Struggling to maintain individuality – Describing the experience of food in nursing homes for people with dementia

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ABSTRACT

Purpose of the study: To describe the food and dining experience of people with cognitive impairment and their family members in nursing homes.

Design and methods: Interviews and focus groups with people with cognitive impairment and their family members (n = 19). Thematic analysis was undertaken using NVivo10 data analysis software package to determine key themes.

Results: The main themes identified tracked a journey for people with cognitive impairment in nursing homes, where they initially sought to have their individual needs and preferences recognised and heard, expressed frustration as they perceived growing barriers to receiving dietary care which met their preferences, and ultimately described a deterioration of the amount of control and choice available to the individual with loss of self-feeding ability and dysphagia.

Implications: Further consideration of how to incorporate individualised dietary care is needed to fully implement person-centred care and support the quality of life of those receiving nursing home care.

1. Introduction

While work towards effective prevention and pharmacological treatments for dementia continues, focus for current management across the disease spectrum centres on optimising quality of life for the person (Laver et al., 2016; National Collaborating Centre for Mental Health, 2007; World Health Organization, 2012). While quality of life is a broad concept, most definitions incorporate multiple domains which influence quality of life such as physical and mental health, the physical and social environment, personality, cultural expectations, relationships, participation, and wellbeing, to name a few (Beckie and Hayduk, 1997; Venturato, 2010). Dementia and cognitive impairment and living in institutional care can all have an effect on a number of these domains of quality of life (Venturato, 2010). Previous studies have also identified the important and multifactorial influence of food and mealtimes on quality of life for older people. Food provides more than just a way to meet the physical nutritional requirements of the body, but can also be associated with memory, social occasions, and emotions, and provide a source of enjoyment, socialisation, nurturing and dignity (Cooney, 2012; Evans, Crogan, & Shultz, 2005; Hall, Dodd, & Higginson, 2014; Vogelzang, 2003). Therefore, it is important to consider the role that mealtimes can play as an influencer of quality of life for people living with dementia in nursing home settings.

There are some factors that appear to put residents at particular risk of a poor mealtime experience, including having cognitive impairment, poor self-feeding ability, and dysphagia requiring texture modified foods or fluids (Ilhamto, Anciado, Keller, & Duizer, 2014; Keller & Duizer, 2014a, 2014b). Poor nutritional status in residents with dementia has been well described, and as the disease progresses problems with feeding and nutritional intake become more common with over 80% of residents with advanced dementia experiencing feeding problems (Hanson, Ersek, Lin, & Carey, 2013; Shatenstein, Kergoat, & Nadon, 2001).

In the significant number of ethnographic studies focusing on the residential care setting published over the past three decades, observational studies particularly have highlighted the overwhelming impact a focus on process, organisational systems, and structure can have on mealtimes in residential care (Barnes, Wasielewska,
consider important (West et al., 2003). For example, staffing and interactions (Henkusens et al., 2014; Kofod, 2012; Moore, 1999; Pasman, The, Onwuteaka-Philipsen, Van Der Wal, & Ribbe, 2003; Pierson, 1999). Deviation from these rules can result in admonishment from others which can be distressing for residents. Studies from the perspective of residents and family members also report a ‘task driven’ and structured approach to mealtimes in residential care, and the negative impact this has on resident experience, quality of life, nutritional intake, and ultimately their health (Bernoth, Dietsch, & Davies, 2014; Cooney, 2012; Hung & Chaudhury, 2011). Other studies have shown evidence of many protocols and guidelines on feeding residents, emphasis on completing records of how much residents have eaten, equipment and protocols for monitoring resident body weight, and completion of generic assessment by professional staff such as dietitians and speech pathologists (Henkusens et al., 2014; Pierson, 1999). On the other hand, little or no attention may be paid to providing adequate staff training regarding feeding residents, and staff duties are often organised to prioritise more ‘important’ tasks such as medication rounds or clerical duties, resulting in a general lack of staff to provide feeding assistance to all residents in need (Kayer-Jones & Schell, 1997; Pierson, 1999; Ulrlich et al., 2014).

A wide variety of aspects of the mealtime experience that are important to older adults in nursing homes have been identified and these include feeling respected, independence, variety of menu and respect for choice, staff knowledge and attitudes, the timing of meals, a calm and comfortable dining environment, as well as the food quality and suitability (Crogan, Evans, Severtsen, & Shultz, 2004; Evans, Crogan, & Shultz, 2003; Shultz, Crogan, & Evans, 2006; West, Ouellet, & Ouellette, 2003). However, these interviews have focused on recruiting residents with good communication skills, leading to questions about whether the opinions of residents with dementia or cognitive impairment are being included. Studies have shown differences in what staff consider to be important to create a quality dining experience for residents, and the factors that residents themselves consider important (West et al., 2003). For example, staff ranked some aspects which were highly important to residents (including feeling at home, ability to self-feed, having a varied menu, and comfortable seating) of lower importance than residents ranked these aspects themselves.

The impact of cognitive impairment, and physical frailty on communication with older people with dementia can result in younger and less impaired people being included in the discourse on health and aged care quality while leaving out the important perspective of the more cognitively impaired and physically frail older adults (Alzheimer Europe, 2011; Clare, Rowlands, Bruce, Surr, & Downs, 2008). Therefore there is a need to purposefully include people with dementia and cognitive impairment themselves in discussions of the meaning and quality of care. Accordingly, the purpose of the study is to determine the key components that influence how people with cognitive impairment and dementia in nursing homes experience food and dining. We aimed to answer the following research questions: (1) Do people with cognitive impairment and their family members think that food and dining in nursing homes is important? (2) What are the aspects of food and dining in nursing homes that support and hinder quality of life for people with cognitive impairment?

2. Methods

To answer these questions, the perspectives of a range of subjects were sought. Firstly perspectives of people with cognitive impairment themselves were sought. These were participants who had a diagnosis of dementia or other cognitive impairment, and who were already interacting with the long term care sector, or were beginning to consider or plan for admission to a nursing home in the future dependent upon the progression of their impairment. In addition, the opinions of family members of people with dementia or other cognitive impairment living in a nursing home currently were sought, as family members are often highly involved in providing care and making decisions on behalf of people with dementia and cognitive impairment, and it was considered that this would assist the incorporation of experiences of people with severe cognitive impairment who were not able to respond verbally to questioning. Participants were recruited from nursing homes and support groups for people with dementia and cognitive impairment, and their family members. This study was nested within a larger qualitative study aiming to determine the characteristics of good quality nursing home care (Milte et al., 2016). Where food was discussed in the interviews and focus groups conducted for the larger study, these comments were also included in the analysis. This study was approved by the Flinders University Social and Behavioural Research Ethics Committee (Approval Numbers: 6394 and 6446).

2.1. Interviews

For people living in either nursing home settings or the community, in-depth one-on-one interviews were conducted by members of the research team experienced in conducting interviews with people with cognitive impairment. Interviews were semi-structured and responded to the cognitive ability of the person being interviewed. Questioning focused on determining the important aspects of food and dining in nursing home settings for the participants and how to meet their preferences. For example, participants were asked to describe the food and dining experience in their current facility. They were asked about whether the taste of the food, having a choice of meal, and the timing of the meal were important to them or not, and to explain why. Basic demographic information about the participants was collected, and the Short Portable Mental Status Questionnaire (SPMSQ) was administered to participants to determine their level of cognitive impairment (Pfeiffer, 1975).

Family members of people with cognitive decline participated in focus groups, facilitated by a trained member of the research team. Staff collected some basic demographic information about the participants, and led the discussion with open ended questions (similar to those covered for the people with dementia) aimed at determining the characteristics they considered important about the food and dining experience in nursing home settings, and their preferences for their relative’s care.

2.2. Analysis

Recordings of the focus groups were transcribed verbatim by a professional transcription service SmartDocs Pty Ltd©. The resulting transcripts were checked for accuracy by a team member (RM). Thematic coding procedures utilizing NVivo version 10 were then undertaken to derive meaning from the transcripts. The analysis was inductive, with all themes developed ‘up from’ or ‘grounded in’ the data itself, without attempts to link back to pre-existing theories. This was because the ultimate aim of the research was to produce new ideas and descriptive insight into the meaning of food and dining in nursing homes to people with cognitive impairment, given the limited involvement of this group in the literature currently (Richards, 2015). The transcripts were coded using cyclical processes of ‘topic coding’, ‘analytic coding’ and ‘coding on’, as outlined below. These coding
processes, described by Richards (2015) align with grounded theory’s open, axial and selective coding stages which guide analysis from initial line-by-line coding designed to ‘fracture’ the data and open up all potential lines of enquiry, to re-constructing the data into related categories and abstract ideas (Glaser & Strauss, 1967). In the initial phase of topic coding, each transcript was coded line-by-line and all data assigned a derivative category (WS). Subsequent analytical stages involved interpretative review of the resulting provisional coding framework, towards development of themes and conceptual categories (RM, WS and MK). Regular meetings were held between the three researchers to facilitate the processes of analytical coding and coding on until no new coding categories were identified. Categories and developing themes were discussed throughout the various stages of analysis until agreement was reached between the authors on core themes. In coding on, these core ideas were re-examined with particular attention to the relationships between them. For example, it became apparent during this stage of analysis that there was a story to tell that traced the changing experience of food over time as the impacts of dementia progress. Though concepts such as choice, preference and individualisation emerged as core ideas, we found these significantly eroded for people with severe impairment.

3. Results

Data collection occurred in October and November 2014. A total of nineteen people participated, including 13 people living with cognitive impairment, of whom 3 participants were living in the community, while the remainder were living in nursing homes. Six participants were family members of a person with dementia. The nursing homes that participants were living in were all accepting residents with a range of care needs, from more moderate to high level needs, and were generalised aged care facilities. These facilities were all based in the metropolitan area, and had standard food service systems in place i.e. pre ordering of meals, meals prepared in a large kitchen on site and sent out to dining rooms where residents ate together at mealtimes. Table 1 gives some basic demographic information for the participants. The mean number of errors for the SPMSQ for the participants with dementia was 5.3 (Standard Deviation 3.0), but the cognitive ability of the participants ranged from 0 (indicating no cognitive impairment) to 10 (indicating severe cognitive impairment). All participants were born in Australia and with English as their main language spoken at home.

The key themes generated from the analysis of the qualitative data collected are discussed below. Explanatory quotes are provided to illustrate each theme. Quotes from participants with cognitive impairment are identified by their gender, their status as either community dwelling or in nursing homes, and a unique identifier based on the chronological number of the interview. For family members, quotes are labelled with the number of the focus group they participated in, and their status as a family member.

3.1. We know what we want, just ask us

Knowing and respecting the individual and their own needs and preferences was a strong theme expressed by people with dementia and their family members. Participants articulated their or their family member’s particular likes, dislikes, preferences, values and needs with regard to food and dining. This demonstrates that there is no ‘one size fits all’, and an individualised approach, where peoples’ specific circumstances, preferences and requirements are known and respected is important. These preferences are shaped by individuals’ past life experiences, which participants often explained. Many liked to have some continuity from what they were used to prior to living in a care facility, with regard to types of foods they eat and the timing of meals.

“Because at the nursing homes, this last one we visited, they said ‘we and we have a continental breakfast’. I thought bloody continental breakfast, I have an egg every morning for breakfast without fail for probably 50 years, 60 years... so I want my egg.” [F, Community, 1]

Participants felt that respect of individual preferences implies having a degree of control and input into all aspects of food and dining, including what food is eaten, the timing, location and size of meals, and the degree of involvement in mealtime routines such as setting tables and clearing up. Some participants were explicit about wanting some control over their meals, including a choice of what, when and how much they ate, reflecting on how normal this level of control was prior to living in residential care.

“Well when you go out to a restaurant, or a hotel, or anywhere, any eating place, you know roughly what they serve up. Well then you get a menu, you say, ‘Don’t think much of that. Oh, that will do.’ And you point to that one” [F, Resident, 6]

3.2. Our wants are not always heard

While family members and people with dementia described to us the importance of food being provided in a way that respected their or their family member’s individualised needs and preferences, and were able to clearly identify these, they described many situations where these individualised needs were not considered or met. People living in nursing homes did not always feel able to speak up about their preferences, or that their requests would be respected, with regards to meal timing, portion size, or choice of meal.

Participant: [Dinner is] too early, and it’s too soon for me after afternoon tea, and quite a lot I’ve been knocking afternoon tea back for that reason, that I feel better if I miss that out and have the dinner meal.

Interviewer: So what would happen if you said, “Look, I’m not really hungry now, I’d like to have this at 6:30; seven?” What would happen?

Participant: I think I might have my throat cut.[F, Resident, 6].

However, some were less concerned about having such choices, or felt that they had adequate choice. Some were able to successfully have input into food options provided. One family member described her mother’s success at achieving change on the menu for the whole facility by asking the management staff at her facility.

“Well they have residents’ meetings. My mother... went on a lot and then she got spinach on the menu so it was fresh spinach and all the people at the table said, oh thank goodness we’ve got this green spinach.” [Focus group 2, Family member]

Some family members also expressed a desire to be able to have input into their family members’ diet, although others were happy to

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Table 1

Demographic characteristics of the participants (n = 19).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Family members (%)</td>
<td>6 (32%)</td>
</tr>
<tr>
<td>Gender (%)</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>14 (74)</td>
</tr>
<tr>
<td>Males</td>
<td>5 (26)</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>78 (10)</td>
</tr>
<tr>
<td>Highest educational qualification received (%)</td>
<td></td>
</tr>
<tr>
<td>No qualification</td>
<td>4 (21)</td>
</tr>
<tr>
<td>Completed high school</td>
<td>7 (37)</td>
</tr>
<tr>
<td>Bachelor degree or professional qualification</td>
<td>5 (26)</td>
</tr>
<tr>
<td>Post graduate qualification</td>
<td>3 (16)</td>
</tr>
</tbody>
</table>

Abbreviations: SD = Standard deviation.
leave this to the facility. One spouse did not feel ‘in the loop’ about what her husband was served, and would like to have more communication about this as she felt the nursing home staff had misinterpreted his likes, dislikes and preferences.

“I saw on a menu that < husband’s name > didn’t like scrambled eggs or rice. Now I didn’t relate to either of those things, and I suspect that perhaps just on the day… they got the wrong end of the stick, and perhaps it was also because of difficulty with communicating. So I was able to clarify that… I think family… we’re an integral part [of such communication]”. [Focus group 2, Family member]

3.3. The tipping point: when consideration of choice and individual preference stops

The issue of loss of control and opportunities to make choices and have individualised preferences met was highlighted as a particular issue for people with more severe cognitive impairment. These individuals were experiencing increasingly severe symptoms of dementia, which impacted on their ability to verbalise or express their needs and choices as they had previously. It was felt that for these highly vulnerable people, all individualisation, recognition of choices and preferences was removed.

Family members talked about the importance of providing appropriate and individualised support to residents at meal times. It was felt that support is not tailored appropriately to individual residents’ abilities. In particular, residents seemed to be “grouped” according to their perceived limitations of either independent or dependant, or requiring a normal or modified diet with little credence being given to the fact that people’s ability levels may change gradually and hence so could their levels of participation.

“I think there’s a difference also between assisted feed and feed. There’s one lady where < husband’s name > is that she’s now in a princess chair because she’s got problems with her legs or her feet or something. Nothing wrong with her hands and she’s quite able. I mean some days she probably can’t feed herself but because she needs supervision and help they tend to think that she needs to be fed when really it would be better for her to feed herself as much as she could with somebody observing and being there.” [Focus group 2, family member]

The transition to modified food was also seen as abrupt. Family members felt that a graduated transition would enable residents to continue to enjoy some of the foods they were still able to eat, rather than to go straight onto a diet where all foods were texture modified.

“…in the early stages they could cope with a compromise between the dishes they’ve been happy [with] and that they’re going to get. There’s an interim period between where you sort of ease them into the [modified food]… so it’s not a distinct break. It’s a merger from one pattern to another, basically.” [Focus group 1, family member]

It was felt that this ‘all or nothing approach’ impacted negatively on the person’s level of independence, dietary intake, and ultimately their quality of life. Control and individualised choice was also a dominant concern for residents on texture modified diets and their family members. A number of participants expressed that a diet of foods with modified texture resulted in no choice at all, repetitive and unappealing meals with no variety and an inability of people to distinguish what they were eating.

Have you ever eaten the pulverised slop? Like if you have swallowing difficulties, and later in the disease process… I already have got some swallowing difficulties, I don’t know if you’ve ever been into aged care or a hospital, you get a scoop of white slop, a scoop of orange slop, a scoop of green slop and a scoop of brown slop, if you eat meat, and if you don’t eat meat then that’s another colour vegetable. Have you ever eaten it? I actually almost threw up. It was so disgusting. [F, Community, Quality of nursing home care interview]

“From what I’ve seen the hardest thing because she had to have vitamised and very soft diet a lot of the flavour was taken out so that when you had the vegetables and you had everything mushed up she’d be saying what actually is that I can’t work it out whether it’s fish or whether it’s something else.” [Focus group 2, Family member]

A number of people provided suggestions to improve the appearance of vitamised food to potentially increase the appeal to those eating the food.

“I think they’ve got little moulds now so that if you’ve got a fish mould and say you’ve got pureed fish you can make that into the little fish [shape]… Even those more advanced [dementia] I think if they can see something that looks like fish I’m sure it would make a difference.” [Focus group 2, Family member]

Another family member suggested that the vitamised food could be accompanied by a sliver of vegetable placed on the plate to identify the pureed food. However, some family members of those residents with severe dementia suspected that enhancing presentation of the meals would have little impact on the dining experience of their next of kin, as they doubted that their awareness was high enough to respond to these cues.

3.4. A tricky balance between health and quality of life

Another key point of conflict that participants identified was the tension between food as a determinant of health, a source of risk for the individual, and a key component of quality of life. They recognised the role of facilities in ensuring residents received prescribed care, including nutritional care. However, some described a tricky balance between maintaining a residents’ quality of life and a healthy diet, and that this balance was weighted too far towards absolute safety and the protection of health at any cost, to the detriment of quality of life. They felt that each resident’s situation was unique, and should be considered in context. One participant described the balance between providing foods that her husband enjoyed but that were considered as contributing to “unhealthy” weight gain.

“So in [husband’s] case we’re torn between giving him what he wants… but then monitoring other things, like the cake at morning tea. So I find that’s quite a dilemma, because naturally you want them to be happy and food is – those little things are part of happiness” [Focus group 2, family member]

One participant described how she wanted to follow a diabetic diet, however that she wanted the ability to choose when to have foods ‘outside’ that diet, as she had the freedom to do while she was living at home. She was concerned that this would be a problem in a nursing home setting.

“But… food should be enjoyable, shouldn’t it… so that’s why I eat my éclair… see, people would disagree with me that I should have an éclair. They said look you say you care about your diabetes, and what do you do? But that’s all very well for people that like everything. But I’m not in that category am I? I am in the awkward category” [F, Community 1]

A wife described the dilemma concerning her husband, who was on a fluid restriction and who complained of being thirsty. She discussed weighing up protecting his health (by sticking strictly to the fluid restriction) verses promoting his quality of life (by providing fluid to quench his thirst).
In addition to the enjoyment people derive from eating meals, participants also described food as a source of socialisation. This socialisation was considered important, and a component of meals that needed to be considered outside the physiological and nutritional aspects of the food. Family members described how important a pleasant social environment could be in affecting the outlook of a person with dementia towards eating and mealtimes. Factors that could affect this environment included having the freedom to sit with who they choose at mealtimes, and having a dining room which was ‘homelike’ in nature and smaller in scale.

Food was also an important social focus with regard to visitors. Food and dining was described by participants as maintaining a sense of normality, and providing a focal point to maintain connections with friends and family. Food provided an enjoyable joint activity, with family members often bringing food to share when they visit, or ordering a meal for themselves from the facility so they could eat with their family member.

It is apparent that there is a tension in the nature of food and dining, where food has both a physiological effect and an effect on social and quality of life outcomes, which need to be balanced. Achieving the optimum physiological effect may have concurrent and sometimes negative effects on enjoyment of the food and vice versa, and this needs to be balanced for each individual according to their own preferences and needs.

4. Discussion

This study adds the voice of people with dementia and cognitive impairment to the discussion of mealtimes in nursing home settings, a group who make up a large proportion of the residents, and are known to be particularly vulnerable to the effects of poor nutritional care and institutional impacts on quality of life (Edvardsson, Winblad, & Sandman, 2008; Jesus et al., 2012; Shatenstein et al., 2001). For this study we specifically focused on the opinions of those with cognitive impairment and their family members regarding food and dining in nursing homes. We utilized in-depth interviews and focus groups with people with cognitive impairment (including those living in the community and in nursing home settings) and their family members to determine the meaning of food and dining in nursing home settings from their perspective, including which aspects were most important contributors to a positive or negative food and dining experience.

The participants discussed a range of experiences, some reporting many negative experiences and dissatisfaction, while others were more accepting of the structure and routines of institutional life. It should be noted that individual characteristics of the participants, for example their background, socioeconomic status, and education level could all have an impact on their expectations and satisfaction for their care, which would impact upon their responses in this study (Jing, Willis, & Feng, 2016). To account for this, we attempted to include participants from a number of facilities from different socioeconomic (although all metropolitan) areas to include participants from different backgrounds in the sample with a range of different views.

In our study, we identified that maintaining choice and individual preferences around food is equally important to people with cognitive impairment, but that their attempts to maintain their individual patterns could be frustrated by a systemic ‘one size fits all’ approach. Previous studies conducted with residents without cognitive impairment have also identified catering to individual preferences and affording choice and input into food and dining systems as integral (Crogan et al., 2004; Evans et al., 2003; Shultz et al., 2006). Flexibility in the provision of food was reported as an issue of key importance to the participants in our study, as has been reported in studies with people without cognitive impairment previously (Adams, Anderson, Archuleta, & Smith Kudin, 2013). It was conceptualised by our participants as catering for and respecting the individual through the provision of a degree of control and involvement in what meals they eat and when they eat them, and this was a key determinant of whether the food and dining experience was a positive one or not. While some of our participants sympathised with the difficulties for facilities due to the impacts on staffing arrangements and associated costs, they expressed frustration at having to give up choice with regard to meals. More consideration of how to support residents to maintain and express control and choice in food and dining, and how to balance health with social and quality of life aspects of food are required to achieve an improved service. Options to be considered could include providing a choice of meal at point of service or ways to establish better communication between providers, residents and their family members, but such consideration should explicitly include people with dementia.

A key finding of our study was that a diagnosis of dysphagia in conjunction with dementia had a strong influence on the mealtime experience for both residents and family members. Texture modified meals and drinks were reported as un-inspiring, repetitive and ignoring individual needs and preferences. The provision of texture modified foods and fluids has been identified as a point of contention previously, but has not been studied extensively from the resident and family member perspective (Ilhamto et al., 2014; Keller & Duizer, 2014a, 2014b). Texture modified foods and fluid can be recommended for a number of reasons, but commonly are recommended for those with more advanced dementia or other neurological conditions which impact the swallowing process (Flynn, Smith, Walsh, & Walsh, 2014). In such cases, foods and fluids can be modified to make them easier and safer to chew and swallow. A significant number of residents of nursing homes experience some form of dysphagia, with studies indicating up to 60% (Flynn et al., 2014; Park et al., 2013). In our sample, it was felt that they received even less choice and control over their food intake, than those without dysphagia. It was also felt that in some cases there was a blanket provision of the modified foods or fluids, without accounting for individual differences and abilities to manage foods of differing textures, an approach which has also been identified as a strategy used by some nursing care managers when a speech pathologist was not involved in assessing a resident with suspected dysphagia (Bennett, Ward, Scarinci, & Waite, 2014). There is a range of modified diets and fluids that are available to be used, ranging from soft diet, which involves minimal modification of the textures of foods, up to a smooth puree diet, where all foods must be smooth and lump free (Atherton, Bellis-Smith, Cichero, & Suter, 2007). Family members wanted the progression to modified textured diets to be more gradual, taking into account the capabilities of each individual. The food provided for the texture modified diet was felt to be poorly presented, which impacted upon the perception of the taste and desirability of the food.

Texture modified foods have been identified as a challenge for residential care staff to provide (Ilhamto et al., 2014), citing difficulty in using standardised recipes, difference in texture and terminology between staff making communication difficult, and frustration of wanting to improve the visual appeal of these meals. There have been few previous studies of the preferences of consumers for texture modified foods, but a qualitative study of patients in rehabilitation centres have identified frustration with lack of variety in meals, the homogeneous appearance, taste and smell of what was provided, and reliance upon seeing this diet as a step in their recovery as a motivating factor to consume the food (Keller & Duizer, 2014b). However for people with dementia where the disease is of a progressive nature, providers cannot rely on the promise of returning to regular texture food as a motivator, making the use of other techniques to address the limitations of these meals so important. There are clear similarities in

"I've actually said, because at one stage he'd have reached his limit by tea time and I said well don't not give him a drink after, if he has a little bit extra it doesn't matter…. It's not worth upsetting him for a cup of tea, you know". [Focus group 2, family member]
the limitations of the texture modified diet identified by the relatively cognitively intact population studied by Keller and Duizer (2014b), and the cognitively impaired population in our study. From our sample it appears the visual and sensory appeal of the food is still highly important, despite their cognitive impairment.

There were differing opinions in our sample with regards to whether people with more severe cognitive impairment, gained benefit from improved visual and sensory appearance of these meals. Some family members were convinced that touches like providing garnishes to help identify the different foods for the meal, and serving each component separately to the individual, would assist with their acceptance of the meal and could enhance their quality of life. Others, however, felt that these changes would have limited impact. There is also debate on this point in the literature (Norberg, Melin, & Asplund, 2003). It is not always clear whether people with severe cognitive impairment are responding to stimuli in their environment, as their ability to communicate their likes and dislikes is impacted by the expression of their cognitive impairment. However, there is growing evidence that people with severe cognitive impairment do maintain response to sensory and perceptual stimuli in their environment, even at the severe and end-stage of the disease, through monitoring physiological reactions, facial expressions and small movements (such as movement of eyes) (Clare, 2010; Cohen-Mansfield, Marx, Thein, & Dakheel-Ali, 2011). While these studies show a response to sensory stimuli is possible, the question of whether an emotional reaction is triggered in the person (for example happiness or disgust) is another separate point. However, differing emotional responses were able to be identified in response to stimuli in people with dementia ranging from mild to severe cognitive impairment in one study (Cohen-Mansfield et al., 2011), and their response to sweet and sour liquids has been found to be similar to healthy adult controls in another study, indicating maintenance of taste (Pelletier & Lawless, 2003). In any case, given the limited evidence available it should not be assumed that people with cognitive impairment do not experience enjoyment or distaste from food. The effect of improvements to the sensory characteristics of texture modified foods as a strategy to improve intake, nutritional status, and quality of life, requires further investigation.

4.1. Future directions

There are strongly emerging consistencies on the importance of the food and dining experience to wellbeing in nursing homes, and in food and dining preferences (Barnes et al., 2013; Henkens et al., 2014; Hung & Chaudhury, 2011; Kayser-Jones & Schell, 1997; Pasman et al., 2003). This study specifically adds the perspectives of people with dementia and their family members to the discourse on food and mealtimes in nursing homes, a group who are overrepresented in the setting, but underrepresented in research studies. This study has clearly identified some areas worthy of action and improvement. Firstly, the nutrition care and mealtime experience of people with severe dementia and requiring a texture modified diet was consistently highlighted as poor. Problems identified included lack of variety in poorly presented and tasting food, which impacted greatly on the nutritional intake and enjoyment of residents, and distressed and frustrated family member carers. There is evidence from other studies that staff members share similar concerns (Ilhamo et al., 2014; Keller & Duizer, 2014a), but that changes to practice are slow to occur. However, there are potential solutions which can improve the presentation of these meals. For example, the use of moulds to form pureed foods into familiar shapes improving recognition of the foods and presentation has shown promise in increasing resident intake and reducing wastage of food (Cassens, Johnson, & Keelan, 1996; Farrer, Olsen, Mousley, & Teo, 2016; Germain, Dufresne, & Gray-Donald, 2006). This strategy while requiring some outlay in purchasing the moulds and training staff in their use, would seem relatively low in cost when compared with the cost of wasted food and treatment of malnutrition associated with long-term food refusal. Another concern highlighted in this study was the lack of an individualised approach to the provision of texture modified foods. It should be noted that the cautious approach (providing the most modified form of food and fluids) is most likely born from a desire to reduce the risk of choking incidents, which can be very distressing as well as potentially life threatening for residents. However, while the motivation is understandable however the approach is detrimentally simple. Increasing the involvement of specialists in assessment and provision of modified food and fluids (speech pathologists and dietitians) could be a potential solution to address this. Such specialists could provide more individualised assessment of the capabilities of residents and recommendations for dietary modifications and support facility staff in their implementation. However, access to dietitians and speech pathologists in nursing homes in Australia is currently ad hoc with many facilities not having access to regular visits from dietitians and speech pathologists and instead relying on ‘once off’ visits from private dietitians and speech pathologists. Nevertheless, given the widespread nature of dysphagia and malnutrition among nursing home residents, there are calls for increased involvement of dietitians and speech pathologists in the sector and appropriate funding and legislative changes to support this (Agarwal, Marshall, Miller, & Isenring, 2016; Weddle & Fanelli-Kuczinarski, 2000).

Our study highlights the need to balance the nutritional benefits of food with other aspects that are integral to the dining experience and quality of life. Yet, how these issues are being dealt with in practice, and how facilities are balancing the needs and expectations of residents and their family members, within practical and cost boundaries evident is unknown. Future work should focus on interventions to improve mealtime practices and support resident quality of life, with particular focus on how to support implementation within the practical and budgetary constraints existing in the current system.

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