Title: Involving Caregivers of People with Dementia to Validate Booklets on Food-related *Activities: A Qualitative Think-Aloud Study.*

Authors:

1) *Iliatha Papachristou, Department of Applied Health Research, University College of London, UK
2) Gary Hickeys, Kingston University and St George's University of London
3) Steve Iliffe, Department of Primary Care and Population Health, University College London, UK.

*Author Correspondence

Dr Iliatha Papachristou

Department of Applied Health Research, UCL
1-19 Torrington Place, London WC1E 7HB
Telephone: 020 3108 3235
Extension: 53235
e-mail: i.papachristou@ucl.ac.uk

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Dr Iliatha Papachristou is a research associate at the Department of Applied Health Research, at the University College of London. Iliatha is a chartered health psychologist with a PhD in dementia, food-related management. She has worked in mental health with the South London and Maudsley Hospital for several years, focusing much of her work with older adults. She is currently working on qualitative methodological elements of health applied research. This includes areas such as, stroke care and ear, nose and throat.

Dr Gary Hickey is the Public and Patient Involvement Lead for Research and Education, at the Centre for Public Engagement in the Faculty of Health, Social Care and Education at Kingston University and St George's, University of London. Gary has gained over a decade of experience working in health and social care research, including public and patient involvement, and over a decade's experience working in research and project management, both in the UK and overseas, on ethics and corruption.

Prof. Steve Iliffe was a general practitioner in inner London for 30 years, and was the first Professor of Primary Care for Older People in the UK. His research interests include mental health in later life, and he was the chief investigator on the Evidence-based Interventions in Dementia programme (EVIDEM), funded by the National Institute of Health Research (2007–13). He was also associate director of the national Dementias and Neurodegenerative Diseases Research Network (DENDRON) for 2006 to 2015.

Abstract

This study is the first to explore informal dementia caregivers' perceptions and outlook on written materials about all food-related processes; shopping, food preparation and eating. The aim of the study was **to develop and** evaluate the content, format and usefulness of two separate booklets (one newly developed and one existing) on food-related processes. Twenty dementia caregivers were provided with one of the two booklets and a Think-Aloud method was used to gather information about their views on the booklets. The findings indicated that incorporating all three food processes in a new booklet could be beneficial for the participant. Shopping, purchasing food, driving and dangers in the kitchen were addressed only in the developed booklet and participants regarded them as important and useful areas to address. Therefore, this study has shown that tailored information may enhance caregivers' confidence and support them in making decisions to help them adapt to food-related changes.

Keywords: dementia, informal care-giving, food-related processes, written information, qualitative methodology.

Introduction

People with dementia become increasingly dependent on others to assist them with everyday activities (Sami & Manthorpe, 2013). Previous research has highlighted the impact of cognitive decline and behavioral difficulties on everyday activities of a person with dementia and the consequences this has on their caregiver (Lopez, 2003; Papastavroue et al., 2007; Pinquart & Sorenson, 2007; Prince, Albanese, Guerchet, & Prina 2014). Dementia affects food-related processes, meaning food shopping, food preparation and eating (Papachristou, Giatras & Ussher, 2013). The inability to maintain a healthy diet and to eat well causes severe health risks, such as weight loss and malnutrition. This area of care can create stress and anxiety for both people with dementia and their caregivers (Holm & Söderhamn, 2003; Bilotta et al., 2010; Papachristou, Giatras & Ussher 2013). In particular, apathy and depression are common causes and source of caregiver stress (Vitaliano, Zhang, & Scanlan, 2003; Livingston & Frankish, 2015).

There have been studies that examined progressive decline in function between dementia caregivers and their care-recipients and how this affected basic activities of daily living (BADL) and instrumental activities of daily living (IADL) (Small, Geldart and Gutman (2000), Østbye et al. (1999), Ory and colleagues (1999)). Overall the majority of these studies found a high percentage of dependence on dementia caregivers in grocery shopping, meal preparation, housework, transportation, finances and eating. These studies have demonstrated that one of the main ADL that impacts greatly the person with dementia and the informal caregiver is food-related processes.

Eating habits of people with dementia may change as the condition progresses. For example, people with dementia may prefer to eat sweets rather than nutritious food or may refuse to eat altogether (Riviere, Gilliette-Guyonnet, & Voisin, 2001; Ikeda, 2002). Weight loss may happen due to eating issues, such as difficulties using utensils or forgetting to eat (Morris, Hope & Fairburn, 1989). Cognitive decline results in a decrease of motivation, appetite and food-intake and leads to malnutrition and frailty (Navratilova et al., 2007). Furthermore, weight loss and malnutrition have been associated with institutionalisation and increased mortality (Andrieu et al., 2001). In turn, these developments affect the caregiver who has to cope with these changes.

According to Keller (1995) the nutritional status of a person with dementia can be improved with the appropriate interventions. However, limited interventions have been developed and are mostly based in institutions with formal caregivers (Watson & Green, 2006). Even fewer interventions have focused on informal caregivers and people with dementia living at home (Francis, Taylor & Strickland, 2004; Isaia, et al., 2011; Manthorpe & Watson, 2003). Studies that have included informal caregivers and investigated food-related processes, focused mainly on exploring spouse relationships and gender differences (Atta-Konadu, et al. 2011; Fjellstrom et al. 2010). These studies examined the whole food-related process of care to discover changes in adapting to dementia progression and abilities to manage food shopping, preparation of food and the eating of food. Fjellstrom et al. (2010) investigated the transitional experience of a caregiver taking on a new role that is best suited to them and the person with dementia while at the same time maintaining the best quality of care in regards to food-related processes.

A qualitative study by Papachristou et al. (2013) explored the perspectives of 20 family dementia caregivers on food-related processes of people with dementia. The findings showed that there was a pattern of decline with regard to daily functioning in food-related processes for the people with dementia. Food shopping was the first ability to decline, followed by food preparation and finally on the ability to eat. Caregivers had to adapt to this decline in abilities and they described this adaptation as stressful yet satisfying as food-related processes were seen as an important social time. In addition, these caregivers regarded food-related processes as an important area in daily living. However, respondents also emphasised that there is little access to food-related information or support services, leading to feelings of isolation (Papachristou et al., 2013; Papachristou et al. 2015).

One means of providing information on food-related processes to caregivers is via printed materials. Hard copy print resources have been identified as a preferred method to deliver information on dementia and management of food-related processes to informal caregivers (Keller, et al., 2008). Providing food-related booklets to dementia caregivers can be economical, beneficial and effective in helping them cope with and adapt to changes in their lives as long as they are appropriately written for lay readers (Done et al., 2001).

An audit of written material on dementia care and food-related processes identified 13 publications (Papachristou, 2014). A thematic analysis of these materials identified five main themes: changes in appetite, changes in food preparation, methods of eating, eating out and dental care and swallowing difficulties. Only one booklet, the Alzheimer Society's *'Food for Thought'*, covered all five themes. The audit did not include food-related process of shopping and a limited amount of information was provided on the process of food preparation. This emphasizes the gap of information available to caregivers; that is food-related process of shopping and preparation information. This supports previous findings by Papachristou et al. (2013) and therefore indicated a need for further investigation.

The research reported upon here sought to assess the content, format and usefulness of two booklets which covered the food-related processes of shopping, food preparation and eating. The intention is to use the findings to inform the development of a booklet which could be used to assist informal caregivers. A Think-Aloud methodology was used to collect data from informal caregivers. This approach is widely used in psychology and generally used for verbalising what a person is thinking while attempting to solve a problem (Ericsson and Simon, 1993). Think-Aloud involves respondents providing instant feedback and reflection on the information provided to them (in this case written material), enabling an evaluation of their thought process (Carr, 1998). Think-Aloud has been previously used with health community dwelling seniors (Jobe & Mingay 2003) and with older adults to get views on a website focussing on falls prevention.

Aim: To develop and assess the content, format and usefulness of two booklets (one newly developed and one existing) from the perspectives of caregivers of people with dementia.

Method

Study Design

The study involved two phases. Phase 1 was the development of a booklet (booklet 2) which incorporated the main themes identified from the audit by Papachristou (2014) and key findings found from the Papachristou et al., (2013) study. Phase 2 was a qualitative study that used a Think-Aloud method to compare two booklets; booklet 1(existing booklet) and booklet 2 (newly developed booklet).

Booklet 1, titled *Food for Thought*, was produced and distributed by the Alzheimer's Society (a UK dementia charity) and is currently accessible for informal caregivers of people with dementia with a total length of 18 pages. This booklet was selected for this study because it covers all five main areas identified from a previous audit study of booklets on dementia care and food related processes (Papachristou, 2014): 1) changes in appetite, 2) changes in food preparation, 3) methods of eating, 4) eating out and 5) dental care and swallowing difficulties. It is worth noting that the booklet does not cover the food-related process of shopping and has limited information of the process of food preparation, such as the decline in a person with dementia's ability to cook, safety in the kitchen and caregivers' adapting to these changes.

Phase 1 - *The development of booklet 2*

Booklet 2 was developed using findings from a previous study (Papachristou et al 2013) which identified, from the perspective of caregivers, key food-related issues. The information in booklet 2 contained information on all three food-related processes (shopping, preparation and eating). In addition, quotes of informal caregivers were taken from the results in the Papachristou et al (2013) study and were used in booklet 2 to provide a personal account of how caregivers experience specific situations in dementia progression and manage with food-related processes. The total length of this booklet was 35 pages. The booklet was evaluated by an expert panel for content validity. This panel consisted of a nutritionist, health psychologist and a dementia caregiver representative. The booklet was revised two times before consensus was reached on the content. Table 1 provides a comparison of the information contained in the two booklets.

[INSERT TABLE 1 HERE]

Phase 2- *Evaluating booklets 1 and 2*

Two groups of dementia caregivers were each given a different booklet and a Think-Aloud method was used to gather information about their views on the booklets. Think-Aloud involves instant feedback and reflection on the written information provided to participants, enabling an evaluation of their thought process (Carr, 1998). A participant reading the information is required to *'stop periodically, reflect on how text is being processed and understood and relate orally what reading strategies are being employed'* (Baumann, et al., 1993, p.190). The approach gives participants the opportunity to voice their opinions on whether they agree or disagree with the statements made, comment on the examples given and the helpfulness of the advice.

The advantages of Think-Aloud are that it enables the researcher to collect the data in 'real time', capturing complex processes in learning, thinking or problem-solving. The data that is captured is being 'simultaneously lived by the participant and witnessed by the researcher' (Koro-Ljungberg et al., 2012, p. 268), drawing vivid and immediate descriptive data from the participant which is 'unfiltered' and unprocessed.

The study was reviewed and accepted by University of Surrey Ethics Committee REC reference EC/2011/70/FAHS in July 2011.

Participants and recruitment

A total of 20 participants were recruited. The eligibility criteria was that participants had to be an informal caregiver (i.e. family, friends) of people with dementia and involved in their food-related processes. The caregiver would be living with the care-recipient or caring for them while the care-recipient lived resided in their own home. The majority of the caregivers provided care full time and had an average age of 70. Furthermore, the majority of participants were husbands caring for their spouses with a moderate stage of dementia (Table 2a and 2b). In addition, none of the caregivers had previously received any written information in this area. Participants were recruited through local community centres, libraries and a local chemist, using posters and leaflets. Caregivers who showed interest in the study were provided with a letter inviting them for a one to one Think-Aloud session along with a consent form which was signed before the session began.

[INSERT TABLE 2a and 2b HERE]

Procedure

One group of ten participants were provided with booklet 1 and the other group of ten the newly written booklet (booklet 2). The participants were randomly allocated to one of the two groups. The Think-Aloud sessions were conducted at the participants' homes at a time convenient for them. The researcher was an experienced qualitative researcher and had previously practiced the Think-Aloud task with a colleague before recruiting participants. Each participant was briefed by the researcher on what a Think-Aloud process entailed and they were then asked to reflect by talking aloud on any thoughts that came into their mind while reading the booklet. Very general verbal instructions were given, simply to 'Think-Aloud' and to verbalise 'everything that passes through your head' (Banning, 2008). However, questions and prompts (for example, "Do you have any thoughts about that?") were used where necessary in order to focus the discussion. Each participant was asked to provide the researcher with a summary at the end of the Think-Aloud session, answering the questions "*What are your thoughts on the layout? What are your thoughts on the length of booklet? Do you have any thoughts on the quotes?"*. The length of the Think-Aloud interview varied from 40 to 60 minutes. All interviews were audio recorded and transcribed verbatim by the researcher.

Data Analysis

The transcripts from the interviews were organised into two separate data sets using a Microsoft Excel spreadsheet; one set included the group of participants who had read booklet 1 and the other set included those participants who read booklet 2. The two data sets were manually coded separately in the first instance. The researcher used an inductive approach to code and analyse each data set (Braun & Clark, 2006). The data was coded and then the codes grouped into themes. The analysis was driven by assessing the content, format and usefulness. The two sets of coding and themes were then compared for commonalities and differences between the groups in terms of content, format and usefulness. A second researcher then checked the codes and themes against the data to ensure credibility and trustworthiness (Patton, 2002). An iterative approach was used as the two researchers discussed any variations in the coding and gradually came to a consensus.

Findings

Table 3 shows the themes that were identified from the thematic analysis. Nine of the themes were common to both booklet 1 and 2. The theme dental and hygiene care was identified only from analysis of responses from the participants who read booklet 1 and five themes were identified only from analysis of responses from participants who read booklet 2. The findings below reflect respondents' views on the booklets themselves as well as how the booklets relate to their own experiences. The findings are reported in terms of commonalties between the two data sets, followed by differences between the two data sets. Finally, the themes have been reported in terms of how they fit with the aims of the study which was to get perspectives of caregivers on the content, format and usefulness of the booklets.

[INSERT TABLE 3 HERE]

Commonalities between the Booklets

Content

Potential dangers in the kitchen

Participants said that their own experiences resonated with the sections in the booklets describing care-recipients hurting themselves with kitchen appliances. They described managing potentially hazardous situations by forming strategies to maintain a safe environment: *"She filled up the electric kettle and put it on the hob. I found her in a terrible state. So after that I used to switch off the electric cooker so she could not do any damage to herself." (Andy- booklet 1)*

Weight Maintenance

Participants were concerned about the weight loss and thought this area was particularly important to emphasise. They commented that the tips recommended for assisting in weight maintenance were good: "*The last section is on eating. My friend lost so much weight she needed cream with her meals and shakes. Nevertheless, gradually she started eating. That worries me if they are not eating. Rice pudding and porridge is good if they are not eating right and putting cream in porridge. So this book give good advice about this" (Gina – booklet 2).*

Participants discussed how they encouraged and prompted care-recipients to eat by choosing food that was familiar, presenting smaller portions and/or cutting food to make coordination easier.

Unable to make decisions with food choices

The participants agreed with the information in the booklets that care-recipients would have difficulties making a choice of which meal to have from a menu. The caregivers would decide on their behalf or alternatively would provide two meal options so as not to overwhelm the person with dementia: *"Choosing food if we were out, I would give him a choice of two dishes, fish and chips or shepherd's pie. There is no good giving him a menu he has no clue. And because I know what he likes, I just choose it." (Mary – booklet 2)*

Appetite change

A frequently mentioned challenge was care-recipients not having an appetite; however, once food was presented the person with dementia would often eat it: "*With the food, sometimes she will say she is not hungry, so I say 'that is ok you can eat it later and she will leave it there'. Then I walk out of the room and come back and she has eaten it. There is no discussion." (Maggie – booklet 1)*

Mostly the participants maintained the same diet as before diagnosis. Many agreed though that there were changes in care-recipients' food preferences, particularly a liking for sweet foods: *"I realized they can eat sweet things all day long but not for their main meal. It must be difficult to manage refusing to eat vegetables and such and instead opt for an apple pie" (Gina – booklet 2)*.

Helpful advice on fluid intake

Participants noted that the booklets mentioned drinking eight cups of fluid a day and expressed concern that eight cups may be difficult to achieve. This was because many of those with later stage of dementia suffer from incontinence, and therefore need to limit their fluid intake. Some participants found tips such as putting a glass of water by the side of the person with dementia useful: *"Eight cups of fluid a day, well I don't think Peter gets that. That is quite good using a clear glass, that is quite interesting, so you can see what is in it. I must do that about drinking, making sure peter has a glass of water by the side of him, as I am concerned that he is not drinking enough" (Abigail – booklet 2).*

Tips on managing eating

The participants agreed that it was important to give tips on how to manage mealtimes and eating behavior such as, providing smaller plate portions.

Tips when eating out

A few participants did not feel that eating out was a 'welcome change to eating at home' as they would feel embarrassed about the care-recipient's behavior, such as wandering around the restaurant. Others talked about how the care-recipient would not feel comfortable to go out, especially when surrounded by many people: "*If there were too many people she would not like that. She felt out of her depth. We went with my granddaughter for her 18th birthday. I think there were 14 of us. I had to bring* *her home, as she felt completely overwhelmed. We used to eat out with my sister and as it was just the three of us she was fine." (Ted – booklet 2)*

Participants agreed with the advice in the booklets that it is useful to explain to others about the care-recipient's condition if they were out, for example, in a restaurant. *"Eating out, I'm with her all the time but I generally say to people what is wrong with her. She'll try and talk to them so I'll try and explain." (Fred – booklet 2)*

Format

Good presentation and personalized quotations

Participants discussed their first impressions of the booklets and felt that it was important to have a clear and well-presented layout. Both booklets were viewed as having a good layout; participants liked the colours and pictures. It was comforting for the participant to read quotes from other caregivers. The quotes made them feel that they were not alone in experiencing food-related difficulties. Participants felt it was encouraging to see that others had experienced similar situations to their own and that the behavior of other care-recipients was not so different from their loved ones: *"It is good to know that things that she does are not that unusual and it is put in writing. I like the booklet, its good." (Maggie –booklet 1)*

Usefulness of the booklets

Caregivers reported that the booklets provided helpful guidelines. Participants thought the booklets were particularly useful for those caring with early stage dementia. However, a minority of participants caring for those with mild to moderate stages of dementia did find some examples and advice daunting as they had not experienced such late stage issues. For example, in both booklets it was suggested that flowery table cloths should be avoided as people with dementia may try to water them. *"It is helpful advice but scary as we are not quite at this stage yet. It is hard to read as I do not want to get to that stage." (Chris – booklet 2)*

Differences between the booklets

Booklet 1 Only

Content

Difficulties managing dental and hygiene care

The majority of the caregivers agreed with the information in the booklet that dental care and hygiene are difficult tasks to manage. Caregivers said they would have to prompt the care-recipient to brush their teeth every evening, which could result in the person with dementia becoming aggressive: *"Regular cleaning of teeth is an absolute nightmare. He no longer uses an electric toothbrush. I put the paste on the brush and he says why? But it's a nightmare. And if he doesn't want to then a couple of times he can turn physically aggressive.*" *(Jean – booklet 1)*

Booklet 2 Only

Content

Not purchasing or overstocking food items

Participants related to the information in the booklet, suggesting that care-recipients may not recognise the need to go and purchase food or might over-stock on items previously purchased. Participants expressed concern for the care-recipient and described the care-recipient as being confused and upset: *"This is for the early signs of dementia, yes that could be quite something if they are over purchasing food. They might say, I need this and I need that, but then you realize they have tons of it!" (Gina – booklet 2)*

Enjoyable day out or shopping alone

Positive and negative aspects of food shopping were discussed. Most participants regarded food shopping as a useful activity, i.e. providing a trip out. Others disagreed as they would encounter difficulties with the person with dementia and therefore would prefer to shop alone: "*I don't agree that it makes a bit out of a trip for both of us, as it's a nightmare making sure he doesn't nick anything and also slows things down by about four times."* (Neil – booklet 2)

Maintaining their usual shopping routine

Participants mentioned that it was a relief to read that care-recipients depicted in the booklet behave similarly to the people for whom the participants care for and that to a certain extent at least, they were doing the right and 'normal' thing by maintaining a routine. For example, caregivers agreed with the advice in the booklet to purchase the same items as before diagnosis: *“This is true that many caregivers maintain a similar diet as before and select the same food when shopping. You do, you stick to what works!” (Abigail – booklet 2)*

Caregiver taking on the driving role

Participants agreed with the information in the booklet that care-recipients stopped driving quite early after diagnosis. Caregivers’ reflected on driving becoming an additional responsibility as this meant driving to the shops for grocery shopping: *“Strangely enough Peter made his own mind up and that was it. So many other husbands put up a fight but I guess it is because their wives do not drive. I always drove.” (Mary – booklet 2)*

Usefulness of written material

Participants who looked at booklet 2 suggested distributing it to organisations such as the Memory Clinic, and the Alzheimer’s Society. Most participants who read booklet 2 requested a copy as he or she felt it was useful and had a rich amount of information: “*I like the idea of the problem and then the possible solution. That reads well I think. Yes that is good I like it. It is full and it is good. You should put this out into the Alzheimer’s Society.” (Chris – booklet 2)*

The participants felt that the booklet 2 gave a wealth of detail for food-related management and was specifically directed towards informal caregivers: *“I suppose life revolves around food. It’s curious that your book is on food, shopping, preparation and eating…. I think you have put your fingers on all the basics that are a concern…. There are interesting points that you have brought up here. And it makes you recognise just how much we are dealing with.” (Ian – booklet 2)*.

Discussion

The research used a Think-Aloud approach to evaluate two booklets on how to cope with the impact of dementia progression on food-related processes. One booklet was already in use and covered the themes of 1) changes in appetite, 2) changes in food preparation, 3) methods of eating, 4) eating out and 5) dental care and swallowing difficulties. The second booklet encompassed these themes but sought to include all three food-related processes (shopping for, preparing and eating food) by adding information on shopping for and preparing food. In addition, this second booklet included quotes from caregivers from a previous piece of research. The study has indicated the potential support this specialized material can provide for caregivers of people with dementia. Furthermore, it provides findings which can inform the development of a future booklet.

Caregivers liked the tips provided in both booklets, for example, those tips that would help the care-recipients to gain weight. Being provided with such information at an early stage was perceived as beneficial. It was noted however, that providing food-related information on later stages of dementia could raise concerns for caregivers caring for people with early stage dementia caregivers as they became aware of future behaviors and challenges. Clearly, sensitivity must be exercised when developing any future booklet.

The participants reading booklet 1 were the only respondents who commented on dental and hygiene care and the caregivers agreed it was a difficult task for the person with dementia to perform. Shopping for food was covered only in booklet 2 and respondents commented on the issues of recipients of care overstocking food items and the importance of caregivers maintaining their usual shopping routine. The participants who commented on booklet 2 found it insightful and a relief that maintaining the same routine in terms of purchasing the same items was advocated. Some caregivers agreed with the suggestion in the booklet that shopping was a day out for the caregiver and care-recipient while others disagreed, preferring to shop on their own due to behavioral difficulties of the person with dementia. This would need to be reflected in any future booklet.

The main eating difficulties reported from previous research were appetite, loss of ability to recognise food, difficulty eating and swallowing (Keller, et al.,2008; Riviere, Gilliette-Guyonnet, & Voisin, 2001).The findings from the Think-Aloud analysis in this study indicates that eating is not the only concern for caregivers in dementia progression but food shopping and preparation are also key issues. For example, shopping, purchasing food, taking on the driving role and dangers in the kitchen were addressed only in booklet 2 and participants regarded them as important issues. Therefore, incorporating all three food processes – shopping, food preparation and eating - in a new booklet could be potentially beneficial for the participant.

The participants, regardless of which booklet they read, felt that the information and format of the written material was beneficial and informative. They were not overwhelmed by the amount of content in the booklet; they liked the pictures and colourful flow. Caregivers who read booklet 2 thought it was important to include quotes from previous caregivers as this helped them engage with the booklet and showed that others have also experienced a similar situation to them.

The participants recognised the importance of receiving specialised food-related information and advice on dementia and spoke of how he or she could develop their coping-skills, such as leaving a glass of water at the recipient's side table to encourage them to drink more water. In addition, participants recognised the benefits of the material and the effect it can have as changes occur within their food role. Those who read booklet 2 suggested that it should be distributed to Alzheimer's organisations for future caregivers to read.

Previous research has recognised that health information that is tailored to meet the unique needs and interests of specific individuals is more effective in behavior change than generic information (Bull et al., 2001; Higgins & Barkley, 2004). The provision of useful food-related information for all stages of dementia can lead to improvements in food habits (Riviere et al., 2001), potentially reducing burden and increasing enjoyment in this area of care.

Findings from this research echo that of previous work which indicates that caregivers would welcome information on food-related processes early in their caregiving role (Chang & Roberts, 2008) and that food-related difficulties are experienced with people with mild and mid stage of dementia as well as those with sever dementia (Morris & Volicer, 2001; Njegovan et al., 2001; Holm & Söderhamn, 2001; Gillick, 2002; Papachristou et al., 2013). This information has the potential to prepare caregivers to take on an active role in decision-making.

Methodology evaluation

This is a small qualitative study focusing on caregivers' initial thoughts and perceptions on information contained in two booklets. Think-Aloud is a quick and cost efficient means of exposing the designers of a product to feedback from those who will actually be using it. It allows participants to provide direct feedback on their immediate thoughts on a product (in this case booklets). In addition, an opportunity to raise and comment on issues that are important to them rather than just respond to what the researcher may think is important. A limitation is that the participants do not have much time, when compared to other methods such as an interview or questionnaire, to digest and reflect on the information provided to them. Indeed, it is likely that not all that they thought is discussed (Ericsson & Simon, 1993). It follows that the Think-Aloud approach generates immediate thoughts and perceptions rather than a more in-depth consideration. Furthermore, although the approach relies less on researcher prompts than other techniques, such as interviews, inevitably prompts were still required as participants tend to want to think about their responses and give a 'smart' answer rather than their immediate thoughts.

The caregivers were all at literacy level therefore, did not have any limitations in understanding, reading or conducting the Think-Aloud task. However, if the participants did have literacy issues then this may not have been an ideal method to use as the amount of comments generated would have been limited. In addition, this study does not assess the impact of the booklet over time. Nor does it address the impact on those caring for people at different stages of dementia Further research could recruit a larger cohort and measure the stage of dementia, using for example the Mini Mental State Examination tool (Folstein et al., 1975) or capturing the care-recipient's nutritional status by using the Mini Nutritional Assessment tool (Vellas et al., 1999) and evaluate the impact of the booklets over time in terms of behavior and coping.

Conclusion

This study is the first to explore informal caregivers' perceptions of written materials about all three food-related processes. This study has shown that tailored information has the potential to enhance caregivers' confidence and support them in making decisions to help them adapt to food-related changes. The findings from this research suggests that the information provided raised awareness, illustrated coping skills and offered practical tips. Booklet two included information and advice on all three food-related processes (shopping for food, preparing food and eating food). The feedback was positive. Furthermore, booklet 2 included quotes from other caregivers of people with dementia. These quotes helped participants engage with the booklet and realize that other caregivers were coping with similar challenges. There were also suggestions for improving on the booklet. Booklet 2 could be further developed and its impact on caregivers evaluated in a larger study.

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References:

Andrieu, S., Reynish, W., Nourhashemi, F., Ousset, P. J., Grandjean, H., Grand, A., Albarede, J. L., & Vellas, B. (2001). Nutritional risk factors for institutional placement in Alzheimer's disease after one year follow-up. *The Journal of Nutrition, Health & Aging, 5*(2),113-117.

Atta-Konadu, E., Keller, H. H., & Daly, K. (2011). The food-related role shift experiences of spousal male care partners and their wives with dementia. *Journal of Aging Studies, 23,* 305-315.

Banning, M. (2008). The Think-Aloud approach as an educational tool to develop and assess clinical reasoning in undergraduate students*. Nurse Education Today28* (1), 8-14.

Baumann, J.F., Jones, L.A., & Seifert-Kessell, N. (1993). Using Think-Aloud to enhance children's comprehension monitoring abilities. *The Reading Teacher,47*(3), 184-193.

Bilotta, C., Bergamaschini, L., Arienti, R., Spreafico, S., & Vergani, C. (2010). Caregiver burden as a short-term predictor of weight loss in older outpatients suffering from mild to moderate Alzheimer's disease: A three months follow-up study. *Aging & Mental Health, 14*(4), 481–488.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Bull, F. C., Holt, C. L., Kreuter, M. W., Clark, E. M., & Scharff, D. (2001): Understanding the Effects of Printed Health Education Materials: Which Features Lead to Which Outcomes? *Journal of Health Communication: International Perspectives, 6*(3), 265-279

Carr S.C. (1998). Assessing Learning Processes: Useful Information for Teachers and Students. *Intervention in school and clinic*, *33*(3), 156–162.

Chang C., Roberts B, (2008). Feeding difficulty in older adults with dementia. *Journal of Clinical Nursing, 17,* 2266-2274.

Done, D. J., & Thomas J. A. (2001). Training in communication skills for informal caregivers of people suffering from dementia: a cluster randomized clinical trial comparing a therapist led workshop and a booklet. *International Journal of Geriatric Psychiatry, 16,* 816-812.

Ericsson, K.A., Simon, H.A. (1993). *Protocol analysis. Verbal reports as data. (Rev. ed.).* Cambridge, MA: MIT Press.

Fjellstrome, C., Starkenberg, A., Wesslen, A., Licentiate, M. S., Backstrom, A., T., Faxen-Irving, G., & The Omeg AD Study Group. (2010). *American Journal of Alzheimer's Disease and Other Dementias,* 25(6), 521-526

Folstein, M., Folstein, S., & McHugh, P., (1975). Mini-Mental State': a practical methods for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12,* 189-198.

Francis, S., Taylor, M., & Stricklamd, A. W. (2004). Needs and preferences assessment for an in home nutrition education program using social marketing theory. *Journal of Nutrition for the Elderly, 24*(2), 73-92.

Frank, L., Flynn, J., & Rothman, M. (2001). Use of a self-report constipation questionnaire with older adults in long-term care. *The Gerontologist*, *41*(6), 778–86.

Isaia, G., Mondino, S., Germinara, C., Cappa, G., Aimonino-Ricauda, N., Bo, M., Nobili, G., & Massaia, M. (2011). Malnutrition in an elderly demented population living at home. *Archives of Gerontology and Geriatircs, 53,* 249-251.

Gillick, M. R., & Mitchell, S. L. (2002). Facing eating difficulties in end-stage dementia. *Alzheimer's Care Quarterly, 3*(3), 227-232.

Higgins, M.M.& Barkley, M.C. (2004). Improving effectiveness of nutrition education resources for older adults. *Journal of Nutrition for the Elderly, 23*(3), 19-54.

Holm, B., & Söderhamn, O. (2003). Factors associated with nutritional status in a group of people in an early stage of dementia. *Journal of Clinical Nutrition, 22*(4), 385-389.

Housen, P., Shannon, G. R., Simon, B., Edelen, M. O., Cadogan, M. P., Sohn, L. & Saliba, D. (2008). What the resident meant to say: use of cognitive interviewing techniques to develop questionnaires for nursing home residents. *The Gerontologist*, *48*(2), 158–169.

Ikeda. M (2002). Changes in appetite, food preference, and eating habits in frontotemporal dementia and Alzheimer's disease. *Journal of Neurology, Neurosurgery and Psychiatry, 73*(4), 371-376.

Jobe, J. B., & Mingay, D. J. (1990). Cognitive laboratory approach to designing questionnaires for surveys of the elderly. *Public Health Reports*, 105, 518–524.

Keller, H., Schindel, M., Dupuis, S., Reimer, H., & Genoe, R. (2015). Strategies to support engagement and continuity of activity during mealtimes for families living with dementia; a qualitative study. *BMC Geriatrics, 15,* 119

Keller, H. H., Martin, L. S., Dupuis, S., Genoe, R., Edward, G., & Cassolato, C. (2010). Mealtimes and being connected in the community-based dementia context *Dementia, 9*(2), 191-213.

Keller, H.H., Smith, D., Kasdorf, C., Dupuis, S., Martin, S., Edward, G., Cook, C., Geneo, R. (2008). Nutrition education needs and resources for dementia care in the community. *American Journal of Alzhermer's Disease & Other Dementias, 23*(1), 13-22

Koro-Ljungberg, M., Douglas, E., McNeill, N., Therriault, D., & Malcolm, Z. (2012). Re-conceptualizing and de-centering Think-Aloud methodology in qualitative research. *Qualitative Research*, *18*(3), 256–265.

Livington, G., & Frankish, H. (2015). A global perspective on dementia care: a *Lancet* Commission. *The Lancer, 386*(9997), 933-934.

Lopez, O. L., Becker, J. T., Robert, A. S., William, K., Kaufer, D. I., Saxton, J. S. Habeych, M., and Dekosky, S. T., (2003). Psychiatric symptoms vary with the severity of dementia in probably Alzheimer's disease. *The Journal of Neuropsychiatry and Clinical Neurosciences, 15*(3), 346-353.

Manthorpe, J., & Watson, R. (2003). Poorly served? Eating and dementia. *Journal of Advanced Nursing,41*(2): 162-9.

Morris, J., & Volicer, L. (2001). Nutritional management of individuals with Alzheimer's disease and other progressive dementias. *Nutrition in clinical care, 4*(3), 148-155.

Nelis, S., Quinn, C., Clare, L. *Information and support interventions for informal caregivers of people with dementia.* The Cochrane collection. John Wiley & Sons, Ltd. 2008.

Njegovan. V., Hing, M.M., Mitchell, S.L., & Molnar, F.J. (2001). The hierarchy of functional loss associated with cognitive decline in older persons. *Journal of Gerontology. Series A Biological Sciences and Medical Sciences, 56*(10), M638-43.

Nyman, S. R. & Yardley, L. (2009). Usability and Acceptability of a Website that provides Tailored Advice on Falls Prevention Activities for Older People. Health Informatics Journal, *15*(1), 27-39.Prince, M., Albanese, E., Guerchet, M., & Prina. *A review of available research. Nutrition and Dementia.* Alzheimer's disease International; the global voice on dementia. 2014.

Papachristou, I. (2014). An audit report on food-related care and dementia written information. *Generations Review*; *24*(2), 19-20.

Papachristou I, Giatras N, Ussher, M. (2013). Impact of dementia progression on food-related processes: a qualitative study of caregivers' perspectives. *American Journal of Alzheimer's Disease and Other Dementias, 28*(6), 568–74.

Papachristou, I., Hickey, G., & Iliffe, S. (2015). Dementia informal caregiver obtaining and engaging in food-related information and support services. *Dementia*, *0*(0)

Papastavroue, E., Kalokerinou, A., Papacostas, S., Tsangari, H., & Sourtzim, P. (2007). Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing 58*(5), 446–457.

Patton, M.Q. (2002). Two Decades of Developments in Qualitative Inquiry: A Personal, Experiential Perspective. *Qualitative Social Work*; *1*(3): 261–283.

Pinquart, M., & Sorensen S. (2007). Correlates of physical health of informal caregivers: a met-analysis. *Journal of Gerontological British Psychological Sci Soc Sci, 62*(2), 126–137.

Riviere, S., Gillette-Guyonnet, S., Voisin, T. (2001). A nutritional education program could prevent weight loss and slow cognitive decline in Alzheimer’s disease. *Nutrition, Health & Aging, 5*, 295–299.

Sami, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family caregivers. *International Psycholgeriatrics, 25*(6), 949-961.

Tana M Luger, T. M., Houston, T. K., & Suls, T. K. (2014). Older Adult Experience of Online Diagnosis: Results From a Scenario-Based Think-Aloud Protocol Source: *Journal of medical internet research*, *16* (1),16.

Vellas, B., Guigoz, Y., Garry, P.J., Nourhashemi, F., Bennahum, D., Lauque, S., & Albarede, J.L. (1999).The Mini Nutritional Assessment (MNA) and its use in grading the nutritional state of elderly patients. *Nutrition; 15*(2) 116-22.

Vitaliano,, P. P., Scanlan, J. M., & Zhang, J. (2003). Is caregiving hazardous to ones’ physical health? A meta-analysis. *Psychological bulletin, 129*(6), 946-972.

Watson, R., & Green, S.M. (2006). Feeding and dementia: a systematic literature review. *Journal of Advance Nursing, 54*(1), 86-93.

Table 1: Comparison of Booklet Content

	Existing Booklet (Booklet 1) –	***New Booklet (Booklet 2)-***
Target User	*For informal caregivers and people with dementia living alone*	*For informal caregivers who live with person with dementia and who live alone.*
Introduction	Two sentences introducing the booklet	Same two sentences introducing booklet as well as what the book consists of, plus index section
Structure and Content	*Structure of booklet 1* A poor appetite A matter of taste Catering for change Drinks and liquids Maintaining independence Laying the table Staying safe Helping the carers Eating out A little too much? Eating behaviour Healthy teeth and gum	*Structure of booklet 2* 1) *Shopping* Going out alone and shopping; Driving; Purchasing food ; Selecting and buying food and drink 2) *Preparation* Laying the table; Safety in Kitchen; Taking on a new role in food and drink preparation ; Decision making difficulties; Timing menu selection; Catering for change; Sharing responsibility with the person you care for 3) *Eating* Appetite and weight change; Help with choices; Diet; Methods of eating Drinks and liquids; Helping the carers; Eating out; A little too much; Healthy teeth and gums

Type of Food-Related Process	The majority of this booklet is based around eating but does discuss some elements in food preparation, such as, catering for change, laying the table and staying safe.	This booklet is specifically broken down into 3 sections, including shopping, preparation and eating.
Helpful Contact Details	Contact details of *Food for Thought* project and Alzheimer's Society	Contact details of a number of dementia and care organisations

Table 2a. Demographics of Participants and Care-Recipients: Booklet 1

Booklet 1	*Pseudonym name*	*Relation to person with dementia*	*Stage of dementia*	*Gender of Caregiver*
1	Tim	Grandson	Mild	Male
2	Jean	Wife	Severe	Female
3	Peter	Son	Severe	Male
4	Maggie	Daughter	Moderate	Female
5	Fred	Husband	Severe	Male
6	Henry	Husband	Severe	Male
7	Sheila	Wife	Moderate	Female
8	Dean	Husband	Moderate	Male
9	Sam	Husband	Severe	Male
10	Andy	Husband	Severe	Male

Table 2b. Demographics of Participants and Care-Recipients: Booklet 2

Booklet 2	*Pseudonym name*	*Relation to person with dementia*	*Stage of dementia*	*Gender of caregiver*
1	Gina	Friend	Severe	Female
2	Chris	Grandson	Moderate	Male
3	Phil	Partner	Moderate	Male
4	Kerry	Wife	Moderate	Female
5	Neil	Husband	Moderate	Male
6	Ian	Husband	Moderate	Male
7	Mary	Wife	Moderate	Female
8	Abigail	Wife	Moderate	Female
9	Ted	Husband	Severe	Male
10	Laura	Daughter	Moderate	Female

Table 3: *Main Themes from Booklet 1 and 2*

Category	*Booklet 1 only*	*Booklet 2 only*	*Booklet 1 and 2*
Content	Difficulties managing dental and hygiene care	Not purchasing or overstocking food items Enjoyable day out or shopping alone Maintaining their usual shopping routine Caregiver taking on the driving role	Potential dangers in the kitchen Weight Maintenance Unable to make decisions with food choices Appetite change Helpful advice on fluid intake Tips on managing eating Tips when eating out
Format	N/A	N/A	Good presentation and personalized quotations
Usefulness	N/A	Usefulness of written material	Usefulness of booklets