Archives of Gerontology and Geriatrics 72 (2017) 52–58

Contents lists available at ScienceDirect

Archives of Gerontology and Geriatrics

journal homepage: www.elsevier.com/locate/archger

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

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ARTICLE INFO

Keywords:
Long-term care
Quality of care
Nutrition and feeding issues
Qualitative research
Dementia

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,

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http://dx.doi.org/10.1016/j.archger.2017.05.002
Received 10 August 2016; Received in revised form 27 March 2017; Accepted 2 May 2017

Raiswell, & Drummond, 2013; Kayser-Jones & Schell, 1997; Moore, 1999; Pierson, 1999; Ullrich, McCutcheon, & Parker, 2014). As a result, staff are often 'task driven' and focused on moving through organisational systems successfully, rather than responding to the experience of residents leading to their individual needs for physical and social care being lost (Henkusens, Keller, Dupuis, & Schindel Martin, 2014; Kayser-Jones & Schell, 1997; Moore, 1999; Pierson, 1999). Dining rooms are often noisy, crowded, busy, and confusing places, with complex explicit and implied rules for resident to staff and resident to resident 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 (Kayser-Jones & Schell, 1997; Pierson, 1999; Ullrich 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