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Experiences and expectations of living with dementia: A qualitative study

Sheridan T. Read (RN, BNurs, PhD Candidate)*, Christine Toye (RN, PhD),
Dianne Wynaden (RN, MHN, PhD)

School of Nursing, Midwifery and Paramedicine, Curtin University, Kent Street, Bentley WA 6102, Australia

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ABSTRACT

Background: There is a paucity of literature detailing the expectations that people with dementia have for the future; therefore the capacity to reflect their views in service provision is limited.

Aim: This paper reports the findings of research that explored and described experiences of people diagnosed with dementia and their expectations of their support needs and how they wished to live their lives.

Method: An application of the grounded theory method was used and data were collected from 24 participants using semi structured interviews. Coding principles and the constant comparative method of analysis central to grounded theory were used to analyse data.

Findings: The core problem that emerged was conceptualised as losing control. This concept encompassed loss of role function and independence, uncertainty about the future and fear of being a burden. To manage the problem of losing control, participants engaged in a process of finding meaning where they sought answers to address their concerns and implemented strategies to assist them to maintain connectedness to their pre-diagnosis life for as long as possible.

Discussion: People with dementia have limited knowledge on a likely dementia trajectory and find it difficult to identify their future support needs. Health care providers are required to help people with dementia identify what these needs might be and how they can maintain connectedness to their pre-diagnosis life.

Conclusion: To empower people living with dementia, information needs to be made available to them and their families to help them construct their plans for the future.

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Summary of relevance

Problem – Little is known about the expectations that people with dementia have for the future.

What is already known

The progressive decreased cognitive functioning that people with dementia experience limits the time they have to understand dementia and to plan for the future.

What this paper adds

Evidence that this group of people with dementia lacked understanding of their likely dementia trajectory, limiting the extent to

which they could identify and address their future support needs and maintain connectedness to society.

1. Introduction and background

Dementia is the name given to a syndrome or collection of symptoms caused by disorders affecting the brain that result in a gradual decline in cognitive functioning (Banerjee et al., 2007). It is estimated that over 46.8 million people worldwide have some form of dementia with this number expected to rise to over 131.5 million by 2050 (Alzheimer's Disease International, 2015). In 2015, it was predicted that there would be 315,963 people in Australia living with dementia, with this number projected to increase to 942,624 by 2050 (Deloitte Access Economics, 2011).

Recent reports indicate the need for a more timely diagnosis of dementia (Department of Health & Ageing, 2012). It is estimated that between 50% and 80% of people do not receive a formal diagnosis until three years after the onset of cognitive change (Department of Health & Ageing, 2012). How a diagnosis is communicated, and

* Corresponding author.

E-mail address: sheridan.read@curtin.edu.au (S.T. Read).

how the person makes sense of the information provided at the time of diagnosis, can impact on their understanding of dementia and their ability to make plans for the remainder of their lives (Stokes, Combes, & Stokes, 2014).

Dementia impacts upon the person's capacity to articulate their needs and therefore to remain central to decision making regarding their future care (Smebye, Kirkevold, & Engedal, 2012). Therefore, it is important to conduct research with people living with dementia while they are still able to articulate their experiences and expectations on how they wish to live their lives. The limited literature in the area suggests that consumers' views differ from those articulated by their caregivers/families (Armari, Jarmolowicz, & Panegyres, 2013) and health professionals (Miranda-Castillo, Woods, & Orrell, 2013).

Previous research including people diagnosed with dementia has focused on their quality of life (Roach & Drummond, 2014), their capacity for decision making (Fetherstonhaugh, Tarzia, & Nay, 2013; Smebye et al., 2012), their day to day needs (Armari et al., 2013; Miranda-Castillo et al., 2013), and their experiences upon receiving a dementia diagnosis (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). However, these studies have not explored the person with dementia's beliefs about their future support needs and expectations for the future.

This research aimed to address this knowledge gap and explore the experiences of people diagnosed with dementia, and their expectations of their support needs and how they wish to live their lives. In this way, it was believed that the voice of this rapidly expanding consumer group could be more clearly articulated to inform the delivery of a person centered philosophy of care where the person is valued, they are the central focus of care and their voice is heard (Kitwood, 1993).

2. Methodology

This Australian research used an application of the Grounded Theory (GT) method developed by Glaser and Strauss (2012). The constant comparative method of analysis, central to the GT method, was used to guide data analysis and to allow categories and sub-categories to emerge. GT stems from symbolic interactionism; an approach to the study of human conduct, exploring social processes that are present within human behavior (Charon, 1995). The constant comparative method of analysis allowed the comparison of individual participant's experiences to occur and the identification of common shared meanings of the phenomena under investigation (Glaser, 2001). Finally, the basic social psychological problem and process were identified. Approval was obtained from the Human Research Ethics Committee of one university and relevant health services.

2.1. Sampling

Participants were recruited to the study if they had a diagnosis of dementia and provided informed consent to participate. The ability of the potential participant to provide informed consent was evaluated by the researcher during the initial contact. To be offered the opportunity to take part in the study, the person needed to demonstrate their understanding of study participation after this was explained, by re-articulating the study's purpose and describing how they would be able to contribute. Purposeful sampling was initially used to recruit people who met these inclusion criteria from a variety of public and private health services. Following initial data analysis, when categories emerged, theoretical sampling was employed to seek participation from people who still met these criteria but who had unique insights and different experiences; for example, people who had taken on consumer advocacy roles within

the community, were diagnosed with dementia at a younger age and/or were proactive in ensuring that their voices were heard. Sampling continued until data saturation occurred, data were rich in descriptions and categories were clearly identified.

2.2. Data collection

Semi-structured interviews were completed in a place convenient to participants and demographic data were collected prior to the interview commencing. The mean interview length was approximately one hour. Field notes and memos were also collected to add contextual meaning to data collected from participants. Questions focused on participants' experiences of the onset of their dementia, the impact of the diagnosis on themselves and their family, plus their future expectations of living with dementia.

2.3. Data analysis

Data analysis commenced with open coding where each participant's experiences were examined (Glaser, 1992). Theoretical coding or second level coding was then employed where inter-relationships among all participants' experiences were identified. Selective coding further integrated and refined the categories and links to subcategories, allowing the basic social psychological problem and process to emerge (Glaser, 1978).

2.4. Trustworthiness of data

The trustworthiness and rigor of data analysis were ensured through adherence to the constant comparative method and coding process outlined in the GT method (Glaser & Strauss, 2012). Furthermore, prior to the research commencing, the principal researcher documented her preconceived ideas about people living with dementia to identify issues that may have impacted on the research. Coding and data checking were validated by other members of the research team to further consolidate the trustworthiness of the data.

3. Results

Twelve men and twelve women consented to be interviewed between November 2013 and September 2015. Their educational qualifications ranged from primary school certification to doctoral degrees and occupations ranged from tradespeople to professionals. Seventeen participants lived with their spouses, two with a son or daughter and five lived alone. The majority of participants were diagnosed in 2013 or 2014, with Alzheimer's disease ($n=8$), Vascular dementia ($n=3$), Frontal Lobe dementias ($n=3$), Semantic dementia ($n=1$) and Posterior cortical atrophy ($n=1$). Eight participants did not know the type of dementia with which they had been diagnosed. The basic social psychological problem of *losing control* and the basic psychological process of *finding meaning* emerged from the data.

3.1. The basic social psychological problem of losing control

The basic social psychological problem was conceptualised as "losing control"; it was expressed by all participants and began before they received a formal diagnosis of dementia. Participants reported experiencing fear and panic as they were confronted daily by situations that were becoming beyond their ability to control. Initially, the loss that participants experienced was not recognised as being permanent as before receiving their diagnosis they expressed hope that there was a solution to the problems they were experiencing: "[I was] hoping that what my problems [feelings of

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