Experiences and nutrition support strategies in dementia care: lessons from family carers.

Abstract

Aim: To explore the perceptions of family carers of people with dementia, with emphasis on feeding-related challenges, burden of care attributable to nutrition support and practical strategies developed to address these challenges.

Methods: A descriptive exploratory qualitative study was undertaken using semi-structured interviews from a sample of fourteen family carers of non-institutionalised individuals with dementia living in Queensland, Australia. Interviews explored carers’ perceptions of feeding and nutrition support, associated burden and strategies applied to address nutrition-related challenges. Interview transcripts were thematically analysed using open-coding and triangular analysis.

Results: Family carers described a range of feeding and nutrition challenges experienced, including physiological, cognitive, emotional, functional and/or behavioural challenges. Carers described the strategies they used to address feeding challenges, which sometimes contributed to carer burden. Family carers felt uninformed and unsupported with respect to nutrition-related care by health professionals. Loss of food intake, weight loss and wasting were reported to be sources of considerable anxiety for the family carers. Most family carers reflected that their experience of nutrition care had been difficult and a significant component of overall burden of care. They developed a range of practical strategies to address feeding and nutrition challenges, including supervising meal times, avoiding disagreements over food and providing regular snacks and finger foods.

Conclusions: Family carers feel unsupported and uninformed with respect to nutrition-related care of individuals with dementia. Health professionals need to enhance the support and education provided to family carers, including recommending low-risk strategies that have been tried and tested by experienced family carers.

Keywords (MeSH): caregivers, dementia, diet therapy, family, nutritional support.
**Introduction**

Dementia is a syndrome characterised by a progressive impairment of brain function, including language, memory, perception, personality and cognitive skills.\(^1\),\(^2\) Approximately 35 million people currently live with dementia globally, and the prevalence is predicted to triple by 2050.\(^1\) Although dementia is not a normal part of ageing, the likelihood of developing dementia increases considerably with age.\(^1\) Australia’s ageing population represents a significant challenge for Australia’s health care system, and dementia has been recognised as a national health priority area.\(^3\)

Studies investigating the relationship between nutrition and dementia have included considerations of the role of nutrition in dementia aetiology, dementia management and the prevention of progressive decline in nutrition status.\(^4\),\(^5\) There is limited evidence regarding the role of nutrition in dementia aetiology;\(^6\),\(^7\) including evidence for interventions such as antioxidant supplementation and calorie restriction to delay the progression of dementia.\(^4\) The sequela of nutritional status deterioration associated with the progression of dementia are common, but individually variable.\(^5\) The nutritional status deterioration may include weight loss, changes in taste and olfaction, anorexia, reduced food and fluid intake and associated nutrient deficiencies.\(^5\) There is little evidence that nutrition interventions improve the length of survival amongst people with dementia.\(^8\) However, the objectives of nutrition support and nutrition-related care for dementia often include a reduction of malnutrition-related morbidity, such as maintaining immune-competence, muscle strength and mobility, and enhancing quality of life.\(^1\)

Individuals living with dementia require significant amounts of care and support, with the type and level of care evolving as the disease progresses. The majority of older people with dementia live in the community and family members are considered to be the most common providers of care.\(^1\) In Australia, it is estimated that family carers provide more than 80% of support for people with a disability, including individuals with dementia.\(^9\) Dementia care is widely acknowledged as being challenging and demanding, creating physical, emotional and financial stress on families.\(^10\) In addition, family carers are predisposed to depression and psychological co-morbidity,\(^11\) indicating that strategies designed to support carers are imperative.
More than half of individuals living with dementia lose some ability to feed themselves, creating a significant challenge for family carers. Individuals living with dementia often experience unintentional weight loss and subsequently are at risk of malnutrition. Nutritional status can be compromised by impaired appetite, dysphagia, forgetting and/or refusing to eat and poor food safety practices. Weight loss, as a proxy indicator for energy imbalance, may also be attributed to increased energy expenditure (pacing, wandering) and/or metabolic disturbances associated with the disease process. For individuals living with dementia, weight loss is associated with decreased mobility and a reduction in activities of daily living. When weight loss extends to ≥3% of body mass, an exacerbation of the disease process, such as cognitive impairment, can occur. These complications can place further burden on individuals and their family carers. In addition, poor dietary intake and observations of weight loss and wasting have the potential to create significant anxiety amongst family carers as they attempt to address insufficient dietary intake.

There is limited literature on effective strategies to optimise the dietary intake of individuals living with dementia, with most focusing on direct nutrition interventions with the individual living with dementia. The four main strategies previously investigated relate to nutritional supplements, behaviour-based eating programs, inclusion of specific foods in the diet and training of family carers. Nutrition education interventions for family carers have been developed in response to the perception by family carers that they lack information regarding strategies that optimise the nutrition intake of individuals living with dementia. These interventions have been shown to reduce the risk of malnutrition and weight loss in individuals living with dementia.

Further investigation of nutrition support strategies and carers’ experiences of nutrition support are warranted due to the high prevalence of dementia care, the likelihood of experiencing food and nutrition support challenges, and the potential contribution of nutrition support strategies on carer burden. The aim of this study was to explore the perceptions of family carers of individuals with dementia, with particular emphasis on feeding and nutrition challenges, burden of care attributable to nutrition support and practical strategies developed by family carers to address these challenges. This investigation will improve our understanding of family carers’ experiences of nutrition
support in dementia care, and has the potential to identify effective nutrition support strategies that have utility for other family carers if shared.
Methods

The qualitative study was informed by a descriptive exploratory approach,\textsuperscript{23, 24} describing family carers’ reflections on their experiences of caring for an individual with dementia, with a particular emphasis on nutrition-related care. A semi-structured qualitative interview design was employed, utilising open-ended questions to guide interviews. Interview questions were informed by a review of published literature using an inquiry logic that reflected the investigative aims of the study. Table 1 outlines each question, including the inquiry logic for each question. The study received ethical approval from the [removed for blinded review] Human Research Ethics Committee.

**INSERT TABLE ONE ABOUT HERE**

Potential participants were English-speaking male and female individuals aged ≥18 years who were current or recent family carers (within last 6 months) of a person living with dementia and living in Queensland, Australia. Mixed-strategy purposive and snowball sampling were utilised to recruit participants. Information about the study was included in newsletters distributed by associated organisations (Alzheimer’s Australia and Victoria RSL), and on Alzheimer’s Australia’s Facebook and Twitter websites. Specific individuals known to the research team were contacted to assist in recruitment using existing carer networks. Interested participants were asked to contact the research team to receive further information, provide informed consent and arrange an individual interview. All family carers who contacted the research team ultimately participated in the study.

Interviews were conducted in 2012 by a researcher who had no prior relationships with the participating carers. Interviews were conducted via telephone using the interview questions described in Table 1, at a time convenient to the participant. Interviews were recorded with participants’ permission, and transcribed verbatim by one interviewer (SJ). After each interview, participants were asked whether they knew of anyone else that may be eligible and interested in volunteering for the study. Data collection and analysis were conducted simultaneously, and participant recruitment continued until saturation of response themes was considered to have been achieved by the interviewer. In practical terms, saturation was considered to have been reached when no new response themes were detected as interviews progressed.
Analysis of verbatim transcripts involved an iterative process of data reduction, systematic comparison and conclusion. Transcript data was thematically analysed using a process of open-coding involving responses being read through, re-read, coded using an iterative coding list developed during the analysis and organised within theme categories. Triangular analysis was conducted by three investigators (LB, SJ, RH) by independently coding and sorting interview data, and then comparing and discussing the themes to reach agreement about common and uncommon response themes. Example quotes have been included to support key and/or contradicting themes identified.
Results

Fourteen individuals (aged 58±17.8 years, range 25 to 85) were interviewed as family carers for fourteen people with dementia (aged 78±11.2 years, range 54 to 91). Two male carers were caring for their wives and the female carers were caring for husbands (4), fathers (3) or mothers (5). The family carers interviewed had been in a caring role ranging from 1 year to 14 years (mean –5 years), and the proportion of their time spent in overall care ranged from occasional assistance through to total supervision and care during waking hours. Most of the family carers had been involved in feeding and nutrition-related care from the outset of the caring period for the individual with dementia; however this was reported by most to have increased as the condition progressed.

Family carers described a range of feeding-related challenges experienced during the care of their relative. The challenges have been broadly categorised as physiological, cognitive, emotional, functional and/or behavioural (Table 2). Cognitive challenges were most common, including the person in care being forgetful, disorientated or confused and needing considerable care and support with feeding. Physiological challenges were also frequently reported by family carers, including swallowing difficulties, loss of appetite and changes in food preferences. Emotional barriers included social isolation, not wanting to be fed by another person, possessiveness, and the person with dementia becoming frightened. These emotional barriers often contributed to behavioural challenges such as anger and aggression, or the hoarding of food and cutlery. Functional challenges included difficulties using cutlery and visio-spatial issues such as not recognising food.

Table 2 summarises the key themes relating to feeding challenges and the strategies employed by family carers to maintain or enhance food intake. Family carers’ descriptions of the strategies they used to address feeding challenges indicated that patience and persistence with care were central themes. The challenges often required an approach that avoided confrontation, diffusing feeding-related anxiety at the point in time, followed soon after by repeated attempts to encourage eating. Many family carers commented that this persistence worked but required a lot of patience. The importance of, and burden associated with, feeding time supervision was also a common response theme.
“Just allow her time to eat, exercising a bit more patience.” (Participant 1, 29 year old female family carer)

“I eat each time he eats; otherwise it’s a battle to get him to eat alone.” (Participant 12, 62 year old female family carer)

Family carers perceived that it was important to recognise and accommodate the specific taste preferences of their relative in order to ensure adequate food intake. These taste preferences often required family carers to change and develop their food preparation practices to suit their relative.

“The best way to cope with it was to let her be the boss and cook the way she wanted me to, and not to push with my knowledge of what was healthy or not.” (Participant 2, 62 year old female family carer)

“We agreed that I will cook two types of food, one for her and one for me.” (Participant 2, 62 year old female family carer)

Family carers often reported developing a number of psycho-social approaches to encourage food intake. These strategies included families sitting to eat together, having plenty of time for a meal and maintaining socialisation with friends at meal times. Some family carers developed strategies such as minimising distractions at meal times or preparing for meals using the same routine each time, which were perceived to enhanced food intake. Others developed food presentation strategies such as serving small and numerous portions in one meal, cutting food into small pieces and using finger foods.

“We found that if we sat with him to eat, you know eating is a social thing, a social experience. So we sat alongside him and had a cuppa while he had his breakfast and that really helped.” (Participant 10, 58 year old female family carer)

Family carers’ experiences and observations of weight changes amongst relatives during their care were varied; however a majority (8/14) reported some weight loss. Weight loss was generally attributed to general decline, part of the disease process, low food intakes and in a number of cases specifically attributed to energy imbalance associated with excessive wandering. Only two of the family carers reported noticing weight gain, but
appeared unconcerned because the gain was due to appropriate nutrition-related care and support, often rectifying previous weight losses. Most family carers reported that they were initially uninformed about expected weight changes related to dementia and had received little guidance from health professionals. A small number of family carers who had health professional backgrounds were aware of the potential for weight loss accompanying dementia and a few reported that they had learnt about nutrition and feeding strategies through their own investigations.

“[Weight loss] has never arisen at any of our meetings or anything. And it has never really come up with the GP [General Practitioner] or [the specialist] or anything.” (Participant 14, 85 year old male family carer)

“From being an RN in aged care for many years and also having a special interest in dementia – I worked with Alzheimer’s Association years ago, I know they do lose weight over time as a part of the disease” (Participant 5, 65 year old female family carer).

Rapid weight loss that manifested as noticeable wasting was a source of considerable anxiety by most family carers. A feeling of failure, helplessness and a significant source of emotional stress often accompanied this anxiety.

“I just went to pieces when she lost weight. I still go to pieces…she was so skinny and bony and unhappy.” (Participant 2, 62 year old female family carer)

For many family carers, these feelings appeared to be compounded by a lack of information and support specific to feeding strategies and weight loss. One family carer, with a background as a registered nurse, described her anxiety and challenge dealing with her relative’s weight loss as “being the biggest challenge of my life” (Participant 10, 58 year old female family carer). This example highlights the potential impact the sequelae of events in dementia care (difficulties feeding, weight loss, carer anxiety) can have on family carers, even with health care experience.

Some family carers discussed the use of food-based strategies to address weight loss, such as providing more nutrient-dense foods, high energy and protein supplement drinks and/or adding calorie dense ingredients to normal foods (e.g. butter, cream). Other strategies to
respond to weight loss mirrored strategies utilised to respond to feeding-related challenges, and are described in Table 2.

Whilst most family carers reported that their initial knowledge and awareness of nutrition-specific issues related to dementia care was low, most had increased their knowledge and awareness through observational learning and trial and error. Support groups and online tools were common sources of information when family carers proactively took steps to be more informed. Most of the family carers reflected that there was little to no education and guidance offered to them by health professionals regarding specific nutrition or feeding issues associated with dementia. Family carers also perceived that there was no training available about nutritional needs for people with dementia or about methods for ensuring adequate food intake. At family carers’ meetings (support groups or association meetings), behavioural issues were a common topic of discussion. Although behavioural issues were considered to be heightened during meal times, strategies for improving food intake at meal times or making meals easier were not the focus of discussions.

Several family carers found that they had a difficult time accessing nutrition support resources, such as nutrition supplements, largely because of costs. Almost half (6/14) of the family carers mentioned a dietitian as a possible source of nutrition support when they were asked about their knowledge of nutrition and dementia, five of whom stated their relative had never been referred to a dietitian by any health professional.

“I could not get supplementation as a person living in the community. The only thing I could get was Sustagen and it was costing an arm and a leg. I phoned the companies that produce the supplements. None of them would supply me as an individual; it had to come via an organisation.” (Participant 10, 58 year old female family carer)

When asked to identify support required to reduce the burden of nutrition care, responses tended to relate to practical relief (such as ‘Meals on Wheels’) or support that addressed anxiety associated with a lack of knowledge and skills relating to nutrition support (such as access to a dietitian). Access to other family carers with ‘real world’ experience dealing with feeding difficulties and providing nutrition-related support was considered highly valuable to family carers.
“Maybe a dietitian who has special training in dementia would be useful.” (Participant 8, 52 year old female family carer)

“Seeing a dietitian once every 6 months or a year for an assessment of their needs, how to interest them in food, and suggestions for preparing food.” (Participant 8, 52 year old female family carer)

“The one thing I found difficult to find was other family carers getting together to talk about food issues. That’s where you are going to get good information from, advice on what is working and what you can do in certain situations; people who have been there before.” (Participant 9, 33 year old female family carer)

When prompted, participants shared lessons from their own experience as family carers that they perceived would be paramount for new family carers to know as they began their journey as a carer. The key response themes from this shared wisdom are summarised in Table 3.

INSERT TABLE THREE ABOUT HERE

Most family carers reflected that their experience of nutrition care had been difficult and a significant component of their experience of overall burden of care. Family carers reported experiencing numerous emotions during their time providing nutrition-related care. This included anxiety, stress and worry that the way they were caring was not ‘correct’, or that their relative was reliant solely on them for food, nutrition and eating. Overall, family carers found nutrition-related care to be a significant challenge, at times frustrating, and often left them feeling distressed. Responses suggest that nutrition-related care had been a major contributor to overall burden of care in this sample.

“It was time consuming and draining because you had to be there and concentrating. It took an hour to feed her. It was a big challenge.” (Participant 1, 29 year old female family carer)

“You never really have a break. You never feel free to actually go and do anything, or stay overnight anywhere without a whole lot of planning and packing.” (Participant 13, 68 year old female family carer)
“Now that he is in care, I can relax more and I enjoy the quality time we spent together now.”

(Participant 5, 65 year old female family carer).
Discussion

The aim of this study was to investigate the perceptions of family carers on their experience of providing feeding and nutrition-related support to individuals living with dementia. Family carers described a range of feeding-related challenges categorised as physiological, cognitive, emotional, functional and/or behavioural challenges. The strategies developed for overcoming these challenges were highly varied. Overall, the participants found feeding and nutrition support to be a significant challenge, and this aspect of care appeared to be a large source of burden for family carers.

The family carers reported that the burden associated with nutrition-related care was significant, yet difficult to quantify in the context of broader conceptualisations of carer burden. Family carers felt uninformed regarding feeding challenges, which resulted in family carers feeling anxious and distressed, and contributed to their feeling of significant burden associated with the care of their relative. This finding is in line with recent literature that suggests that family carers feel overwhelmed and stressed when provided with inadequate resources, or resources that are inappropriate to their level of medical knowledge, or do not adequately resolve their ongoing problems.\textsuperscript{14} Therefore, the educational resources and support provided to family carers needs to incorporate practical (and where possible carer-tested) strategies to ensure that appropriate and sufficient support is provided to family carers to ameliorate the burden associated with feeding and nutrition-related challenges.

Participating family carers felt they had not received adequate information and support from health professionals or carer groups about nutrition-related care. Evidence from earlier studies also suggest that the nutrition-related resources provided to family carers are usually of low quality and do not address the concerns of family carers.\textsuperscript{14, 15} This evidence of inadequate information and support suggests a need for strategies and services focusing on family carer education. Family carer education has previously been a focus of nutrition-related interventions for individuals living with dementia,\textsuperscript{22} including the provision of carer support.\textsuperscript{20} Interventions such as these have successfully improved the rate of malnutrition of individuals living with dementia.\textsuperscript{21} Notably, none of these interventions have been implemented and evaluated in the Australian setting, and the potential for improving the
education provided to family carers requires consideration and collaboration between health professionals and relevant health organisations.

The feeding and nutrition-related challenges faced by family carers in this study varied considerably, reflecting earlier studies. This variability makes the development of guidance resources that meet the general needs of family carers challenging, and generic advice for family carers regarding nutrition may not be useful. Instead, health professionals and services should work in partnership with family carers to focus on identifying nutrition-related strategies that meet the individual needs of family carers and their relative, and focus on the range of factors that make feeding support challenging. These partnerships between health professionals and family carers can be enhanced by sharing other family carers’ practical and field tested strategies, such as those identified in this sample of carers. The recommendation of such strategies should be appropriately assessed by qualified health professionals as causing no harm before broader dissemination.

It is noticeable that the strategies identified as commonly developed in this sample of family carers are low risk in terms of nutrition or broader health status, and focus on practical behavioural management strategies. This finding is probably not unexpected given the nature of the investigation into the family carers’ perceptions of their experiential learning, and the prevalence of behavioural challenges associated with dementia that impact on feeding support. However, this study has some limitations in terms of the generalisability of findings to other family carers. The participants’ varied experience and currency of dementia care (in terms of duration, reflections of caring now or in the past) may have contributed to the variability of experience with regards to challenges observed, strategies developed and the effects of feeding care on family carer burden. However, this study has not aimed to collect data to represent a shared experience across all family carers, but instead amongst a purposively sampled, information rich sample.

The emphasis and value given to carers’ field tested strategies and other lay knowledge in this study is based on the assumption that family carers can, and will, develop knowledge and solutions to problems they experience. We are unable to confirm the extent to which the strategies described by the current participants were developed independently of health professionals and in situations of limited health professional support. The present results
therefore do not assume the strategies developed by family carers are effective or indeed safe, but simply worthy of note and consideration. It is advised that these strategies are assessed for risk of potential harm, and if appropriate, be shared with other family carers.

In conclusion, family carers of people with dementia experience a wide and individually variable range of issues surrounding feeding and nutrition-related support. Family carers have developed a range of strategies to deal with these challenges, worthy of dissemination amongst other family carers after being assessed for risk. The family carers in this study reported lacking appropriate information, support and guidance, which contributed to their perception of feeding-related burden of care.
References


