


Impact of Dementia Progression on Food-Related Processes: A Qualitative Study of Caregivers' Perspectives

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Abstract

As dementia progresses, one area that can help maintain connection and memories with others is within the food domain. There is little research in this area particularly from the informal caregivers' perspectives. Therefore, a qualitative study was conducted to explore the impact of dementia progression on food-related processes from the perspectives of informal caregivers. The aim of the study was to document the methodology used and to disseminate the findings to researchers, care providers, and policy makers. A total of 10 men and 10 women caregivers of those with dementia underwent a semistructured interview. Transcripts were analyzed using thematic analysis. The caregivers' narratives indicated a set pattern of decline, with food shopping being the first ability to decline, followed by food preparation and the ability to eat. Caregivers adapted to their food roles, for example, by becoming responsible for financial issues. These adaptations were described as stressful yet satisfying as food care was seen as an important social time. Educating caregivers' about the likely adaptations to food processes may increase food satisfaction in both the parties.

Keywords

dementia, informal care, food management, mealtimes, caregiving, food behavior, environment

Introduction

Dementia is a syndrome whereby a person loses his or her cognitive ability, affecting his or her memory and everyday activities.¹⁻² An area of everyday activity, which has an impact on people with dementia is the food domain.³ This is an important area, as the inability to maintain a healthy diet and to eat well causes severe health risks, such as weight loss and malnutrition, among those with dementia.⁴ Food, and in particular mealtimes, have been described as important for those coping with dementia and their caregivers, as these occasions create connections and memories with others.⁵ To date, there is relatively little understanding of how dementia affects the meaning and experience of mealtimes for persons living with dementia or their informal caregivers (i.e., family, friends, and neighbors).⁶ It is particularly important to assess informal carers and how they manage with dementia and food, as there is a heavy dependence on informal caregivers, with more than twice as many informal carers as formal carers (ie, health professionals, such as nurses or care assistants).⁷⁻¹¹ However, informal caregivers receive the least training.¹² Most of the empirical work conducted on dementia and food focuses on the physiological consequences of irregular eating patterns.¹³⁻¹⁵ Nevertheless, recent reviews highlight the importance of the meaning and experience behind mealtimes and the extent to which dementia affects

communication between caregiver and recipient.^{16,17} These reviews discuss the physical decline in care recipients due to their inability to manage food-related processes (eg, weight loss in people with dementia from not eating properly). They also highlight psychological distress, such as that due to changes in the relationship between caregivers and the individual with dementia.

Most studies of informal caregivers have investigated spouse relationships and gender role changes around food.¹⁸ As dementia progresses, there are changes in relationships and gender roles concerning food.^{19,20} As dementia increases, spouses' responsibilities also increase and their role changes according to this increase.¹⁹ Keller and colleagues^{5,6,21} devised the first known studies that considered the perspective of informal caregivers as well as that of the individual with dementia. Their qualitative studies addressed informal caregivers' perceptions

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Table 1. Demographics of Participants and Care Recipients.

	Caregiver pseudonym	Relationship to person with dementia	Type of dementia	Stage of dementia ^a
1	George	Husband	Alzheimer's disease and agoraphobia	Severe
2	Henry	Husband	Alzheimer's disease	Moderate
3	Maggie	Friend	Senile dementia	Severe
4	Jeff	Son	Unknown ^b	Moderate
5	Ana	Sister	Vascular disease	Mild
6	Tammy	Wife	Alzheimer's disease	Moderate
7	Mary	Wife	Alzheimer's disease	Moderate
8	Betty	Wife	Unknown	Moderate
9	Patrick	Son	Alzheimer's disease	Severe
10	Fran	Wife	Alzheimer's disease	Severe
11	Wendy	Wife	Unknown	Moderate
12	Robert	Husband	Alzheimer's disease	Moderate
13	Duncan	Husband	Alzheimer's disease	Moderate
14	Andrew	Husband	Alzheimer's disease and vascular disease	Mild
15	Rita	Wife	Alzheimer's disease	Moderate to severe
16	Dave	Son	Alzheimer's disease	Moderate
17	Sid	Husband	Unknown	Mild
18	Danny	Son	Unknown	Severe
19	Trisha	Wife	Unknown	Severe
20	Juliet	Sister	Unknown	Moderate

^a Participants were asked "What stage of dementia are they?" Mild, moderate, or severe.

^b Participants were asked "What type of dementia do they have?" They responded "unknown" if care recipients had not been diagnosed or if they were uncertain.

of changes that happen during eating and mealtimes as a result of dementia progression and associated coping strategies. It was shown that the social experience of sharing a meal, around a common table, is paramount in maintaining relationships between caregivers and people with dementia. It was concluded that informal caregivers might benefit from being educated about the adaptations necessary to engage with all food processes related to dementia progression (eg, shopping, meal preparation, and eating). As females of the older generation tend to be the main person in the family who shops and prepares food, it is also important to gain more insight into the male's perspective.²⁰ Additionally, it is of interest to investigate the role of women who assist male informal caregivers in managing food-related processes.¹⁸ To summarize, it is important to understand how informal caregivers address change in food-related conduct for those with dementia. This should not only be during mealtimes but be during the whole process of food care management, including changes in routines when shopping for food and in food preparation. No previous research could be identified, which has examined dementia progression and managing shopping, preparing, and eating from the informal caregiver perspective. This study explored this topic using qualitative methods to collect in-depth information on food-related care.

Aim

The aim of the current study was to explore the impact of dementia progression on food-related processes from the perspectives of informal caregivers. In addition, the aim of the manuscript was to document the methodology used and to

disseminate the findings to researchers, care providers, and policy makers.

Method

Participants and Recruitment

The participants were 10 male and 10 female informal caregivers (family, friends, or neighbors) looking after people with dementia at home and who manage their food-related processes (shopping, preparation, and eating). The sample size was appropriate for an in-depth qualitative research methodology.²² All participants were given pseudonyms. The participants' and care recipients' demographic characteristics are shown in Table 1. The qualitative method was used to design, conduct, and analyze 20 semistructured interviews. All the interviews were face to face and took place during an 8-week period in April to May 2010, with the interviews lasting 45 to 60 minutes. The interviews were conducted in the caregiver's home or in a private room in a public library. All interviews were recorded and transcribed verbatim. Participants were recruited by advertising, via leaflets and posters, in a local chemist, a community center, and a national charity (Alzheimer's Society) in South West London. Health care professionals working with dementia and older adults were also contacted and asked to recommend potential participants.

Those providing contact details were telephoned to further explain the study and to arrange an interview. In addition, volunteers were asked a few screening questions to check their eligibility to participate. Before the interview, an information sheet and consent form was posted to the participants. People

Table 2. Caregivers' Perception of Food Shopping.

Type of food-related processes	Main themes	Preliminary topics
Shopping	Rapid decline in food shopping among those with dementia	First food process to decline Changes in paying for food and drink routine Traveling to the shops
	Caregivers' difficulties shopping for food	Decisions on buying food and drink items Behavioral difficulties while food shopping Stress adapting to a new routine Reducing care recipient's involvement Hoarding food
	Purchasing food	Purchasing the same items of food as before diagnosis Purchasing different items from before diagnosis
	A day out	Opportunity to be outside Change of environment Enjoying and connecting

Table 3. Caregivers' perception of Food Preparation.

Type of food process	Main themes	Preliminary topics
Preparation	A gradual decline in food preparation	Adapting to gradual change Forgetting steps in food preparation Specific incidents that gradually decline
	Safety in the kitchen	Dangerous incidents in the kitchen Taking precautions to eliminate hazardous incidents
	Adapting to food preparation roles	New experiences for male caregivers Simplifying food preparation
	Shared responsibilities	No changes in food preparation since diagnosis Receiving help and support Maintaining preparation activities Problems sharing responsibilities

with dementia, who had the capacity to understand and be informed of the study, were also sent an information sheet and a form to consent to their caregiver being interviewed. Capacity to give consent was ascertained by their caregiver. If the person with dementia lacked the capacity to give consent, the informal caregiver acted in his or her best interest. The interview was not conducted until written informed consent had been obtained from each participant and, if appropriate, from the person with dementia. Ethical approval was granted by the University of Surrey Ethics Committee.

Interview

All interviews were semistructured. This gave participants the opportunity to describe their experiences and feelings in caring for a person with dementia and their food-related processes. The interview was divided into two sections: (1) demographics: describing a caregiver's relationship with care recipient, type of dementia, stage of dementia, and decline in abilities of activities of daily living; (2) caregivers' perspectives on care recipients' decline in their ability to manage each food processes (shopping, preparing, and eating), from point of diagnosis to present time.

Data Analysis

All 20 transcripts were analyzed using Luborsky and colleagues' technique for thematic analysis.²³ This thematic analysis technique is considered particularly appropriate for the analysis of qualitative interview data obtained from in-depth semistructured interviews. Thematic analysis is a representation of a participant's opinion, which describes their beliefs, perceptions, and direct experience.²⁴ Thematic analysis is a flexible tool, and with it, one can gain a rich, detailed, and complex set of data.²⁴ Therefore, the themes identified were driven by an analytic interest in shopping, food preparation and eating, and ways the participants adapt to changes and experience stress. All 20 transcripts were read through once for familiarity. Second readings of all transcripts were completed to identify preliminary topics and main themes. The preliminary topics and main themes were captured. All preliminary topics and overall main themes are summarized in Tables 2 to 4.

Findings

Within the domain of food shopping, food preparation, and eating, a preliminary set of 38 topics were identified, and these

Table 4. Caregivers' Perception of Eating.

Type of food-related processes	Main themes	Preliminary topics
Eating	A slower decline with the ability to eat	The last process to decline Difficulties eating in later stages of dementia
	Diet	Maintaining the same diet Change in preferences for food
	Appetite and weight changes	A significant amount of weight loss Deciding what to eat first Portion sizes Weight loss solutions
	Mealtime behavior	Difficulties using cutlery Food and drink to mouth Implementing strategies Difficulties knowing what to eat
	Eating out	Difficulties chosen from menu Restaurant sized portions Enjoying everyday environment

were subsequently modified into 13 main themes as presented in Tables 2 to 4.

Food Shopping

Rapid Decline in Food Shopping. The ability of the person with dementia to procure food declined rapidly. They increasingly found traveling to the shops difficult, as they would forget directions and managing finances and selecting food became too demanding. Food shopping was generally the first food-related process that deteriorated. Caregivers had to manage all aspects of shopping, including finances, travel, and selecting and paying for food. "I have to buy the stuff now but we go together as it's a joint effort. I look after the money and make sure we buy food" (Henry).

Care recipients had great difficulty deciding what to buy, "I had to take her round and explain everything to her. She would ask questions, not in an aggressive way but she would ask questions as she can't analyse anything" (Andrew).

Caregivers' Difficulties Shopping for Food. Care recipients' behaviors included unsteady on their feet, tended to wander off, questioned why items were selected, and were often demanding during shopping. These incidents increased as dementia progressed and caregivers adapted, "She is able to come shopping with me without the aid of the trolley. She is a bit of a nuisance now, as she does not stop walking. I have to direct her into one of the aisles and put the brake on the trolley. Otherwise, she will be flying round the supermarket with it!" (Danny). Caregivers excluded people with dementia from shopping if it was quicker and less stressful to shop alone, "I just decided that it would be easier to shop on my own. It would take longer if I went with Audrey, as she puts unnecessary items in the trolley and shopping became stressful" (Juliet). Due to the overall increase in responsibility and stress, as dementia progressed, shopping alone was considered a necessary adaptation to reduce stress. Some

participants discussed how they would receive help, from family or friends, such as with driving to the shops and so on.

Purchasing Food. Participants described how they maintained a similar diet for themselves and the recipient as before the person had dementia. They coped by keeping to what they knew before being a carer (eg, buying food that they always bought) and were reassured by recognizing the items going into the basket. For the majority of the male carers, food shopping was a new experience. Men adapted by buying what they knew had been bought prior to the diagnosis or buying ready meals, "Within the last year but more so now we buy these readymade meals. I don't think you can beat these readymade meals. Another thing is we go to Marks and Spencer, not often, as it is quite expensive. We buy fish from them, cod mash potatoes with vegetables, they are £2.99 each, ready meals from M&S" (Henry).

A Day Out. Some participants described food shopping as a positive experience, as an opportunity to get outside with the care recipient and connect with them. For example, a few participants mentioned that they would have a coffee together on shopping trips. Shopping was viewed as an outing and as a change from the home routine, "It actually makes a bit of a trip out for both of us. That's the way we arrange most of our food shopping, through supermarkets" (Duncan).

Food Preparation

A Gradual Decline in Food Preparation. Overall, this section describes care recipients as having a slightly slower progression of decline in food preparation compared with food procurement. Informal caregivers adapted to food preparation as dementia progressed. As the illness progressed, the care recipient would prepare meals less frequently or forget how to prepare a meal. The participants commonly described the decline in the care

recipient and their ability to prepare food through the example of making a cup of tea. They described this step-by-step task and how the care recipient would slowly be unable to complete it, "My mother hasn't made tea even before going into hospital. I believe that with Alzheimer's, making tea is too complicated, like putting a bit of water and filling it up with milk or putting the water and milk with no tea bag. My mother used to do that sort of thing" (Danny).

Safety in the Kitchen. As dementia progressed, the kitchen became an increasingly hazardous area for care recipients. Participants mentioned that dangerous incidents would occur, such as the recipient trying to boil water by putting the plastic kettle on the hob or burning themselves on the stove. As a result, informal caregivers took precautions to reduce dangerous incidents by removing sharp knives and electrical appliances in the kitchen, particularly if the person with dementia lived alone. Some informal caregivers would not allow care recipients into the kitchen because of the dangers of kitchen appliances. These strategies were seen as extreme measures but the only way accidents could be prevented.

Adapting to a Food Preparation Role. For some caregivers, particularly for male caregivers, preparing food was a new experience. Although they adapted to a new role out of necessity, they described this as an educational and enjoyable process. These participants developed and gained confidence in food preparation, as they would actively build their skills, for example, by learning new recipes from cookery books. They were able to develop skills that they felt provided them with the security that the person with dementia would remain on a healthy diet, "I do all the preparation and cooking at home now. It just dawned on me that I needed to do the cooking, so I went on a cookery course and from there it just progressed" (Robert). Other caregivers, who had previous experience in food preparation, were mainly female caregivers. These participants described how they prepared food for the person with dementia even before diagnosis, and therefore it was not a concern for them even when decision making for the person with dementia had declined, "I don't have to ask him now what to cook. I can just cook it. There's no more trying to think of what he wants to eat. I've learnt to make the decision" (Rita).

Sharing Responsibility. Some participants found it important for care recipients to assist them in the food preparation procedure, such as laying the table. However, in some instances the person with dementia had no capacity to help, making it more difficult for the caregiver. This added to caregivers' responsibility and increased stress, "My husband could lay a tray for a meal, but now he's got to a point whereby he says to me, 'Where's the tray?' Even if he wants a glass of water, he'll wander around the bungalow and say, 'Where do I get water from?' 'The tap is in the kitchen!' 'Tap?' So everything is repetitive." (Tammy). Also, not all people with dementia would be able to contribute even if they wanted to, creating a stressful situation for both themselves and the caregivers: "She gets very annoyed with

me because I try to help and say, "set the table and you need your knife and fork" and she gets very annoyed and says, "I know what I want!" she doesn't quite know where things are. I find the saucer in the fridge and the cheese among the cups." (Andrew).

Eating

A Slower Decline in Ability to Eat. Eating was described as the last food-related process to decline. The majority of people with dementia could feed themselves and had no problem eating. Problems would occur mostly at the final stages of dementia.

Diet. The majority of the participants maintained the same diet as before diagnosis. Although people with dementia showed no preference for any food in particular, it was reassuring and built confidence in caregivers to know that care recipients were eating a meal they used to enjoy prior to having dementia. This also emphasizes the importance caregivers gave to maintaining a routine that they had before taking on the carer role and, therefore, achieving a sense of normality in their daily lives. Many people with dementia changed food preferences; in particular, participants described the recipients as wanting to eat sweet foods (eg, chocolate). Their eating habits changed, they refused to eat, or were disinterested in eating certain foods, such as carbohydrates, vegetables, and fruits. This was worrying the participants, as they felt they had little control over providing a healthy diet: "He says he's going off the taste! And about bread, it seems to be the carbohydrates. Before he would eat any amount of bread and potatoes and now he doesn't want so much" (Tammy).

Appetite and Weight Change. Participants described people with dementia as expressing little interest in eating and showed no sign of being hungry. The care recipients would not eat as much as they used to, rejecting food, consuming smaller portions, or eating slowly. Deciding what to eat became increasingly difficult, particularly if they had a variety of foods to choose from on their plate. Participants adapted new techniques, such as providing the care recipient with smaller plate portions than previously, although snacks were offered between meals to keep up food intake. As a result, participants would be concerned with the reduced appetite and weight deterioration of the care recipient. Over time, the person with dementia would eat less and gradually lose a substantial amount of weight. In some cases, the participants were able to develop good coping strategies to help the care recipient gain weight by dedicating time to prompt and encouraging care recipients to eat.

Mealtime Behavior. The way in which people with dementia ate declined progressively, especially with regard to difficulties in using cutlery appropriately, in judging how close to put food to their mouth, or in holding things upright. The difficult behaviors that care recipients have during mealtimes lead to increased stress for the participants. However, participants described being able to develop effective coping strategies, making mealtimes easier, more enjoyable, and less stressful for both

parties. These strategies included cutting food for the person with dementia to make it easier to pick up food with their fork, having finger foods and, where possible, avoiding “sloppy” foods such as soups.

Eating Out. Eating out was described as a problematic yet enjoyable experience. Participants described the need to select from the menu, as people with dementia would become confused when expected to make a choice. Other issues with eating out were eating slowly, being overwhelmed by big portions, or offering food to others. Overall, for most caregivers, eating out was an opportunity to maintain an enjoyable activity, which was something they did before dementia was diagnosed.

Discussion

From the narratives, it was found that caregivers described a set pattern of decline in the way dementia progresses and the effect this has on the ability of a person with dementia to manage their food-related processes. Shopping was described as the first ability to decline, followed by preparation and finally eating. The participants described various ways they adapted to these changes, difficulties they faced, and routines that were adjusted in order to maintain a sense of normality. Although they talked about stressful events, there was also a sense of enjoyment around the food area. In addition, male and female caregiver differences were highlighted, for example, female caregivers found it difficult to manage all the food shopping tasks on their own (eg, driving and handling money). This supports a recent Swedish study, where mostly the females caring for a spouse with dementia found it difficult to transition from shopping as a team to managing alone.²⁰ The present study found that food roles, such as cooking and preparing a meal, were a unique and in most cases achievable challenge, particularly for male caregivers. Male caregivers are not necessarily familiar or skilled in food preparation, which was also mentioned in the Swedish study.²⁰ Those participants who bought ready meals were developing their coping skills by selecting items that were less complicated and, therefore, less stressful. This enabled them to transition into a new role and a “new norm.”²¹ As in another recent study of the male spouse caregiver, the latter study indicates that all informal caregivers, regardless of gender, slowly adapt to their new food roles as they find ways of coping with dementia progression.¹⁹ Some areas that the caregivers spoke of were contrary to the previous research, for example, the decision not to take the care recipient for shopping conflicts with the theory of working and connecting together¹⁹ and may be isolating and disempowering for the person with dementia.¹⁴ In the long term, the decision to manage food shopping on their own may be more effective for both parties. Many studies show that people who have supportive social relationships have better physical health.¹⁴ Physical health was not measured in this study, but some participants mentioned having family or friends helping them with food care and described this area of care as less stressful than those who manage completely on their own.

The majority of people with dementia could feed themselves and had no problem eating until the final stages of dementia;

therefore, the ability to eat was described as the last food-related process to decline. This supports previous theories that eating difficulties increase more in the later stages of dementia, increasing care recipients’ malnutrition and caregivers’ stress.⁴ Most of the participants were able to manage the challenge of the recipients’ weight loss and inability to consume food. This is encouraging, as the majority did not have much outside help, including social support from friends or family. In some cases, caregivers were able to stabilize and even increase a person’s weight through dedicating their time to help them eat. This supports theories that giving care recipients the right attention and accommodating their needs can limit their physical decline.¹⁹ In addition, maintaining a connection with the person having dementia through mealtime activities can result in a positive outcome in weight maintenance and, in turn, reduce the burden and worry for the caregiver.^{16,17} Furthermore, having the ability to adapt to changes successfully, through connecting and maintaining the relationship with the recipient, reduces stress and results in positive outcomes.^{19,20}

Practical Implications

This study demonstrates, from the perspectives of informal caregivers, how food-related processes decline as dementia progresses. This gives a unique account of changes in all 3 food processes and how caregivers manage and cope with little informal or formal support or information. This study provides information and strategies for managing food care. During dementia progression, decision making and coping skills for food-related processes may be aided by social support and education. With appropriate management skills and information, positive transitions in food-related care may be achieved, increasing satisfaction with food-related life for both care recipient and carer.

Conclusion

This study is the first to explore all 3 food-related processes from informal caregivers’ perspectives. Their narratives suggested that there is a pattern in decline in the abilities of the care recipients to manage their food role. People with dementia, with mild to severe stages, were described first as losing their ability to shop, then preparing food was affected, and then mealtimes. The participants adapted to this decline by changing their roles and developing new coping skills. Both caregivers and care recipients experienced stress and frustration due to dementia progression and changes in their food routine; however, enjoyment and sharing food-related processes were also discussed. As most participants managed on their own, without any additional support or information specifically on dementia and food, a further study could focus on the importance of educating caregivers about food care.

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