

# Care staff perspective on use of texture modified food in care home residents with dysphagia and dementia

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**Background:** Dysphagia and dementia are conditions, which combined, can lead to complications for the person and require good nutritional care. There is very little evidence-based literature regarding nutritional care for people with dysphagia and dementia. It is clear that care staff plays a vital role, and that communication and informed decision-making are critical to the process, yet little is known regarding the use of available interventions such as texture modified food (TMF), and their acceptability and feasibility for care staff and residents. Therefore the aim of this study was to investigate the experiences of care staff when providing nutritional care for people with dysphagia and dementia, and their impressions and experience of using TMF as a new intervention for nutrition.

**Methods:** This was a qualitative study with an inductive approach, which aimed to explore the experience of care staff using TMF in a care home setting. Data were collected using focus group interviews, an approach which is validated as a means of supporting and developing the understanding of a phenomenon, through interactions and discussions in the group. Participants were care staff working in a care home setting in Norway.

**Results:** Twelve participants were recruited to this study across two focus groups. The cohort included four nurses, six practical nurses, one nurse assistants and one student nurse. Four main categories emerged from the focus group discussions regarding the use of TMF. These were: (I) emotional strain; (II) deficient nutritional care; (III) increased self-efficacy with use of TMF; (IV) better nutritional care with TMF.

**Conclusions:** Use of TMF to improve nutritional care for people with dysphagia appears to have merit for both residents and care staff, and should be considered as a means of improving nutritional care for people with dementia in care homes. Minimizing feeding difficulties and increasing nutritional intake is an important goal when caring for this vulnerable group of people, and there is a need to provide better training and support for care staff to ensure they feel confident and empowered to provide high quality nutritional care. The existing Norwegian Directorate of Health checklist for nutritional care may provide a helpful basis for improvements to guidance that accounts for the needs of staff and institutions. Further research and evaluation of an intervention for tailored nutritional care is warranted to improve this critical aspect of dementia care.

**Keywords:** Nutrition; dementia; dysphagia; care staff; self-efficacy

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## Introduction

Dysphagia is defined as difficulty with swallowing. It can occur as part of a disease or as a consequence of age-related changes in the human anatomy (1,2). About 8% of the worldwide population experiences difficulties eating regular food because of dysphagia (3). Dysphagia is particularly common in neurodegenerative conditions such as dementia (4) and often presents itself in the late stages of dementia (5). Baijens and colleagues (6) conducted a large European study on dysphagia as a geriatric syndrome and reported that as many as 93% of persons with dementia at an advanced stage are affected. Dementia is a devastating condition characterized by the progressive loss of cognition and function, leading to loss of cognitive abilities, communication, mobility and independence, and eventually to death. Decline in self-care and nutrition, leading to a range of feeding problems, are also closely associated with the progression of dementia (6). People with dementia often lose the ability to maintain their own eating strategies and nutritional status, often resulting in inappropriate eating and indifference to food in the early stages of the condition, and later manifesting as difficulties with swallowing and aspiration in later stages (5). Thus, moderate to severe dementia are risk factors associated with dysphagia (5).

Approximately one third of people with dementia reside in institutions such as nursing home or residential care settings, and make up 80% of residents (7). In a recent study performed by Park and colleagues (5) dementia was found to be a significant predictor of dysphagia in care home residents. However, reliable figures for the prevalence of dysphagia amongst residents in these environments are not currently available and no studies to date have provided accurate prevalence figures for Norwegian care homes. Feeding difficulties and the risk of developing dysphagia in dementia are major healthcare issues in care homes, and are associated with severe impacts on people with dementia (8). Problems often emerge during interactions between the patient and care staff in meal situations, where refusal to eat or declining assistance from care staff can lead to negative interactions and distress (9). If not addressed, these issues lead to malnutrition and weight loss (10,11), increasing the risk of infections, such as pneumonia (4), and possible hospitalization, both of which are major risk factors for reduced quality of life and mortality (12). The impact of dysphagia and feeding problems also extends to care staff in these settings. The organization of nutritional

care and mealtimes is challenging, and can be demanding and stressful. Staffs are at high risk of emotional strain and stress, both of which are risk factors for burnout (13,14) and depression (15). Feeling of mastery and self-efficacy, defined as having faith in being able to reach a set goal (14,16,17), are directly impacted, with recent studies indicating a causative link between burnout and low self-efficacy (13).

Ensuring patient safety, high standards of nutritional care and good quality of life in this vulnerable group of people is a multifactorial challenge. Food and meals are an important part of everyday life and a source for pleasure and quality of life. Norwegian public documents emphasize that food and mealtimes should play an important role in Norwegian nursing homes (18) and the Norwegian Directorate of Health has published dietary guidelines for these settings (19). The document is intended to support care staff and leaders in providing high quality nutritional care. The document includes a checklist to help staff optimize mealtimes, customize food, ensure appropriate amounts of food are provided, provide pleasant environment and offer assistance when needed. However, this process requires a high level of competence and knowledge amongst care staff (10,11) who should be equipped to carry out accurate assessment of the feeding requirements and difficulties for individual residents in order to decide on appropriate, tailored interventions to maintain a healthy nutritional status. This is especially important for people with dementia who are likely to experience difficulties with both eating and swallowing, and who may be unable to communicate these issues to their caregivers. Various subjective and objective measures can be used to identify difficulties in eating and impaired swallowing, such as bed-side sipping tests and fluoroscopy imaging (5,20). A range of approaches is taken to promote nutrition in people with dysphagia. Usually, these people are offered regular food, which is blended or diluted to a density the person is able to swallow. However, the resulting food is unappealing, leading to a loss of appetite. The food may also still be problematic to swallow, especially as it quickly loses the original and intended consistency, with the consequence of a reduction of nutrient intake and willingness to eat (21,22). To ensure a dignified meal experience and high nutritional status, various means have been developed and trialed such as medical food, protein shakes and texture modified food (TMF). TMF is a product where the ingredients are blended separately into a puree before being molded into different shapes of their original foodstuff, maintaining a consistent texture. The

different ingredients are arranged and combined on a plate like a regular meal. The food will then dissolve in the mouth without the need for chewing. The TMF was produced by an industrial food manufacturer, who distributes regular food, as well as TMF to care homes in a municipality.

There is very little evidence-based literature regarding nutritional care for people with dysphagia and dementia. It is clear that care staff play a vital role, and that communication and informed decision-making are critical to the process, yet little is known regarding the use of available interventions such as TMF, and their acceptability and feasibility for care staff and residents (23,24). Therefore the aim of this study was to investigate the experiences of care staff when providing nutritional care for people with dysphagia and dementia, and their impressions and experience of using TMF as a new intervention for nutrition.

## Methods

### Study design

This was a qualitative study with an inductive approach, which aimed to explore the experience of care staff using TMF in a care home setting. Data were collected using focus group interviews, an approach which is validated as a means of supporting and developing the understanding of a phenomenon, through interactions and discussions in the group (25,26).

### Participants

Participants were care staff working in a care home setting in Norway. The participants were recruited through the municipality manager of health care, who identified care homes recently introduced to TMF. The care home managers were then contacted and invited to participate in the study. Care staff with a permanent position in the care home who had been introduced to the use of TMF prior to the focus group, were recruited. All eligible staffs were involved in mealtime situations with persons with dysphagia and dementia based on care home diagnoses and they had been using TMF weekly or daily.

### Data collection

Published procedures for performing focus group were followed (25) and participants were divided into two

groups of 5 and 7 respectively. The interviews took place in January 2016, at a care home. Both focus groups lasted for approximately 60 min, and were conducted by the main researcher (LBH) and co-researcher (CTF). A semi-structured interview guide with open-end questions was used (*Table 1*). The questions were designed to encourage reflections and discussion based on the main topics of the study.

### Analysis

Focus group interviews were recorded and transcribed verbatim immediately afterwards. Data analysis was performed according to systematic text condensation, which is based on Giorgi's psychological phenomenological analysis (27). Transcripts were read through by the researchers to obtain an overall impression. After reading the transcripts several times, the researchers agreed on some preliminary main themes. Meaning units were then identified and classified into codes. Researchers discussed the coding of the meaning units and the decontextualized material. The codes and meaning units were rearranged several times before subgroups were created for each code group to view important aspects. Condensation and abstraction of the meaning units within each code and writing artificial quotes was then performed. Finally, content from the previous steps was re-contextualized into an analytical text with a category heading. Artificial quotes from the third step were rewritten into a longer description of each category and assembled with a quote that was representative of the category (see *Table 2*).

### Theoretical framework

The aim of the phenomenological analysis was to develop knowledge about the participants' experiences (27). Phenomenology is focused on the study of a phenomenon from the perspective of the individual. It is important to approach the phenomenon with an open mind to ensure that the topic of research is not sculpted into predetermined categories and emphasizes a contextualized description that is close to what was experienced (27). The theoretical background of the study is based on person-centered care (PCC) in persons with dementia (28,29), promoting tailored person-centered interactions and activities in the overall care as well as providing high level nutritional care. Nutritional care for persons with dementia includes

**Table 1** Interview guide

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Question 1: "What were your experiences with persons with dysphagia and dementia during meal time?"

Question 2: "What is your perception of current organization of the meal and the food that is being served now?"

Question 3: "What are your thoughts on the introduction of texture-modified food?"

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**Table 2** Example from the analysis step 3 (and 4)

Code	Condensed meaning unit	Artificial quote	Analytical text
Lack of confidence	<i>"It was a terrible experience and I was shaking when I left work (...) that is an experience that will stick with you"</i>	The care staff experienced frightening situation when patients had trouble eating. The situations were serious and the care staff felt scared after experiencing this	The participants expressed that they had experienced serious and frightening situations when the patients were served regular meals. They experienced fear in conjunction with mealtimes and patients with dysphagia and these feelings lingered with them after the workday was over

Category: lack of confidence in mealtime situations with persons with dementia and dysphagia.

psychological and social needs as well as nutritional needs and the meal is therefore of great importance as it provides an area of support for the persons wellbeing and quality of life (30,31). Albert Bandura's theory of self-efficacy and how it affects the behavior of the care staff also shaped the framework for this work (16,17). Bandura's theory emphasizes that if a person's self-efficacy is high, the person characterizes new tasks as challenges that can be mastered. In this perspective, a high level of self-efficacy will lead to a higher effort towards new challenges, compared to an individual with a lower level of self-efficacy. Previous experiences are important when facing new challenges, from both a positive and a negative perspective (32).

### **Ethical considerations**

The study was approved by the Norwegian Center for Research Data (NSD) on 29<sup>th</sup> of September 2015 and registered at the Department of Research at Stavanger University Hospital in Stavanger. All participants signed an information and consent form prior to participating. The form contained information about the interview itself, information concerning the storage of data and that the participants would remain anonymous. Information about the interviewers' confidentiality was given verbally and the participants were informed that they could withdraw from the study at any time. If so, the information about them would be completely erased.

## **Results**

### **Cohort characteristics**

Twelve participants were recruited to this study across two focus groups. The cohort included four nurses, six practical nurses, one nurse assistants and one student nurse. Four main categories emerged from the focus group discussions regarding the use of TMF. These were: (I) emotional strain; (II) deficient nutritional care; (III) increased self-efficacy with use of TMF; (IV) better nutritional care with TMF.

### **Emotional strain**

Care staff often described experiencing challenging situations during mealtimes with people with dysphagia and dementia. This led to emotional strain and a lack of confidence in mealtime situations with this group of patients as defined in the following subcategories:

(I) Life threatening experiences and fear.

Patients with dysphagia often encountered difficulties swallowing normal food and were likely to choke on the food, while eating.

*"One time we almost lost a patient because she was choking (...) we thought that we were going to lose her".*

The participants described experiencing serious and frightening situations when residents were served regular meals, which led to life-threatening events. These situations were common experiences

and were reported as an emotional strain, which continued to impact on participants long after the incident occurred.

*“It was a terrible experience and I was shaking when I left work (...) that is an experience that will stick with you”.*

## (II) Helplessness and guilt.

Difficult situations involving life-threatening events and fear were associated with feelings of guilt amongst the care staff. They described feeling guilty if a resident had trouble swallowing and choked while eating. Mealtime situations with patients with dysphagia were often accompanied by guilt and helplessness.

*“You get a sense of guilt and what am I doing wrong so that she is not able to swallow, at least I feel like that”.*

The care staff reported trying to avoid situations where they worried about the person's difficulties in swallowing.

### **Deficient nutritional care**

Providing good nutritional care and serving appropriate food for a person's needs were perceived as important, yet challenging for the care staff.

### **Time pressure**

Assisting patients with dysphagia was reported as time consuming and affected care staff capacity to help other residents who also required assistance.

*“If you have two or three patients who need assistance, then the mealtime can be very time consuming (...) I feel like you don't get enough time to take care of the patients”.*

### **Lack of stimulation of appetite**

The presentation of the food was also perceived to be important and that this did not receive the attention it deserves.

*“Of course it matters a lot how we choose to present the food (...) to be attentive when serving the food so that you don't stir everything together into a mixture”*

### **Lack of communication between kitchen, care staff and the topic of nutrition**

In general, communication between the kitchen and care staff was felt to be lacking. Participants expressed a need for

more communication between themselves and the kitchen in order to meet each person's individual needs related to nutritional care.

*“The chefs should come up here and be present when we serve dinner, so that they could talk with the patients themselves”.*

Furthermore, they expressed an impression that their own opinions and views concerning nutrition and meal were not taken into account.

*“I have never been asked about this before, I have never been asked about topics like food and nutrition, and what my views on the topics are”.*

### **Increased self-efficacy with use of TMF**

When this group of care staff was introduced to use of TMF in persons with dysphagia and dementia they reported an increased feeling of safety and self-confidence, which led to a sense of self-efficacy.

### **Increased feeling of safety**

The care staff reported that they felt safer in the meal situation when they served TMF to patients with difficulty in swallowing.

*“I think that it is absolutely a source of a safer everyday, both for us and the patients, for us to feel comfortable”.*

Furthermore, they felt more able to provide sufficient nutritional care that was customized according to the patients needs, and that could be eaten with fewer problems.

*It feels good to see them eating the food with fewer problems, (...) that it is safe when you see what kind of problems they have with swallowing”.*

### **Increased feeling of self-confidence**

Care staff reported that the TMF looked delicate and appetizing. They also described taking less time preparing the food because it was delivered to the care staff pre-heated and in portions ready to serve. They also felt confident in having time to assist the patients who needed help.

*“I think the food is really good (...) The food they make here is fantastic and it looks appetizing”.*

The care staff also reflected on what the consequences for residents would have been if TMF had not been made available, expressing relief that TMF enabled them to provide nutrition and avoid life-threatening events to residents who were most in need.

*“I just think about the consequences if they hadn't gotten it, their health will decline further, if they don't eat enough food”.*

### **Better nutritional care with TMF**

The use of TMF was viewed as an important measure for people with dysphagia as it was perceived to lead to better nutritional care.

### **Weight gain amongst the patients**

Participants reported that residents who were eating TMF were able to consume food without having problems swallowing and subsequently gained weight. Participants also described situations where the residents themselves had expressed a preference for TMF.

*“One of the patients wants that type of food, because she knows that she is able to swallow it”.*

### **Nutritional care to persons with dementia**

Staff observed specific self-feeding patterns with people receiving TMF. One such behavior involved eating meal objects in sequence depending on the type or appearance of the items.

*“I see that persons with dementia eat differently when they eat TMF, they start eating in one spot on the plate and then continue eating until they are left with the mashed potatoes”.*

Participants also reported that people with dementia were able to self-feed more effectively with TMF without the need for cutlery, which would formerly have been problematic. Staff found this a positive change, which was associated with increased independence of the residents.

*“When they are given texture-modified food and a spoon, they eat well and by themselves. When you serve them regular food, they have no idea how to cut it in to bites”.*

## **Discussion**

The aim of this study was to examine the experiences of care staff when introduced to the use of TMF for care home residents with dysphagia and dementia. The qualitative study has provided valuable insight into this novel nutritional intervention, and into the attitudes and experiences of staff who are regularly involved with nutrition of people with swallowing and feeding difficulties.

Emotional strain, such as feelings of fear, helplessness and guilt related to patients with difficulties in swallowing were common amongst staff. This is particularly pertinent to dementia care since residents often do not have insight into the caring relationship or the need for assistance with feeding (9). This situation is often reported as a trigger for negative interactions between residents and care staff, which

in turn impact on staff self-efficacy and belief in their ability to provide nutritional care (10,11). Staff also described major events such as choking which were associated with fear. These aspects of care staff experience are consistent with the literature. A study performed by Karlsson and colleagues (33), found that care staff often worried about hurting residents, leading to frustration and stress. Previous research also shows that health professionals who work with care home residents with dementia have a higher risk of exhaustion and emotional burn-out (13). Thus these aspects of the analysis are consistent with current evidence in the field and serve to emphasize the importance of support and guidance for care staff working in these situations.

There is a lack of clear guidance and support for staff in improving nutritional care, and this was highlighted by several of the discussion points raised by the participants. This included awareness of the importance of food presentation, but a lack of time and support to improve on the current situation. Furthermore, participants identified the need for effective communication with residents in order to improve their nutrition, but that time pressure was a major barrier to this ambition. Additional challenges included a lack of opportunity to discuss nutrition with management and kitchen staff, and the impact of cognitive deficits in residents which hampered effective communication and care planning. A report published by the Norwegian government in 2007 (18) highlighted the challenge of malnutrition in care homes due to the lack of available time for high quality nutritional care. Thus these are major themes that are already recommended in government guidelines, but for which there is little practical or consistent support for staff in their day-to-day role. Person-centeredness in care is well recognized as the gold standard for dementia care, and evidence-based training in PCC is known to result in improvements to quality of life and other aspects of wellbeing such as behavior (34). However to date this has not been applied to individualization of nutritional care or decision-making around this aspect of the care. This would appear to be an urgent need for research and training within the sector.

Care staff described an overwhelmingly positive experience when using the TMF dietary approach. This manifested in reports of feeling less challenged and safer during mealtimes, which was attributed to the reduced risk of choking and the observation that residents were able to safely eat the TMF with fewer complications overall. In turn, these positive experiences were associated with improved perception of self-efficacy amongst staff and a

greater belief in their own ability to support the residents. This is an important illustration of the theoretical aspect of self-efficacy, resulting in increased confidence in self-efficacy and goal attainment in accordance to Banduras theory (16,17) on self-efficacy. Self-efficacy is an important variable in regards to reducing the risk of burnout and depression (13) amongst care staff, which in turn is linked to overall quality of care and job satisfaction.

Participants also reported direct impacts on the residents themselves, including weight gain. This is consistent with the preliminary evidence pertaining to TMF. One recent study showed an increase in nutritional status and body weight after implementing a food program consisting of personalized TMF (22). Furthermore, participants described an improved perception of food and an interest in nutrition amongst residents. Anecdotal reports from the focus groups even described a resident who, having previously required full support for feeding, began to self-feed when introduced to TMF. This finding indicates a potentially valuable and important additional benefit of TMF aside from the direct benefit of improved nutritional intake. Apathy and lack of interest are common in people with late-stage dementia, and this is associated with reduced quality of life and overall outcomes. Any intervention that prompts an increase in engagement and pleasure and independence is therefore of great potential value and certainly merits further investigation.

This study therefore provides new and valuable insight into nutritional care for people with dementia and dysphagia in care homes. The validity and reliability of the study is a central aspect and is based on how data is gathered and processed (25). The reliability of this study is increased by a precisely executed analysis and an accurate presentation of the approach. However, there are limitations that must be acknowledged. This was a small study, conducted in one care home, which challenges the reliability of the data. Furthermore, participants in the focus groups worked together on an everyday basis, which may reduce the scope and variety of comments that were gained, particularly since focus group participants are known to be led by each other in common themes of conversation. The validity of qualitative studies revolves around whether the methodological approach reflects the aim of the study and represents the reality in an accurate form (25). This study was based on a strategic selection to ensure a varied and wide range of material. The participants in the selection held a variety of different educations and experiences to ensure the study's external validity. The participants were

highly engaged in the topic, gave rich descriptions of their experience and appeared confident to express their opinions. Using the same interview guide for both interviews ensured the study's internal validity. Thus despite its small size this study provides valid data that warrants further investigation in a large-scale evaluation.

## Conclusions

Use of TMF to improve nutritional care for people with dysphagia appears to have merit for both residents and care staff, and should be considered as a means of improving nutritional care for people with dementia in care homes. Minimizing feeding difficulties and increasing nutritional intake is an important goal when caring for this vulnerable group of people, and there is a need to provide better training and support for care staff to ensure they feel confident and empowered to provide high quality nutritional care. The existing Norwegian Directorate of Health checklist for nutritional care may provide a helpful basis for improvements to guidance that accounts for the needs of staff and institutions. Further research and evaluation of an intervention for tailored nutritional care is warranted to improve this critical aspect of dementia care.

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## Footnote

*Conflicts of Interest:* The authors have no conflicts of interest to declare.

*Ethical Statement:* The study was approved by the Norwegian Center for Research Data (NSD) on 29th of September 2015 (No. 44853) and registered at the Department of Research at Stavanger University Hospital in Stavanger. All participants signed an information and consent form prior to participating.

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