Positive Attitudes towards Food-related Dementia Care for the Caregiver and Person with Dementia

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Introduction

Food has been described as important to a person’s identification and culture, as well as providing a strong link to social interactions and psychological well-being [1]. Interacting with others during food-related activities, for example food preparation, enables people to maintain relationships and in turn creates meaning to a person and brings a sense of enjoyment and pleasure. Food-related activities can play a positive role in dementia care. However, dementia progression affects cognitive and behavioural functions, particularly in food-related activities [2] and health care providers struggle to maintain this source of enjoyment for people with dementia [3]. As food-related activities have been found to be an enjoyable part of caring [4], this area needs to be discussed in order to find ways of maintaining this pleasure.

A Canadian study by Keller, Edward and Cook, undertook interviews with 23 informal caregivers and found that while they do appreciate the importance of social interaction and that food brought positivity to their lives, mealtimes and food-related activities caused a lot of frustration and difficulties for them [5]. Similarly, Keller, et al., interviewed 55 informal caregivers and their care-recipients [6]. As was the case in the study by Keller et al., the results from this study also indicated that they viewed mealtimes as an opportunity for cognitive and emotional enjoyment and connection. Informal caregivers described mealtimes as not just sitting at the table eating but an opportunity to engage with the person with dementia during the mealtime process, whereby they discussed additional food-related tasks, such as preparing the food and laying the table. Caregivers found that working together with the care-recipient during food-related activities was satisfying and described the connection they have as increasing their self-worth and self-esteem. This highlights the importance of the relationship between caregiver and care-recipient during food-related processes [7-8].

The limitations to these studies by Keller and colleagues [5-6], is that they did not research into the ways the abilities of a person’s food-related activities decline over time, nor how the caregivers’ process of adapting to this decline is managed. A study that later addressed this was a qualitative study by Genoe, et al., which looked into how 27 people with dementia and 28 caregivers adapted to mealtimes as dementia progressed over a two-year follow-up [9]. The results indicated that informal caregivers developed strategies to maintain their mealtime routines with the person with dementia. They captured the emotional attachment experienced during mealtime activities, for example, as it was a time to sit together and share food. Genoe et al., suggested that this helps to provide a critical insight into supporting informal caregivers and care-recipients at home and that providing them with food-related information will make the transition between different stages of dementia easier.

A more UK recent study by Papachristou, Giatras and Ussher, revealed through interviewing family dementia caregivers that shopping could be seen as a ‘day out’ and would be an opportunity to spend time with the care-recipient out of the house [10]. Other caregivers, particularly male caregivers, who had to learn how to cook out of necessity, found cooking an enjoyable process. They described it as an opportunity to train themselves with new skills and felt it provided security for their loved ones. By sharing the responsibilities when preparing food, such as laying the table, helped to maintain a routine as well as fostering a feeling of working together. Maintaining the same diet was comforting for the caregiver as they knew the care-recipient would have enjoyed the food before diagnosis. Finally, eating out was important to continue as much as possible in order to have a sense of social life, normality and reduce the feeling of isolation.

As dementia progresses and affects food-related activities it is important that the carer and health services are aware of the benefits these activities can bring to the person with dementia and their caregiver. In a current study, dementia caregivers agreed that food was an important area of care, however, they highlighted that there was little access to information or support services [11]. In conclusion, in order to maintain positivity around food care it is important to understand the difficulties experienced from point of diagnosis and throughout the food-related process. Therefore, further needs to be developed worldwide in this area to address these issues, both in research and implementation of interventions.

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