

# Care workers' voices in designing assistive technologies for preventing malnutrition in older people with dementia: Innovative Practice

Dementia

0(0) 1–7

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DOI: 10.1177/1471301217722852

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## Abstract

Technology may be considered a way to promote nutritional health in people with dementia living in their home. For technologies to be effective and accepted by users, understanding technological needs prior to technology development is crucial; however, this necessitates greater research investment. Consequently, our focus is to derive needs for nutritional health promoting technologies for older people with dementia by understanding perceptions of care workers recruited by the aged care industry. In this paper, we provide a brief description of the theoretical framework that underpins the research study and the research methods selected. Significant learning outcomes related to the research methods include managing hierarchical relationships among participants, engagement with the care workers working in the community and using external material to spark discussion.

## Keywords

dementia, nutrition, care workers, assistive technologies, research methods, community dwelling

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## Introduction

Dementia, an umbrella term for the decline in cognitive ability, is a major cause of disability and dependency among people around the world (Alzheimer's Australia, 2013). The number of older people with dementia is rapidly increasing with an estimate that 46.8 million people worldwide living with dementia in 2015 (Alzheimer's Disease International, 2015). Poor nutrition is common among people with dementia living in their own homes and can lead to functional decline, reduced wound healing and even death (Alzheimer's Australia, 2013; Aselage & Amella, 2010; Duane, Brasher, & Koch, 2013; Visvanathan & Chapman, 2009; Visvanathan et al., 2003). It can further complicate the cognitive level of people with dementia and threaten their ability to live independently.

With recent technological advances, it is possible to design a wide array of technologies to support people with dementia to maintain their nutritional health and their care workers to provide a better support to their clients. The less time consuming and straightforward approach to developing such technologies is to define technological needs based on technology designers' own assumptions and experiences. However, the effectiveness of interventions following such an approach may be questionable in the long run (Bharucha et al., 2009; Fleming & Sum, 2014; Kerr, Tan, & Chua, 2014).

For technologies to reach their desired maturity and to obtain user acceptance for the end product, it is crucial to take user needs and preferences into account (Bharucha et al., 2009; Fleming & Sum, 2014). Although there are a number of technology development studies that involve users at evaluation stage, there are limited numbers of studies that consider co-designing technologies with users (Hedman, Lindqvist, & Nygård, 2016; Robinson, Brittain, Lindsay, Jackson, & Olivier, 2009; Wherton & Monk, 2008). Gaining deeper insights into nutrition and mealtime situations of people with dementia living in their homes is challenging, yet crucial to identify the needs for technologies geared towards promoting their nutritional health.

This paper mainly focuses on informing technology designers and developers on how nutritional health promoting technologies can be applied to older people with dementia living in their own homes by considering their care workers' perspectives. Unfortunately, there are no studies that focus on the needs for such technologies. According to previous research, nutrition and mealtime situations of older people with dementia living at home are often overlooked compared with hospitalised people or those who are in nursing homes (Aselage & Amella, 2010; Whear et al., 2014). Limited non-technology research in this space mostly focused on family members' perceptions but care workers' voices have rarely been taken into account (Ball et al., 2015; Johansson, 2013; Johansson, Björklund, Sidenvall, & Christensson, 2015).

Care workers, specifically care coordinators and home support workers, employed by aged care organisations are well experienced in providing care support to multiple older people. They can be considered reliable reporters of the nutrition and mealtime issues specific to older people living in their own homes with limited or no family support. Therefore, we anticipate that care workers' voices will allow us to identify needs for technologies geared towards promoting nutritional health in the target population, including identifying the:

- challenges older people with dementia, living in their own homes, face that may prevent them from maintaining good nutrition

- challenges care workers face when trying to ensure good nutrition in clients
- kinds of technological assistance that may be valuable during mealtime related activities to assist older people and their care workers, and design considerations useful for effective technology development.

This paper provides an explanation about how the study evolved, research methodology, research methods and methodological learning outcomes. Human research ethics approval was received for the study (H-2014-246).

## **Research paradigm and research design**

An interpretivist/constructivist paradigm is best suited for this research as it allows us to explore participant's perceptions without being committed to any theories or assumptions in advance (Thanh & Le Thanh, 2015). When using this paradigm, the qualitative design is a natural choice. In particular, the qualitative descriptive design is chosen for the study as the focus is on describing and understanding perceptions of care workers. Qualitative descriptive studies do not concentrate on theory development, or culture of people or influence the phenomenon in any way, but present the findings in everyday language (Sandelowski, 2010).

## **Research methods**

### *Sample*

Purposeful sampling was employed in this study to recruit care workers, from four aged care organisations in South Australia, who provide care support to people with dementia living in their homes. There are mainly two types of care workers for in-home support services: (i) home support workers and (ii) care coordinators. Home support workers are required to work at various locations and within private homes, providing day-to-day services for individual clients. They generally assist their clients with activities relating to personal well-being, household management and lifestyle. Care coordinators hold a range of responsibilities that include assessing personal and social needs of clients, coordinating, monitoring and reviewing the provision of services to individual clients, supervision of staff involved in the provision of direct client services, periodic evaluation of clients' well-being and identifying their unmet needs. To increase the variation in sampling, both types of care workers were included in the study. Participants were remunerated as a part of their employment and were rewarded with a certificate of participation which they could submit for professional Continuous Professional Development points.

### *Data collection*

A semi-structured focus group guide was developed by the research team and applied in four focus groups; two with home support workers and two with care coordinators. Focus groups gave us the freedom and flexibility within a semi-structured format to explore care workers' nutrition and mealtime perceptions in detail.

Each 90-minute focus group was digitally recorded and included a moderator and note taker. Each focus group began with the moderator requesting the participants describe the support they currently provide to their clients to maintain nutritional health. Questions were

designed to explore care workers' experiences and issues in providing care. Phrases such as "According to your experience . . ." were used to motivate the participants to share their stories. The final question was designed to explore care workers' wishes on types of technologies that would help them and their clients. Prior to closing, the moderator conducted a 5–10-minute presentation on commonly used in-home technologies in order to stimulate ideas among care workers about what might be useful to ensure good nutrition among people with dementia.

### *Data analysis*

Data collected were transcribed and analysed using the NVivo™ software. Qualitative inductive content analysis as reported by Elo and Kyngäs (2008) was performed. In an inductive approach, the categories are derived directly from data collected and work toward generating theories or conclusions. This approach is well suited for qualitative descriptive studies (Sandelowski, 2010). Notes taken by the note taker were read to clarify discussion points in the recordings. In order to reduce the subjectivity involved in the data analysis process, the data analysis in our study was conducted by two researchers (Milne & Oberle, 2005).

### *Lessons learnt*

The significant learning outcomes from the type of methodology and methods used in this study are explained below.

### *Managing hierarchical relationships among participants*

Hierarchical relationships among two types of participants can potentially challenge free discussion. Data collected from each type of care worker brought unique perspectives to enrich the findings. We found that having focus group meetings with each type of care worker was beneficial as this enabled participants to relate to each other's experiences, thereby providing richer data. Discussions involved sensitive matters related to participants' organisational position, hence, having separate focus groups created inviting 'safer' environment for the care workers to freely express their perceptions in the absence of their supervisors or subordinates.

### *Engagement with the care workers working in the community*

Although recruiting care workers was a challenging task due to their limited availability as a result of their workloads, during focus groups, we learnt that they were receptive to participation, eager to assist and treated the opportunity to participate in group meetings as a platform to describe their perceptions. There were instances where some participants: (i) wanted to continue the discussions beyond the time allocated; (ii) expressed their willingness to participate in future research; (iii) appreciated the opportunity to share experiences others in a similar role and (iv) appreciated the initiative taken by researchers to give attention to their perceptions before technology development. Perhaps, their motivation to participate in research may be due to the feeling of having a voice and the power to create an impact in current and future research.

### *Using external material to spark discussion during focus groups*

We used the presentation on commonly used in-home assistive technologies as a tool to brainstorm and to stimulate ideas in participants. The presentation included images and a video of assistive technologies. This made participants think, based on their experiences, of other areas of technology that may suit in relation to meal times and nutrition of older people with dementia living independently. However, we believe that while showing external material during a focus group can be useful, it has to be done with caution so not to create biasness. If the meeting is diverted towards technology from the outset, there is a higher chance that participants trying to relate their experiences with their understandings of technology, unknowingly mask other valuable information. Therefore, we strategically conducted the presentation towards the end of the meeting as an introduction to the closing question that focused on care workers' expectations on malnutrition preventive technologies.

### **Conclusion**

Dementia compromises people's ability to maintain a good nutritional status while demanding increased care and support services. Developing technologies to promote nutritional health among people with dementia living in their own homes while helping them retain independence and dignity as much as possible is worthwhile. By identifying potential technological opportunities through involving care workers in the design process, it is expected that the developed technologies are more likely to be usable, acceptable, easily translated into practice and assimilated where required, rather than being forced into areas based on technology designers' experiences and assumptions. Although this study mainly considered a population of older people with dementia, it can be expected the findings may generalise to people with dementia in all ages. However, future research needs to be conducted to confirm this, as study reported in this paper relied on voices of care workers recruited from aged care industry.

### **Declaration of conflicting interests**

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Renuka Visvanathan is a member of the board of Resthaven Inc. Renuka Visvanathan previously has received educational grant funding and honorarium from Nestle Inc.

### **Ethical approval**

Ethical approval for this study has been received from the Human Research Ethics Committee (HREC), the University of Adelaide (ethics approval number: H-2014-246).

### **Funding**

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was supported by a grant from The Hospital Research Foundation (THRF) and the Australian Research Council (DP130104614). The authors would like

to acknowledge the support received from Southern Cross Care (SA & NT) Inc., ECH Inc., ACH Group and Resthaven Inc. for conducting focus group meetings.

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