. Being left to his own devices, he acquired information in a rather ad hoc manner. He stated:

I've found out [about dementia] along the way . . . sort of got bits and pieces of information . . . only sort of read [about dementia] out of . . . a brochure . . . I found at a chemist. We don't really know nothing [*sic*] about it [dementia] really . . .

Similarly, Jackie explained that despite her mother-in-law receiving a formal diagnosis of dementia, which required consultations with the GP and a specialist, she and her husband received little information that would help them to understand the disease process. She explained the development of her lay understandings:

. . . we took her to the [GP] and then we were advised to take her up to [the psychogeriatrician] . . . he [the psychogeriatrician] just talked to us about it [dementia], not a great long talk. I probably read more than what he told us . . . I don't think he really told me anything I didn't know.

Jackie later conceded that her own efforts had not substantively improved her knowledge of dementia in relation to its trajectory. She stated that she wanted information on "how it [dementia] might progress" and "what will happen in the future". Another participant, Carol, was unsure whether her mother had received a formal diagnosis of dementia, however she recalled



that, when her mother's cognitive impairment was brought to the attention of the GP, little helpful information was offered. She stated:

[My GP] contacted mum's doctor and said that there was a problem [with mum – referring to the cognitive impairment] so all he sort of said [was]. . . take her out to outings . . . to day-centers and things like that . . .

Carol shared the informal strategies she used to try and gain an understanding of her mother's dementia. The below comment highlights the link between informal/ad hoc strategies and lay sources of knowledge:

I've learn[t] mainly as we went along . . . [by] what people [friends and work colleagues] have been saying . . . there are some girls at work . . . their parents, the same thing is happening. Actually one of the girls from work rang me a couple of weeks ago because her dad is in the same situation only his dementia is different to mum's because he is undressing himself. So to me that is entirely different . . . and [we] spoke to one another on the phone for nearly two hours.

Other family members also reported learning about dementia through informal methods and were unsure if their relatives had received a diagnosis prior to their admission to the DSU or subsequently. When Lydia was asked if her mother-in-law's GP provided her with information or discussed dementia she responded: "No not really I mean I used to take mum to the doctor . . . but no, I haven't sort of sat down and talked to him about it". In an almost identical statement to Carol she stated: "Just sort of learning [about dementia] mainly as [I] went along". Marion shared similar

accounts, stating that she had “never spoken” to her mother’s GP about dementia, nor had she adopted any rigorous or proactive approach to seeking information. She explained: “my brother gave me [information] to say what dementia was. I’m not sure where he found it... he’s better at that sort of thing than me” Marion explained that, without additional assistance, she did not know how to locate resources and, as such, she had not been in receipt of any other information.

In contrast to the above accounts, two family members stated that they had undertaken more extensive, systematic efforts to find information, prior to and early on in their relatives’ admission to the DSU. For example, Robert explained that he proactively sought information from a range of different sources after his father’s GP had provided a diagnosis of dementia. Robert explained that he was motivated to find dementia-related information through having had an academic background in research. As such he reported contacting an interstate Dementia Behavior Advisory Service and Alzheimer’s Australia<sup>1</sup> to obtain information. However, consistent with comments from other participants with respect to resources available from their primary health provider, he explained that his father’s GP provided him with limited information and therefore suggested that the GP “was not really clued up on it [dementia]”, Another participant, Emma, indicated that, after her father had received a diagnosis of dementia from a psycho-geriatrician, she attended Alzheimer’s Australia support groups while her father was receiving care at home. She also shared accounts of being proactive in her efforts to find information about dementia, through both formal and informal channels. She stated: “I found various articles in the newspaper [about dementia] . . . located . . . information on the internet and . . . tried to talk as . . . much as possible.”

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<sup>1</sup> Alzheimer’s Australia is the national peak body and charity representing Australian Living with dementia (see <https://fightdementia.org.au/about-us/our-organisation>)

Overall, finding dementia-related information was, for most family members, an ad hoc activity that was largely unsupported by engagement with health care professionals.

### *3. Lack of dialogue with aged care staff*

For most participants, their informal and ad hoc approaches to acquiring information continued after their relative was admitted to the DSU. Family members reported that their knowledge of dementia had failed to markedly improve following admission. All of the family members stated that they did not receive any formal information about dementia or guidance on how to access such information from DSU staff or their relative's GP. Interactions, with either nursing or care staff, were largely described as informal and superficial. For example, Peter described his interactions with nursing staff about his father's dementia as "a bit of a chat" and went on to state: "you don't really go right into it [dementia] . . . not in much detail". Allie reflected on her communication with care staff on the DSU: "they [staff] don't really discuss [dementia], they don't really come to us and say anything". Allie explained that she was perplexed as to why staff members were not more proactive in approaching her to talk about her father-in-law's condition. Marion held similar sentiments and stated ". . . if I want to know something, I've got to go and ask". On the whole, family members held an assumption that staff would not invite them to discuss their relative's dementia and consequently some participants described this as a disincentive to actively seeking information from staff. For example, Carol described herself as trapped in a "vicious circle", wanting to elicit information about her mother's dementia while at the same time feeling sidelined by staff who she considered reluctant to communicate with her. Marion described similar circumstances, highlighting how she felt peripheral to information-sharing about her mother's dementia when she stated: "I'm on the outside looking in". Family

members clearly desired better communication and information sharing on the part of staff members. When asked about the role of their relative's GP in assisting them to understand the dementia trajectory after being admitted to the DSU, the family members indicated that they had limited contact with these professionals. Contact with the GP occurred largely in response to an acute change in the condition of the person with dementia. For example Peter stated "... basically never seen the bloke, I would only (see him) if Dad had a health problem". Jackie shared similar sentiments when she explained

Apparently he (the GP) comes in every fortnight, we don't see him, I assume he'd tell us if there was any problems but as far as the dementia goes, no he's not given us information a such.

#### *4. Disconnections between dementia and death*

Conspicuously missing from family member accounts was any mention of issues pertaining to progressive deterioration and/or death of their relative. Given this absence of such dialogue, as well as family members' lay understandings about dementia, it is perhaps not surprising that seven of the ten family members failed to recognise dementia as a terminal condition or at the very least a potential contributor to their relative's death. Lacking knowledge about the implications of progressive cognitive impairment, family members believed that their relative's death would most likely result from a sudden, catastrophic health event that they considered to be unrelated to dementia itself. For example Lydia stated:

... I don't think she [Mum] will die from dementia, I think she will die from a heart attack or stroke ... some other medical condition but not dementia ... do people die from dementia? I've never ... heard of people dying [from it].

Both Tom and Jackie were emphatic that dementia would not be the cause of death for their relative and did not consider dementia to be terminal. Jackie stated: “there would have to be another cause [of death] . . . like a stroke”. In agreeing with this, Tom asserted that in a medical sense his mother was not unwell. He stated:

You see there is nothing wrong with her [Mum] . . . She’s not on any medication, so apart from her mind, which probably is not real, real bad at the moment I could see mum living another 10 years even though she’s 80, ’cause she’s not on any blood pressure medication or anything like that.

Robert echoed Tom’s sentiments when asked if he thought his father would die as a result of his dementia. He stated:

. . . [Dad] has no medical problems, he’s never had heart problems; he’s got arthritis . . . a couple of minor things but no major ailments . . . he could live for a bloody long time.

Having no recognition of the connection between dementia and death, these family members discounted dementia as even a potential contributor to their relatives’ demise. However, both Emma and Robert, who had taken a number of proactive steps to increase their knowledge about dementia (as outlined in section 2) also failed to acknowledge the link between dementia and death. For example, when challenged with the concept of dementia as a terminal condition, Emma stated with surprise: “. . . I read a lot, I read books, I read articles, I studied on the net, I attended workshops and I never put those two together!” Robert was somewhat more perplexed about the construction dementia as a terminal condition. He stated: “I mean, how can you die of dementia? All the neurons in your brain decide not to function?”

Three family members did recognise a connection between their relative’s dementia and

death. However, this connection remained ambiguous at best. For example, Marion believed that her mother's death would be a quick event. She stated: "I know Mum is going to die, 'cause once your brain stops functioning that's it, you die . . ." Similarly, Susan believed that the death of her relative could result from a rapid progression of the dementia, but on further questioning she was unable to articulate what such a progression might entail. Peter surmised that dementia would cause his father's death. However, when prompted to explain how he thought this might happen he also had difficulty envisaging his father's future deterioration. For example, he stated: "I think he [Dad] is about as far as he can go . . . he doesn't really walk around . . . he can't really get worse . . ." Like the other respondents, Peter, Susan and Marion lacked knowledge about the likely course of their relative's dying, the progressive nature of the dementia and common complications that contribute to mortality (e.g. swallowing difficulties, infections) in the advanced stages of the disease process.

## **Discussion**

In advanced dementia, planning care that promotes quality of life and limits futile interventions is enhanced by family collaboration and involvement in decision-making with health care professionals (ADoHA, 2006). In this paper we contend that to engage in decision-making processes such as advance care planning, family members require an accurate understanding of the dementia trajectory and symptoms associated with disease progression. Therefore, our study aimed to qualitatively explore whether family members possess this important knowledge by addressing the following research questions: (i) how do family members understand the condition of dementia; (ii) what are family members' understandings about the terminal nature of dementia; and (iii) how have family members developed their understandings about dementia?

Data obtained in this study from 10 relatives of people with advanced dementia on a DSU revealed that dementia was not recognised to be a terminal condition or even a potential cause of death. This finding was consistent across participants regardless of their relative's length of stay on the DSU and their level of cognitive decline. Similar to other research findings (Chung, 2000; Gessert et al., 2000-2001; Stokes et al. 2014), participants in our study did not understand how progressive cognitive impairment leads to other medical complications in advanced dementia (such as decreased mobility, problems with swallowing and infections) and ultimately death. Most participants relied on lay understandings, which as Gillies (2012, p. 673) suggests may be an attempt to 'seek explanation' for their relative's condition and deterioration 'in something familiar and comprehensible'. The implications of family members having limited knowledge of common features of advancing dementia meant that most assumed their relative would die from a sudden event such as a heart attack or stroke – which they considered unrelated to the dementia. Similar findings have been reported elsewhere, in studies investigating how family members engage in end-of-life decision making (Gessert et al. 2000-2001; Forbes et al. 2000). Our study makes a unique contribution to the field, in that we explicitly asked family members whether they considered dementia to be terminal condition (See Table 2, Qn ii) and if their relative would die because of dementia (See Table 2, Qn iii). In response to this direct line of questioning participants demonstrated a disconnect in their understandings of dementia and death, underpinned by a reliance of lay knowledge. In contrast to the findings of Forbes et al. (2000), all family members in our study understood what "terminal illness" meant and most were categorical that it did not apply to dementia. These findings suggest that family members may struggle to engage in discussions with health professionals to plan care that is responsive to a prolonged

dying process. Clearly, this is an issue of concern in the delivery of a palliative approach to care for people with dementia, which is predicated on the implementation of advance care planning discussions (ADoHA, 2006).

The findings of this study also add new insights into the means by which family members obtain information and knowledge about dementia. Our data highlights that most participants acquired information incidentally and opportunistically. Thus, perhaps it is not surprising that family members shared predominantly lay understandings about dementia. The lack of structure or process in their information seeking undermined the capacity of family members to develop a comprehensive understanding of the disease process. This finding supports recommendations from other research (Fortinsky & Hathaway, 1990; Robinson, Elder, Emden, Lea, Vickers & Turner, 2009; Stokes et al. 2014), that family members need to be better equipped with skills to locate and access information across the dementia trajectory – arguably from the point of diagnosis. Herein, the role of health care professionals such as aged care staff and GPs has been recognised as pivotal in assisting and supporting family members in this respect (Gessert et al. 2000-2001).

Notwithstanding the importance of better preparing family members to access information in more formal and systematic ways, our findings also suggest that family members were themselves quite passive in their efforts to locate information and resources despite having a desire to know more. This finding contrasts with those of Stokes et al. (2014) who found that family members actively searched for information in the absence of being provided with it after diagnosis. However, unlike Stokes and colleagues' (2014) study, where seven out of the 10 participants were recruited from dementia support groups, only one family member in our study



had any such connection. A lack of access to existing support services may account for the participants in our study reporting more passive approaches to information seeking. Woods, Keady and Seddon (2008) argue that access to formal support services is especially important to enhancing family member's understandings about changes observed in the person with dementia, associated the disease trajectory, and especially during the severe stage. Additionally, while our data did not raise the issues of stigma and dementia, other authors (Stokes, et al. 2014; Clare, 2002) highlight that the social undesirability of a dementia diagnosis may also be a barrier to family members actively seeking information and support after diagnosis.

Participants in our study also expected aged care staff to provide information about dementia generally and their relative's condition following admission to the care facility. This finding may reflect an assumption by family members that staff are equipped with knowledge about the dementia trajectory as well as their relative's condition, which it is incumbent on them to share. From this perspective, the location of care may influence the information seeking behavior of family members. However, as noted previously, our recent research (Author, 2014, p.162) revealed that all levels of aged care staff lack knowledge about the 'life limiting nature' of dementia and 'physical symptoms associated with disease progression'. Moreover, other studies have also highlighted that GPs and aged care staff lack the knowledge and skills to engage in substantive communication and information exchange with family members about dementia and death and dying (Hennings, Froggatt & Keady, 2010; McDonnell, McGuigan, McElhinney, McTeggart & McClure, 2009; Turner et al. 2004; Carter, van der Steen, Gallway & Brazil 2015). Stokes et al. (2015) points out that family members' reluctance to talk to about dementia is linked to a lack professional support for such conversations, a lack of information about the terminal

nature of dementia and their experiences professional nihilism. Moreover, there is evidence to suggest that dialogues about death and dying are not integral to the culture in aged care settings (Froggatt, 2000; Whittaker, Kernohan, Hasson, Howard & McLaughlin, 2007). The taboo status of such dialogues is reflective of sequestration of death in broader public spheres (Froggatt, 2001, p.320)

The absence of formal, continuing dialogue between aged care staff and family members about dementia and dying, also suggests that communication processes, underpinned by a strong knowledge base on the part of professional staff, need to be significantly improved. Without substantive ongoing communication processes, wherein aged care staff can work with family members in partnership to articulate the connection between dementia and death, opportunities for enrichment of family members' understandings are severely limited. Such circumstances raise concerns for ongoing quality of care. In the absence of robust understandings of the disease and its clinical complications, family members may be less likely to advocate for comfort measures and palliation for the person with dementia at the end of life (Mitchell et al. 2009).

By exploring with family members their understandings about advanced dementia as a terminal condition, far from promoting a sense of helplessness, such discussions may better equip family members to work in partnership with staff to advocate for their relative's quality of life and engage in decision making processes that promote individually tailored end of life care strategies. Such an approach would be reflective of a more thoughtful integration of palliative care and person-centered care (Small, Froggatt & Downs 2007). We acknowledge that improvement in knowledge alone cannot transform care or decision making processes, however we do argue along with Author et al. (2014) that shared understandings about advanced dementia

as a terminal condition can provide a foundation for conversations whereby family and staff member may work in partnership to negotiate care decisions . Consistent with Stokes et al. (2015) we argue that family members will need prolonged engagement with professionals to help them understand the implications of the progressive and terminal nature of dementia. We also argue that such interactions can foster a relationship centered approaches (Nolan et al. 2004) to care that respect shared understandings.

### **Limitations and Recommendations**

This study has a number of limitations and as such our findings should be interpreted with caution. Firstly, our data is highly context-specific, as it originates from a small number of participants recruited from one DSU, using purposive sampling. Considering the large proportion of people with some form of dementia in the general nursing home setting (AIHW, 2012), future research is also needed to focus on the family members of people with less severe dementia and those who are not residing in a dementia-specific environment. Such research may assist our understanding of the particular nuances between these environments. Additionally, future research should also focus on how care environments may influence the way family members understand their relative's condition and their perceptions about care at the end of life. This remains a relatively unexplored area but could have major implication for how we construct care in the future.

### **Conclusion**

The findings of this study confirm that family members did not understand the terminal nature of dementia. Informal and ad hoc approaches to finding information about dementia contributed to

participants' struggle to understand the connection between dementia and death. Moreover, a lack of dialogue between aged care staff and family members about dementia and dying further limited opportunities for improvement in family members' knowledge and understandings. Our findings should alert aged care staff that even though collaborative decision making in advanced dementia is advocated as best practice, family members could be at risk of entering into such processes ill-equipped with the requisite knowledge to participate. Moreover, this research emphasizes the importance of continued support: firstly in the form of research into strategies that will build family members' knowledge and understanding about the disease trajectory prior to and after admission to long term care; and secondly in the form of practice development for aged care staff to promote open, collaborative, and on-going dialogues about dementia as a terminal condition with family members.

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**Table 1: Family Member and Resident Information**

Family member participants <sup>a</sup>	Relationship to the resident	Residents' length of stay on DSU at time of interview	GDS of resident
Robert	Son	3 months	Stage 6 (severe cognitive decline)
Tom and Jackie (Husband and wife)	Son and daughter-in-law	3 months	Stage 6 (severe cognitive decline)
Peter and Allie (Husband and wife)	Son and daughter-in-law	12 months	Stage 7 (very severe cognitive decline)
Emma	Daughter	3 months	Stage 6 (moderately severe cognitive decline)
Marion	Daughter	36 months	Stage 6 (severe cognitive decline)
Lydia	Daughter-in-law	14 months	Stage 6 (moderately severe cognitive decline)
Carol	Daughter	3 months	Stage 6 (severe cognitive decline)
Susan	Daughter	2 years	Stage 6 (severe cognitive decline)

<sup>a</sup>Pseudonyms used

**Table 2: Interview Schedule Listing Key Questions.**

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Key interview questions

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**Icebreaker question:**

*Can you tell me about your relative and how long they have been on the DSU?*

**Participants' knowledge and understandings about dementia as a cause of death and common complications in advanced dementia:**

*(i) Can you tell me how you understood dementia before and around the time of admission of your relative to the DSU?*

*Prompt: Is this different to how you understand dementia now?*

*(ii) Do you consider dementia to be a terminal condition? (i.e. a condition that progressively gets worse, has no cure and leads to death).*

*(iii) Do you have an understanding about will could happen as your relative's dementia progresses?*

*Prompt: Do you think that you relative will die because of the dementia?*

*Prompt: Can you tell me what some of the common complications that people with advanced dementia experience?*

**The means by which participants acquired information/knowledge about dementia.**

*(iv) How did you develop your understandings about dementia?*

*Prompt: Did you access information about dementia? (e.g RACF staff, GP, specialist, community related information)*

*(v) Has anyone at the facility (eg staff, GP or someone else) ever talked with you about your relative's condition/dementia?*

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