Resistive behavior

adversely affecting the intake of food and fluids in persons with dementia

Incidence, nature and impact

Eline van Buuren

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General introduction

Dementia is a syndrome caused by various diseases that affect the brain, characterized by cognitive decline, changes in behavior, and function loss that affect the ability to perform daily activities (1). Alzheimer's disease is the most common cause, accounting for 60-70% of cases, followed by vascular dementia, dementia with Lewy Bodies, frontotemporal dementia, and mixed forms. Globally, approximately 55 million people live with dementia, making it one of the top ten causes of death (1). In the Netherlands, around 310,000 people are affected, including 15,000 under the age of 65 (2). Due to population aging, these numbers are expected to rise significantly, with dementia prevalence among migrant communities projected to triple (2). This increasing prevalence places immense pressure on healthcare systems. Dementia profoundly impacts not only persons with dementia, but also their relatives, healthcare professionals, and society at large (3-6).

In the Netherlands, most persons with dementia live at home (2). As the functional impairments resulting from the dementia increase, the complexity of problems experienced in daily life intensifies as well. Due to a growing care demand, a point may be reached where home care no longer suffices because the person with dementia requires 24-hour care and may be admitted to a nursing home. In nursing homes, multidisciplinary teams strive to tailor care to individual needs in collaboration with relatives.

As the disease progresses, persons with dementia frequently experience difficulties related to eating and drinking (7). These difficulties can significantly limit food and fluid intake, leading to severe consequences such as malnutrition or aspiration pneumonia (8, 9). Other consequences include dehydration and increased mortality (10). The causes of eating and drinking difficulties can be functional and cognitive, or behavioral in nature.

Functional and cognitive problems include challenges such as reduced attention, a lack of initiative to eat, or even a failure to recognize food (agnosia) or difficulty using utensils (apraxia) (11). Other causes of eating and drinking difficulties include chewing and swallowing problems, which are reported in about 50% and can be observed at any stage and type of dementia (12, 13). Effective eating and drinking requires alertness, food and fluid recognition, and physical ability. As dementia progresses, function loss increases as well, leading to deterioration of eating and drinking ability and further complicating eating and drinking.

In addition to functional or cognitive problems, behavioral causes can also hinder effective eating and drinking. These may manifest as resistance during mealtimes, such as refusal of assistance. Behavioral changes associated with dementia can pose significant challenges during the course of the disease and complicate the intake of food and fluids (14). In the Netherlands, challenging behavior is defined as any behavior that causes distress or poses a risk to the person with dementia or people around them (15). This includes psychotic, depressive, anxious, apathetic, and agitated behavior. Challenging behavior is observed in approximately 80% of persons with dementia living in nursing homes, although prevalence varies depending on the definition, dementia type, and disease stage (16, 17). Little is known about the occurrence and manifestation of resistive behavior in younger persons with dementia, although it is known that neuropsychiatric symptoms in general are more prevalent and severe in younger persons compared to older persons with dementia (18). Specifically, previous research has indicated that younger persons with dementia more frequently exhibit symptoms of agitation and irritability (19).

Resistive behavior may involve refusal of assistance with activities of daily living (ADLs), such as washing, dressing, or medication intake (20, 21). Similar resistive behavior can occur during eating and drinking situations. According to the Dutch guideline on resistive behavior around eating and drinking, such behavior may stem from not wanting to eat, not being able to eat or not understanding how to eat (22). Practice experience and prior research indicate that the characteristics and underlying causes of this behavior can vary widely between individuals and even per moment (7), as illustrated by the following example:

> *Annie is 81 and lives in a nursing home. For the past few weeks, she has become more easily irritated and is eating less. She increasingly walks away from the table during mealtimes. When she does remain seated, Annie seems unsure of what to do with the food. However, when assistance is offered, she refuses, becomes angry, pushes away the plate or caregiver, and eventually walks off. Annie says she doesn't want to cause any 'trouble' and insists on deciding for herself when and what to eat. A week ago, she struck a fellow resident who told her to stop making a fuss and just eat. Over the past three months, Annie has lost 4.5 kilograms of weight.*

Annie's case illustrates the complex nature of resistive behavior that adversely affects the intake of food and fluids. The cause may neither be purely behavioral nor solely related to eating and drinking difficulties resulting from the functional loss caused by dementia. Because of the variety in characterizations and causes, identifying the specific causes of an individual's resistive behavior poses significant challenges for healthcare professionals who are involved in such situations (23). The complexity is reflected in the fact that there is no uniform definition or formulation used in the literature. Terms such as *mealtime behaviors*, *eating behavior*, and *food refusal* are commonly used (7, 24-26), yet they describe different problems. This lack of consistency in terminology complicates the interpretation of the behavior and consideration of directions of possible effective interventions. Furthermore, due to the use of varying definitions, the actual occurrence of these specific situations with resistive behavior is unknown.

The complexity of these situations increases even further when serious consequences result from resistive behavior. When resistive behavior persists, there may come a point where the nutritional intake is inadequate or the person no longer consumes food or fluids at all. At such a critical point, the treatment plan guides what interventions are applied or not. In some cases, advance care planning outlines the preferred course of action, should eating and drinking become impossible or the resistive behavior persist. In such situations, this predetermined plan guides the decisions about whether to actively offer food and fluids to the person with dementia. In the absence of a predefined plan, decisions must be made ad hoc. This can be particularly distressing for relatives who must make an important decision on behalf of their loved one—one that may ultimately mark the end of life (27). At this point, ethical dilemmas can arise, such as whether or not to administer artificial nutrition and hydration or to refrain from offering food and fluids (28, 29). Decision making, including what actions to take or to avoid, is a collaborative process involving healthcare professionals, the person with dementia, and his/her relatives. However, when considering to actively refrain offering food and fluids, religious or cultural objections may arise (27). For some, it may feel unethical to stop providing food and fluids. These objections and possible differences in ethical beliefs can complicate or even prevent reaching consensus on a treatment plan. If consensus cannot be reached, moral case deliberation may be helpful, aimed at reaching a joint agreement on the treatment plan (30, 31). However, it remains largely unknown how decision making unfolds in these situations and what the impact is on the persons involved (32). It is therefore important to unravel how healthcare professionals deal with these situations. Last, it is essential to know the exact impact of situations with resistive behavior on all involved and how frequently these situations occur.

Rationale

This thesis focuses on resistive behavior that adversely affects eating and drinking in persons with dementia with serious consequences. Understanding the nature and frequency of resistive behavior, as well as how decisions are made in such situations, is crucial. Greater insight into these areas can provide directions for developing effective strategies to manage resistive behavior. Ultimately, this knowledge can contribute to more person-centred care for persons with dementia living in nursing homes.

Aim and research questions of this thesis

The overarching aim of the studies in this thesis is to understand the nature, impact and incidence of resistive behavior that adversely affects the intake of nutrition and hydration in younger and older persons with dementia. The following research questions are addressed:

Research question 1:
How can we explore and map the complexity of mealtime behavioral problems and related complex issues in nursing home residents with dementia?

Research question 2:
What is the incidence of resistive behavior that adversely affects the intake of food and fluids in younger and older persons with dementia and what are the characteristics of this behavior?

Research question 3:
How do relatives and healthcare professionals navigate treatment and care decisions in persons with dementia whose behavior complicates the intake of food and fluids and what are possible ethical dilemmas related to decision-making?

Outline of this thesis

The first research question is addressed in chapters 2 and 3. **Chapter 2** describes a focus group study on eating- and drinking problems in persons with dementia with healthcare professionals, in order to explore their perspectives in relation to an existing conceptual model. To further unravel the concept of resistive behavior around eating and drinking, **chapter 3** describes a group concept mapping study among relatives, researchers and healthcare professionals.

Chapter 4 describes the outcomes of an incidence study in a group of younger and older nursing home residents with dementia who were followed during 12 months, including descriptions of the characteristics of situations with resistive behavior.

Chapter 5 describes the exploration of the decision making and impact of situations with resistive behavior on relatives and healthcare professionals involved in persons with advanced dementia and mealtime behavioral problems. Three overarching themes reflect dilemmas and the impact of decision making, as experienced by the persons involved.

Chapter 6 describes and discusses the main findings and conclusions from all studies. Recommendations and implications for clinical practice, education and future research are also provided.

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2

The complexity of nutritional problems in persons with dementia: expanding a theoretical model

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Abstract

Background

Persons with dementia are at risk of developing nutritional problems. Theoretical models on nutritional problems have been developed, but have not been evaluated with healthcare professionals.

Objective

This study aimed to explore the comprehensiveness and applicability of a theoretical model of nutritional problems in persons with dementia for daily nursing home practice.

Methods

A qualitative design employing a combined deductive and inductive approach was used. Healthcare professionals were eligible to participate if they 1) had expert knowledge of and experience with nutritional problems related to dementia, and 2) worked in a nursing home affiliated with an academic network covering the east and south of the Netherlands. Three focus group interviews with 20 healthcare professionals from seven professions were held. We conducted thematic analysis and we compared themes with existing theoretical models from the literature.

Results

We identified six themes, four of which corresponded with the existing models (observing and analysing nutritional problems; consequences of nutritional problems; functioning of the person with dementia; environmental factors). Interprofessional collaboration and ethical factors were identified as new themes. The analyses indicated interactions within each theme, between themes, and a bidirectional connection between themes.

Conclusion

This study demonstrated the relevance of interprofessional collaboration and ethical considerations in nutritional problems related to dementia. It uncovered complex bidirectional relations within and between factors regarding nutritional problems. All aspects should be taken into account to minimize the consequences of nutritional problems for persons with dementia.

Key words: Nutritional disorders, feeding behavior, dementia, theoretical model, long-term care, Alzheimer’s disease

Introduction

Nutritional problems are common in people with dementia, with prevalence rates from 30% to 60% (1, 2). These problems refer to any problem occurring during eating and drinking that cause inadequate intake of fluids and food (3). The consequences can be serious, such as malnutrition, dehydration, aspiration pneumonia, and even reduced social participation. Dehydration and aspiration pneumonia are two main causes of death in persons with dementia (4-6).

When identifying causes of nutritional problems in dementia, one could distinguish factors in several domains: physical, cognitive, and behavioral factors. The nature and severity of these factors varies between individuals, depending on the cause of the dementia and progression of the disease (7, 8). Persons with dementia experience increased difficulties with chewing and swallowing, and apraxia in the more advanced stages of dementia in comparison with early stages (8, 9). However, the motor and sensory components of swallowing are often overshadowed by cognitive and behavioral factors (7, 10). Cognitive symptoms that limit effective nutritional intake are the inability to recognize food and reduced comprehension of language (10-12). Other impairments include difficulty bringing food to the mouth due to apraxia or agnosia. Dental problems are an example of a physical factor that is known to affect nutritional intake (7, 13, 14). Environmental aspects, such as the influence of social interaction and dining environment on eating and drinking are of influence on effective nutritional intake as well (7, 10, 12). Wandering during mealtimes, apathy, or food refusal are behavioral symptoms that can result in inadequate intake of fluids and food (15).

Research has focused on single underlying causes of nutritional problems, but often lacks the context of multiple interrelated causes that are seen in clinical practice. Chang and Roberts developed a model to capture the problems and influencing aspects (14). The model describes three aspects: (a) antecedents, such as perceptual deficits, cognitive impairment, and a lack of motor control, which influence (b) behavior, (nutritional problems). These problems can have (c) consequences, such as inadequate food intake, weight loss, or aspiration of food or liquid. Subsequently, this model was extended by Aselage, Amella and Watson by including contextual factors, such as the mealtime environment, mealtime patterns, and dyadic interaction (15). However, both theoretical models were derived only from the literature and it is unclear whether their application in daily nursing home practice takes into account all relevant aspects in this context. This study aims to explore the comprehensiveness of these models related to their applicability in daily nursing home practice, considering experiences of professionals in daily care practice.

Methods

Design

A qualitative design with focus groups using a combined inductive and deductive analytic approach was applied in this study. We followed the consolidated criteria for reporting qualitative research (completed COREQ checklist in the supplement) (16).

Sample

Participants were purposefully sampled to represent a variety of relevant disciplines in each focus group session. Candidate participants were eligible to participate in the study if they met the inclusion criteria of 1) being experienced with dementia and dementia-related nutritional problems, and 2) working as a healthcare professional in a nursing home affiliated with the University Knowledge Network on Old Age Care in Nijmegen. Due to the multifactorial nature of the topic and to obtain a profound understanding of the topic, family caregivers were also invited when they met the first inclusion criterion. Family caregivers included close relatives, friends, and neighbors involved with the care. Participants were recruited by email and in person by the researcher EvB.

Data collection

Data were collected during three face-to-face focus group sessions with healthcare professionals working in three different nursing homes between January and June 2019.

A topic list was used to guide the focus group discussions (Appendix), based on relevant literature, and the main themes of the existing theoretical models (e.g. behavior/nutritional problems, causes/antecedents, and consequences) (14, 17). All focus group discussions started with an introduction by the facilitator (EvB), observer (occupational therapy student), and participants, followed by a discussion guided by the topic list. The observer made field notes during each discussion. EvB was working as a speech and language therapist at the time of the study. She clarified her role as a researcher at the start of the sessions as she was known to several participants, as some of them were colleagues. The focus group discussions were video recorded, for which the participants provided their written consent. A copy of the informed consent and certificate of attendance was offered to the participants. The topic list (Appendix 1) covered six open questions for which we deemed pilot-testing with healthcare professionals prior to data collection unnecessary.

Data analysis

Data were transcribed verbatim by the researcher EvB. Thematic analysis was supported using Atlas.ti 8 [18]. Data were analyzed by the researcher EvB, trained in the basics of conducting qualitative research while the research team's expertise covered extensive qualitative and quantitative research. EvB coded small units. Through this open coding process, new codes were identified in an inductive way, and discussed by the researchers EvB, MO, and HK [18, 19]. Subsequently, the codes were compared to the themes of the existing models, to secure the deductive part of data analysis. After three rounds of data collection and -analysis, an adapted model was developed by the researcher EvB based on the codes and themes that were identified during data-analysis. The existing theoretical model [14] was complemented with the findings from this study. The connections between the themes in the model were discussed with the participants of the focus group sessions and research team, and adapted in the model. The model was discussed in phases, first with HK and MO, both of whom are researchers with experience in qualitative research and backgrounds in speech and language therapy. Subsequently, the model was presented to all participants of the three focus group sessions by individual email and adjusted based on their feedback to offer member checking and create a final model. Next, we involved additional researchers with specific expertise and various backgrounds to support the quality of the study. The adaptation of the model was discussed with MP and JvdS, both experienced dementia care researchers with backgrounds as a general practitioner and methodologist, respectively. The three researchers discussed the themes on code level to examine the content and relationships between the themes. Finally, the model was reviewed by RK and CB, who are experienced dementia researchers with a background in elderly care medicine and psychology in dementia, while RK and JvdS are also experts in palliative care.

Ethical considerations

This study was conducted according to the principles of the Declaration of Helsinki (version 13) (20). The study was declared exempt from the Medical Research Involving Human Subjects Act by the research ethics committee of the Radboud university medical center Nijmegen (file number CMO: 2019-5139).

Results

A total of 20 healthcare professionals (19 women) participated in three focus group sessions, with participants from seven professions employed by three nursing homes. No family caregivers were willing to participate. The focus group discussions lasted 60 to 90 minutes, and took place in a conference room at one of the nursing homes. Five participants responded by e-mail to the member checking invitation. Details of the participants are shown in the Appendix.

Thematic analysis resulted in six themes capturing nutronal problems and related factors: (1) observing and analyzing nutritional problems; (2) consequences of nutritional problems; (3) functioning of the person with dementia; (4) interprofessional collaboration; (5) ethical factors; and (6) environmental factors. Below, we describe the six themes, after which we detail the complex nature of the relationships between the themes.

1. Observing and analyzing nutritional problems

The participants reported having witnessed various problems during mealtimes regarding the ability to get food into the mouth, such as an inability to recognize or use cutlery or food.

> *"The way that they handle cutlery is not what it was and, ehm, people no longer know how to bring the food to their mouth (…). So I think that handling cutlery is already a basis, so to speak. And that can be strength, or cognitive." (cognitive rehabilitation therapist 1)*

An inability to chew and swallow were indicated as frequent problems. Coughing due to aspiration during eating or drinking was referred to as the most frequent and severe problem in persons with dementia. Moreover, suffering from a lack of proper dentures or pain in the mouth were mentioned as reducing chewing ability, making eating bothersome or painful. Finally, an altered sense of hunger and thirst was referred to as a problem. A person with dementia may experience not feeling hungry, and therefore they might refuse to eat or only eat a small portion.

> *"The stimulus is no longer transmitted properly either. So, ehm, there is no feeling of hunger or thirst sometimes." (dietitian 2)*

The participants identified adequate detection of nutritional problems as essential. Analyzing the problems, searching for the underlying causes of eating and drinking problems was described as a shared task and was sometimes experienced as challenging. It was mentioned that the consequences of eating and drinking problems are observed at times, while the underlying causes are not always detected. Moreover, multiple nutritional problems may interact, such as oropharyngeal dysphagia and apraxia. Combinations of problems were mentioned as being challenging and call for alertness of all persons involved.

2. Consequences of nutritional problems

Aspiration pneumonia was mentioned as a serious consequence of swallowing problems. Further, the participants stated that consequences may be underestimated. Persons may lose weight gradually over a longer period, which may go largely unnoticed when not weighted regularly, so it may look like a less serious problem than is actually the case.

> *"What we sometimes see is that, ehm, the progression of weight loss. Well, if that is really measured over six months, and someone has lost, say half a kilogram every time, then they often look at the last weight and say "oh, that's actually not that much" (…) Then you sometimes see that it can be ten kilograms in six months and then it's rather late in the day." (dietitian 3)*

A decline in mobility and cognition were considered as consequences that may occur when there is a reduced intake of food and fluids. Social aspects of eating and drinking - such as less enjoyment at mealtimes or reduced acceptance by others - may result in an overall decline in the quality of life experienced according to some participants.

> *"The social aspect, where one realises that things are not going so well anymore, that shame also plays a role so that quality of life decreases" (occupational therapist 3)*

When weight loss is not detected in an early stage, it can be difficult to start an effective intervention and stabilize the weight loss, in particular when a person with dementia has less energy, resulting in an insufficient amount of daily nutrition. In this case, participants identified a vicious circle, because eating requires energy, and may become increasingly difficult.

3. *Functioning of the person with dementia:*

Agitation, anxiety, and mood were mentioned as factors affecting eating and drinking.

> *"That they are fed, for example, and it goes too fast, right, the feeling that they have no control. You can become anxious". (speech and language therapist 4)*

The interpretation of mental and cognitive aspects, such as the influence of depression on the intake of nutrition, was experienced as difficult by most participants. Additionally, agitation was frequently observed, in terms of walking away from the table at mealtimes. Being distracted was the most frequently reported cognitive problem. A relationship between distraction during mealtimes and a lower intake of food and fluids was suggested by some participants. Reduced initiative was also expected to be strongly associated with an inadequate intake of nutrition.

> *"People sometimes forget that they've eaten." (speech and language therapist 5)*

Some participants considered physical problems, such as incontinence or urinary tract infection, to influence the intake of nutrition, in terms of not feeling well or walking away from the table. It was mentioned that medication can cause drowsiness, resulting in reduced focus on a meal or (almost) falling asleep, and side effects on intake being underestimated. Pain and feeling sick were also recognized as factors that could influence food intake.

4. Interprofessional collaboration

The participants indicated that often no one has a sufficient overview regarding the development of problems or the overall daily nutritional intake of persons with dementia. It was questioned whether detecting nutritional problems should be the task of nurses only. Some participants felt that every team member should be a stakeholder regarding the detection and management of nutritional problems. Analyzing nutritional problems and subsequently considering consulting a healthcare professional, such as a speech and language therapist or occupational therapist, was pointed out as crucial.

Detection and collaboration between nurses and other healthcare professionals was an important topic of discussion. Nutritional problems are not always detected, due to insufficient knowledge of what these problems are or which healthcare professional to consult. The consequences of nutritional problems were sometimes seen in practice, but not always linked to the appropriate cause(s), resulting in inadequate or late consultation of healthcare professionals. In addition, a lack of continuity at care units - in the sense of increased presence of flex workers - was referred to as a limitation in adequately detecting problems.

> *"Well, it all starts with the person observing, doesn't it? If you have a good permanent team then, ehm, with people who know the residents, yes, then things go well. If you come to a facility with a lot of workers with flexible contracts, then, ehm, where there is a lot of alternation in care... Yes, then I think you can make improvements there." (occupational therapist 1)*

The motivation of a team to provide good care of a person with dementia was experienced to influence the way the team handles nutritional issues.

> *"What kind of team do you have. Because you also have teams that stimulate each other a lot and… "come on, let's get cracking", "we're going to take good care of this resident", and "let's go"… yes, those are much more motivated than the others who can't be bothered." (psychologist 1)*

5. Ethical considerations

Some participants said that opinions on nutritional intake determine the detection and management of nutritional problems in practice, because teams can struggle with handling problems in case of different norms and values of family members.

> *"That can be very difficult at times. I've organised a moral deliberation for such a resident at times, to take a good look and see, like, what are our values and standards and those of the family. On the one hand, you want to allow them room for their own standards and values, but also set a limit somewhere regarding what is acceptable for the resident's safety. So you discuss all those perspectives together." (elderly care physician 2)*

Accepting that safe and efficient eating and drinking is problematic or nearly impossible, was appointed by particpants to result in a struggle for both healthcare professionals and family. They experienced that sometimes persons with dementia have a limited freedom of choice about what to eat and where to eat, and preferences of persons with dementia are ignored.

> *"If he has a cheese sandwich once, he is always offered cheese sandwiches, even though he may want ham. I think that choice is important too." (nurse 1)*

Religion was found to influence decision making and agreement between relatives of persons with dementia and healthcare professionals. Finding the balance between being professional and showing respect towards religion was considered to hold importance.

> *"It's even more important for families from a different background from a religious point of view, like, we must have done everything and then it's in the hands of God or Allah. You must feel that they have tried everything, but they sometimes cross certain boundaries of the care unit or certain caregivers in this." (elderly care physician 2)*

In advanced stages of dementia, nutritional intake may be very limited or even become impossible or unsafe. At such a critical point, decision making is regarded a collaborative task. Differences in norms and values regarding eating and drinking were said to influence decision making, and sometimes result in moral dilemmas. In such situations, it was considered important to keep an open dialogue to reach a mutual decision.

> *"The context allows family to say that it suits him to keep his mouth shut right now and stop eating and drinking, followed by a consensus to accept the behavior. Another family may say "he was never like that", then he probably, ehm, won't have had breakfast or maybe he's afraid or, ehm, he has a rotten tooth. In fact, you have to come to some kind of consensus about what actually suits this person well." (elderly care physician 1)*

6. Environmental factors

Persons with dementia may have difficulty recognizing modern food or utensils in contrast to, for example, traditional china or other dinnerware that they may know from their past.

The use of modern food or utensils can therefore be an influencing factor that may limit their intake of food and fluids during mealtimes. Noise during mealtimes was believed to increase agitation and noise at the care unit was stated as an issue that could be improved.

> *“Sometimes it seems as if a construction worker is at work, loud music, visitors who come in anyway, one joins the meal, the other doesn’t. The walkers among the residents. The unrest. The telephone. Other disciplines coming in during dinner.” (psychologist 1)*

The position when seated at mealtimes was discussed as another environmental factor. The accessibility of a plate or a glass is sometimes hindered when sitting too far away from the table.

> *“The positioning. Not just in terms of who sits opposite whom at the table. Is someone sitting at the correct table height? Is he sitting comfortably in his chair or wheelchair? I regularly visit people whose wheelchair is slightly tilted, whereby they sit with their knees against the table top and cannot reach their food.” (occupational therapist 1)*

The social environment, such as having a meal and activities at the same table, was thought to have an influence on eating and drinking.

> *“If you sit at that dining table all day, right, for coffee and everything, then it’s kind of your hangout. But then it’s not very clear what your starting moment is, like what’s the intention of the activity? Whereas when you’re away from the table, the table is set, like, “come, Mrs Smith, we’re going to eat” and everything’s already there. Then it’s immediately clear, because it won’t take too long before you give a helping hand. And there’s the smell, then you are much further in habituating, like, “oh, I understand what the intention is here”.” (occupational therapist 3)*

Additionally, the influence of the person assisting the persons with dementia was frequently mentioned. Nurses can have limited time, resulting in a hasty offering of food. This may lead to an increased risk of aspiration for persons with swallowing problems. Moreover, eating alone in a room or amidst a group was mentioned as an environmental factor. Given that short timeframes for daily nutritional intake exist at nursing home care units, persons with dementia may lose their appetite and not want another meal, causing a limited nutritional intake.

> *“That people don’t get out of bed until eleven o’clock and then eat breakfast and maybe start another meal an hour or an hour and a half later. But people who go to bed again*

> *very early, just after the evening meal, so that they don't eat anything in the evening. So that time of eating is often quite limited, which reduces the intake." (dietitian 1)*

Ordering of meals with an adapted consistency was mentioned as challenging at weekends, due to financial cuts in the organization or policy, because disciplines such as speech language therapists or dietitians are absent at weekends.

> *"When you go to the kitchen on a Saturday morning, like, we have this and this admission, it's not always easy to get that [meal with adapted consistency] arranged without the advice of a speech therapist or dietician." (nurse 2)*

One has to deal with the supplies of the organization. For instance, the kitchen of the facility does not provide hot meals at different times. Furthermore, a limited selection of food is available for people diagnosed with oropharyngeal dysphagia.

> *"If you now said, for example, like, "I want to have my hot meal at 5 PM or served at 5.30 PM", then, well, no, that's not possible because as a kitchen we have been set up so that it is ready at 12. How can you then respond to the client's wishes and how do you facilitate that?" (psychologist 1)*

Proposed adaptation of the theoretical model

We found complex interactions within each of the aforementioned themes. Further, connections between themes add to the complexity of dementia-related nutritional problems. Based on these findings, we adapted the existing model, showing the relationship between themes (Figure 1). The management of nutritional problems requires interprofessional collaboration, because it is advisable to identify underlying causes in order to start appropriate interventions and prevent or minimize the consequences of nutritional problems. Regarding swallowing problems, the nature and severity of swallowing should be examined by clinical observations, taking the influence of cognitive and behavioral factors into account [7, 21]. Moreover, a mutual understanding of tasks and coordination of addressing nutritional problems is warranted in clinical practice. Ethical factors in turn influence interprofessional collaboration, each team member having their own norms and values and cultural background. These differences affect the interpretation and management of nutritional problems. Finally, we consider a third level of complexity. Analyzing and discussing the themes and codes, different from a unidirectional relationship between themes as displayed in the existing model, we found a bidirectional relationship between observing and analyzing nutritional problems (theme 1) and consequences of nutritional problems (theme 2). Moreover, we found bidirectional relationships between other themes as well. We illustrate the multifactorial nature of nutritional problems resulting in a vicious circle using an example:

Behavioral problems such as food refusal (functioning of the person with dementia) leads to limited or no intake (observing and analyzing nutritional problems). This may result in weight loss and subsequent malnutrition (consequences of nutritional problems), which makes the person with dementia feel sick or weak (functioning of the person with dementia), further leading to increased weight loss (consequences of nutritional problems) or difficulty swallowing (requiring reobserving- and analyzing problems) that may increase the risk of developing aspiration pneumonia (consequences of nutritional problems) when taking action is delayed.

Further, ethical and environmental factor influence nutritional problems more indirectly in comparison to the other themes. Moral dilemmas may occur in decision-making on diagnostics and treatment in advanced dementia, when a vicious circle and subsequent deterioration appears. In these situations, decision making can be difficult. Environmental factors, such as the position of a person and the social environment during mealtimes influence nutritional problems as well, but are more distantly related to the themes in the middle of the model which relate directly to what can be seen and to the persons involved.

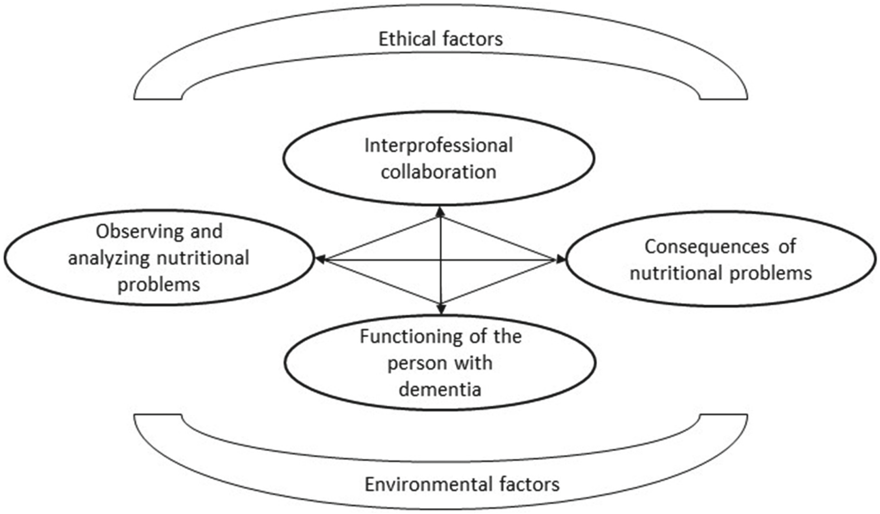

Figure 1. Proposed model of nutritional problems in persons with dementia applicable in daily nursing home practice. It includes the two new themes interprofessional collaboration and ethical factors, and a bidirectional link between the themes.

Discussion

We adapted an existing model comprising four themes regarding nutritional problems, adding two new aspects: interprofessional collaboration and ethical factors (14, 15). As such, this study builds a bridge between the theory around nutritional problems in persons with dementia and daily clinical practice in nursing homes. The other four themes were confirmed in our study by professionals from clinical practice (14, 15); observing and analyzing nutritional problems, consequences of nutritional problems, functioning of the person with dementia, and environmental factors. Beyond these aspects, connections within each theme, between themes, and a bidirectional connection between the themes were identified. This differs from previous models, which describe a more linear connection. Environmental factors influence mealtimes and are therefore most strongly related to functioning of the person with dementia. Interprofessional collaboration and ethical factors are related to the other themes in the model, but mainly to observing and analyzing nutritional problems and minimizing consequences of nutritional problems. The relation between these two themes and functioning of the person with dementia and environmental factors is more indirect, which explains the position in the model. Ethical factors, such as norms and values of healthcare professionals, influence interprofessional collaboration. Additionally, collaboration of the multidisciplinary team influences the timing of observation and analysis.. In case of late timing, for example, a person may have lost a lot of weight and therefore experience more severe consequences. These new findings underline the complexity of nutritional problems in daily clinical practice.

The newly added theme of ethical factors was found before to influence the way nutritional problems are handled, not only by healthcare professionals, but by relatives of persons with dementia as well (15). Norms and values are known to differ per person and are of influence on situations around eating and drinking (3). Persons with advanced dementia depend on decisions taken by healthcare professionals and relatives, because their own decision making capacity is impaired (22, 23). Decision making is considered a struggle for relatives and professionals involved when nutritional intake becomes (nearly) impossible or unsafe, especially when norms and values regarding end-of-life-decisions differ (24). Such end-of-life decisions can be difficult and complex, and should be made as a team and family together with respect towards each other despite possible differences (24-27). In these situations, artificial nutrition and hydration may be considered. However, because observational studies indicate that enteral feeding does not prolong life or improve a person with dementia's quality of life (28-30), this is rarely applied in the Netherlands.

Interprofessional collaboration as a relevant influencing factor was identified as a novel theme as well. In the Netherlands, it is common to work as a team on care units in a nursing home, with nursing staff being the heart of the professional team, supplemented with other healthcare professionals. In most nursing homes, all healthcare professionals - including an elderly care physician as primary practitioner - are employed by the nursing home (31). Although interprofessional collaboration is considered a very important aspect of nursing home care, our study showed that detecting nutritional problems as a team was identified as challenging, referring to a delay in consulting the right expert. However, interprofessional collaboration is necessary to provide adequate patient care, especially in complex cases such as nutritional problems (32, 33). Moreover, our finding that insufficient knowledge of the problems can influence problem analysis and subsequent consultation of the right healthcare professional, was confirmed in earlier qualitative research (34). Another factor that we found to contribute to late detection is the increased use of temporary flex workers to compensate for staff shortages at care units. This underlines the importance of a stable team of professionals who know their residents and are therefore able to timely detect subtle changes and problems. None of the healthcare professionals involved is present all the time, so communication and task division were considered very important by the participants of our study. This is also discussed by Sloane et al. (35), who describe inadequate staffing at care units, which can be linked to logistic limitations.

The results of this study should be interpreted taking its strengths and limitations into consideration. The main strength of this study is the contrasting design compared to other studies, that investigated nutritional problems in persons with dementia by reviewing the literature only, rather than being informed by those working in clinical practice (14, 15). We consider reaching theoretical and inductive thematic saturation, because we identified no new codes and themes during the third focus group discussion and codes regarding the new themes (interprofessional collaboration and ethical factors) were mentioned in each focus group discussion. Moreover, the content of these new themes corresponds with what is known from recent literature about multidisciplinary collaboration more generally (36, 37). We applied the following important qualitative research quality criteria. We performed a member check to support the validity of the study results by sending a brief report to all participants after each focus group for feedback. Moreover, multiple researchers with different research and clinical backgrounds (investigator triangulation) were involved in the data analysis and development of the model to promote credibility.

A potential limitation of this study is possible researchers' bias. The researcher who led the focus group discussions (EvB) was known to several participants as some of them were colleagues. Thus, participants might have been reluctant to share all of their experiences due to this existing professional relationship and knowing EvB was working as a speech and language therapist. However, on the positive side this might have promoted a sense of safety for the participants, encouraging them not to hold back on sharing what they wanted. Another limitation of this study is the absence of family caregivers, despite the fact that they were invited to participate. Family caregivers might have described nutritional problems from another perspective.

Future perspectives

This study adds further support to the view that all aspects related to nutritional problems in dementia should be considered when assessing and subsequently minimizing its consequences. It may be challenging for case managers andcoordinators to keep all team members aware and alert of the complexity of this issue. Also, the growing number of people with dementia [38] requires optimal care models and future research is awaited to demonstrate how nutritional problems in dementia can be managed in the best way possible.

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Marielle Olthof-Nefkens, Christian Bakker and Marieke Perry have no conflict of interest to report.

Data availability statement

The data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Appendix

Table 1. Participant Characteristics

	Focus group 1	**Focus group 2**	**Focus group 3**
N=20	N=6	N=7	N=7
Gender			
Men	1	0	0
Women	5	7	7
Profession			
Speech and language therapist	1	2	2
Occupational therapist	1	1	2
Dietitian	1	1	1
Psychologist	1	1	0
Cognitive rehabilitation therapist	0	1	1
Nurse	1	1	0
Elderly care physician	1	0	1
Total	**6**	**7**	**7**

Table 2. Topic List

Questions	**Prompts**
What eating and drinking problems do you come across in your practice?	*What exactly do you think these nutritional problems are?* *Can you give examples?* *Can you describe an example situation?* *What causes have you identified?*
What consequences do eating and drinking problems have?	*How do you know that?* *Can you give examples?*
What is your role in eating and drinking problems?	*What exactly do you do?* *How?*
When are you called in?	*Who calls you in?* *How do you feel about the timing?*
Do you ever collaborate with someone else when it comes to eating and drinking problems?	*Who do you work with?* *Why do you collaborate with them?* *How does that work?* *How often do you work together?*
What issues have we not yet discussed?	

3

Understanding mealtime behavioral problems in nursing home residents living with dementia: A group concept mapping approach

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Abstract

Background

Persons with dementia frequently experience mealtime behavioral problems that can result in reduced or lack of intake of food or fluids. Multiple underlying causes and expressions of mealtime behavioral problems complicate its interpretation and intervention, because problems originating from cognitive and functional decline and behavioral changes may interact. Healthcare professionals and family caregivers may encounter a variety of practical and moral dilemmas in dealing with these problems. We aimed at a better understanding of mealtime behavioral problems and related complex issues in nursing home residents with dementia from a daily practice perspective.

Methods

We used a mixed-method Group Concept Mapping approach in this study, and collected data online with a panel of 67 healthcare professionals, researchers and relatives from across The Netherlands. The participants contributed to either or all of the following phases: 1) the generation of ideas (brainstorm), 2) sorting, and 3) rating of the ideas. Subsequent phases included data analysis with Groupwisdom® software and interpretation of the results. Multidimensional scaling and hierarchical cluster analysis resulted in a concept map visualizing the coherence and importance of ideas. Bridging values were calculated, with low values indicating a distinct, clear concept.

Results

Brainstorming resulted in 285 statements representing 85 ideas. The concept map visualized three categories capturing ten clusters which describe the management of mealtime behavioral problems, causes of mealtime behavioral problems, and expressions and interpretations of mealtime behavioral problems. Concepts reflecting direct consequences, ethical components, and considerations to handle challenging situations overlapped on the concept map with the highest bridging values (range 0.58-0.87).

Conclusion

This study added to unraveling the complex nature of mealtime behavioral problems, as perceived in practice. It is recommended to comprehensively analyze all components in the management of these problems, in particular being aware of ethical factors and align care for residents with dementia accordingly.

Keywords

Concept mapping, dementia, behavioral problems, nutrition, hydration

Introduction

Mealtime behavioral problems often occur in persons with dementia, and can cause a critical status of nutrition and hydration when these problems impede the intake of food and fluids (1-5). In this study, we refer to mealtime behavioral problems as any behavior that may indicate resistance of residents with dementia to eat or drink, not exclusively observed during mealtime. Mealtime behavioral problems occur in any type of dementia but express differently across the phases of dementia (6, 7). Previous studies have mainly focused on older persons with dementia, but appetite and eating changes are reported among the most common behavioral changes in persons with young-onset dementia as well (8). Therefore, in this study we consider a broad spectrum of dementia, regardless of age of onset and dementia type.

Malnutrition is a common consequence of mealtime nutritional problems, and the prevalence rates of malnutrition resulting from insufficient nutritional intake vary (5, 9). A recent meta-analysis reports 32.5% of older adults with dementia being malnourished, and 54.7% being at risk of malnutrition. In general, prevalence rates increase in persons who are diagnosed with dementia and reside in a long-term care setting, and rise even further with increasing care needs (9). Poor nutritional intake may lead to dehydration as well, and is reported in 0.8%-38.5% of nursing home residents (10). Adverse outcomes of mealtime behavioral problems further include reduced quality of life, aspiration pneumonia, and an increased mortality risk (5, 11-14).

Mealtime behavioral problems are caused by a variety of factors (15, 16). Physical and cognitive changes associated with dementia result in functional decline and may lead to increased difficulties with expressing needs, greater dependency upon others during meals, and problems such as apraxia (1, 5). Deterioration of sensory capabilities may lead to an altered sense of taste and smell, influencing the experience of eating and drinking (1). In addition to functional problems originating from physical and cognitive decline, behavioral symptoms may relate to, display or exacerbate at mealtimes (16, 17).

Behavioral changes that result from the dementia and complicate the intake may be expressed during the mealtime by throwing food or cutlery, refusing to eat or leaving the table (1, 11, 18). Such behavioral changes can be perceived as challenging by professionals and relatives who assist persons with dementia during mealtimes. They may also encounter moral dilemmas when situations around intake of food and fluids lead to severe malnutrition and decisions on dietary interventions need to be made (2, 14, 19).

The variety of underlying causes and expressions of mealtime behavioral problems complicate their interpretation and related interventions, also because problems originating from physical and cognitive decline, and behavioral changes often interact (3, 16, 18).

Our study aimed to improve the understanding of complexity of mealtime behavioral problems in persons with dementia. We describe and define these issues to better unravel and collaboratively manage these problems in daily practice.

Materials and methods

Study design

In this study, a group concept mapping approach was used to map mealtime behavioral problems that impede the intake of nutrition and hydration in nursing home residents with dementia.

Group concept mapping is a mixed-method approach which combines quantitative and qualitative research methods to map ideas of a group of participants (20). The input of participants enables researchers to clarify a complex topic (21). The approach has been used in various contexts, including health care. Group concept mapping consists of five phases and Table 1 provides an overview of the actions, actors and results of Group Concept Mapping per phase. Data was collected online using Groupwisdom® (22). The participants contributed to the data collection between November 2021 and February 2022 (phases 2 and 3). Data analysis and interpretation (phases 4 and 5) took place from March 2022 until November 2022. The researchers analyzed and prepared each step of data collection.

Sampling and participants

In group concept mapping, the aim is to capture a broad perspective of the subject, and therefore the participants need to be selected carefully (23). We purposefully sampled persons we considered experts on the subject of this study, and approached healthcare professionals, researchers, and relatives of persons with dementia. Participants were eligible when meeting the criteria of 1) having experiential or theoretical knowledge of mealtime behavioral problems impeding intake of nutrition and hydration in persons with late onset or young onset dementia, and 2) having some digital skills, because of online data collection. We aimed to include 100 participants to ensure a variety of input from participants with different backgrounds. In this study, we refer to young-onset dementia when the onset of the dementia was below the age of 65 years and to late-onset dementia when diagnosed at the age of 65 or over (24). Healthcare professionals and relatives were recruited from nursing homes affiliated with the University Knowledge Network of Older Adult Care Nijmegen (UKON) and the Young-onset Dementia Knowledge Center, the Netherlands. Researchers were approached via the network of the research team, and developers of the current Dutch guideline on this topic were recruited as well (25). No incentives were used for recruitment and participants did not receive financial compensation.

Data collection and analyses

Phase 1: preparation

The process of group concept mapping starts with a central problem or question, that is translated into a focus prompt to guide the content of the data collected. The focus prompt we developed was: *'When I think of mealtime behavioral problems in people with dementia, I think of…'*. It was pilot tested by five healthcare professionals, which resulted in a quite broad but relevant range of statements. We maintained the formulation in order to generate a comprehensive range of ideas. The participants received instruction per email to create an online Groupwisdom account and gave their consent online. Subsequently, they were asked to provide the following demographic characteristics: gender, profession, and years of experience with mealtime behavioral problems, target group of experience (young-onset dementia, late-onset dementia, or both) and type of experience (role as relative, clinical, theoretical). All participants who registered and gave their consent were invited to at least the generation of ideas (brainstorming activity), but also to contribute to the structuring of statements (sorting and rating activity).

Phase 2: generating ideas (brainstorm)

In a brainstorming activity, participants were asked to complete the focus prompt. The participants could share as many ideas as they wished. After closing the brainstorm activity, researchers EvB, JvdS, and MP reduced the statement list by removing duplicates and merging similar content. For example, statement 41 was merged with 10 other statements that contained the same content, varying from pushing away a plate, shoving a plate away, pushing a hand away, making a gesture of rejection etc. The duplicate statements were removed and reformulated into one statement that captured all examples with a similar meaning. Further, statements that contained multiple ideas were split; statement 48 was split into not wanting to eat, and not being hungry. Lastly, statements were reformulated to improve clarity. For example, statement 249 'A way for the person with dementia to maintain some control' was reformulated to 'That defensive behavior is a way for the resident to retain some sense of control'. We aimed at a maximum of 100 statements as recommended in literature (23, 26).

Phase 3: Structuring of statements

The structuring of statements consisted of a sorting and importance rating activity. For the sorting activity, participants reviewed the final statement list, created piles with statements they considered to represent similar concepts, and formulated a label for each pile. Subsequently, participants were asked to rate the statements on a 5-point Likert-scale, ranging from not important at all to very important (1-5). The results were reviewed by EvB, JvdS, and MP in order to determine what entries of individual participants could be included for data analysis. A minimum of 75% completion of both the sorting and rating task was maintained for inclusion in data analysis. Additional criteria that we used for reviewing the sorting data sets were minimal coherence of the statements in the piles, and an average of 10-15 piles per participant (23). Raw sorting and rating results were checked by EvB, and in case of doubt, the data set was discussed with JvdS and MP, before reaching consensus on a final decision. We included 33 data sets for data analysis from participants who both completed the sorting and rating activity.

Phase 4: Data analysis

In data analysis, a similarity matrix was formed based on the 33 data sets from the sorting task. This matrix reflects the number of participants that sorted each pair of statements together. Next, multi-dimensional scaling was applied which resulted in a point map visualizing how statements were sorted based on the similarity matrix. Statements that were sorted together frequently in a pile are depicted close proximity on the point map. The amount of points represent bridging values (range 0-1); the lower the value, the more defined the concept of a group of statements is. A high bridging value implicates a less defined concept, because in this case the statement was linked to statements that are more distant on the point map. Further, a stress value that represents the goodness of fit was calculated for the point map. A high stress value indicates discrepancy between the similarity matrix and visualization of the data in the point map. The cut-off value in group concept mapping is .39 (23, 26, 27). Subsequently, hierarchical cluster analysis was applied, based on the positions of the statements on the point map along with the bridging values. Hierarchical cluster analysis results in a transformation on another level, zooming out from individual statements to conceptual themes (or clusters). This is visualized via a cluster map capturing the concepts and suggesting labels for the overarching concepts based on the labels provided by the participants during the sorting activity. To decide about a cluster map solution, we assessed a range of 3-20 clusters as recommended (23). The basic principle in hierarchical cluster analysis is to arrange clusters in a hierarchical tree structure and choose a cluster solution that is the most desirable for interpretation of the concept being studied. Because the group concept mapping approach does not provide specific techniques or actions to carefully handle possible influence of the research team (28), we employed standards for analyses of qualitative data. Researchers EvB, JvdS, and MP individually examined and merged the clusters in a stepwise manner, followed by comparing proposed adaptions and solutions, and discussing them until reaching consensus. This resulted in the selection of a concept map with 10 clusters that described mealtime behavioral problems in the most detail.

Phase 5: Interpretation of the concepts

The proposed concept map was discussed by the research team and an independent expert group that was involved with the study, resulting in a final concept map. The expert group consisted of an independent panel of various professionals and caregivers that advised the research team. The expert group members did not participate in data collection.

Table 1. Description of the phases of the group concept mapping

Study phase	Actions	Actors	Results
Phase 1: preparation **September - October 2021**	- Writing a concept mapping plan	EvB	- Concept mapping plan
	- Developing a focus prompt	EvB, MP, JvdS, CB, RK	
	- Pilot test of the focus prompt with five healthcare professionals	EvB	- Focus prompt (to guide data collection)
	- Adjustment of the focus prompt	EvB, MP, JvdS, CB, RK	- Final focus prompt
Phase 2: generating the ideas (brainstorming activity) **November – December 2021**	- Sharing individual ideas by completing the focus prompt in online individual brainstorm session	69 participants	- 285 statements
	- Idea analysis after brainstorm session: reducing the statement list by removing identical statements, splitting in case of >1 idea, combining overlapping statements	EvB, MP, JvdS	- Final statement list of 85 ideas resulting from idea analysis
Phase 3: structuring of statements (sorting and rating activity) **January – February 2022**	- Structuring 85 statements in piles and providing labels	41 participants	
	- Rating 85 statements on importance	40 participants	
	- In- and exclusion of datasets for data analysis	EvB, MP, JvdS	- 33 sorting and rating data sets included in data analysis

Table 1. Continued.

Study phase	Actions	Actors	Results
Phase 4: analysis (representation of ideas in concept map) **March-June 2022**	- Choosing a scenario for data analysis	EvB, MP, JvdS	- Final scenario based on data sets of 33 participants who completed both the sorting and rating activity
	- Multidimensional scaling		- Point map visualizing 85 ideas - Concept map describing 10 clusters based on the 85 ideas
	- Hierarchical cluster analysis		- Cluster rating map describing the lowest and highest rates (both on statement level and cluster level)
Phase 5: interpretation **June-November 2022**	Discussing the results	EvB, MP, JvdS, CB, RK, expert group	Final labels and descriptions of the concepts on the cluster map

Results

Participant and process characteristics

A total of 93 participants out of 14 nursing homes were assigned to Groupwisdom®. The response rate for the brainstorming activity was 72%, for the sorting activity 44%, and for the importance rating activity 43%. Most participants (85%) were female and most (90%) were healthcare professionals (Table 2). The participants had a mean of 12.5 (9.4) years of experience in dealing with mealtime behavioral problems in people with dementia, and most participants (58%) had knowledge of problems related specifically to older people with dementia (Table 2).

The focus prompt was completed 285 times by 67 participants who formulated one or more statements in the brainstorm activity (phase 2). The sorting activity was completed 41 times and the rating activity 40 times, of which 33 data sets were included for data analysis. Multidimensional scaling using the sorting data resulted in a point map. In hierarchical cluster analysis, we agreed upon a final concept map of 10 clusters comprising statements regarding mealtime behavioral problems (Figure 1, final concept map). The stress value of the concept map was 0.26 (range 0-1), indicating a high goodness of fit and with it sufficient representational validity. An overview of the clusters with descriptions along with the statements per cluster is provided in Table 3. The clusters and statements are sorted in ascending order of bridging values.

Table 2. Participant characteristics

Participant characteristics N=67 (72%)	
Sex (%)	
Male	9 (13%)
Female	57 (85%)
Other	1 (2%)
Role (%)	
Relative	3 (4%)
Researcher	4 (6%)
Healthcare professional	60 (90%)
- Nursing staff	*16 (26%)*
- Care staff	*5 (8%)*
- Nurse	*7 (12%)*
- Psychiatric nurse	*2 (3%)*
- Kitchen/mealtime support staff	*2 (3%)*
- Physician	*12 (20%)*
- Psychologist	*9 (15%)*
- Speech therapist	*8 (13%)*
- Dietician	*5 (8%)*
- Occupational therapist	*5 (8%)*
- Physiotherapist	*4 (7%)*
- Spiritual counsellor	*1 (2%)*
Years of experience, mean (SD), range	12.5 (9.4), 1-45
Knowledge and experience related to[1]	
People with young-onset dementia	6 (9%)
People with late-onset dementia	38 (58%)
Both people with young- and late-onset dementia	22 (33%)

[1] missing

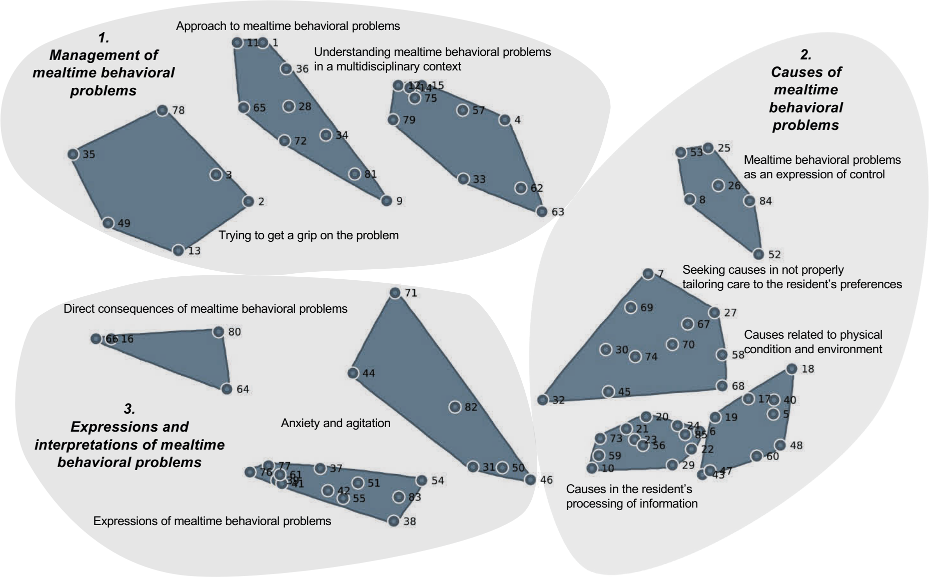

Figure 1. Final concept map representing mealtime behavioral problems

Legend: Visualization of 85 statements in ten clusters which describe 1) the management of mealtime behavioral problems, 2) causes of mealtime behavioral problems, and 3) expressions and interpretations of mealtime behavioral problems.

Interpretation of the concept map

The final concept map represents 85 statements divided into 10 different clusters. The average bridging value on cluster level was 0.41 (range 0.05-0.87), and the average importance rating value was 3.51 (range 3.06-3.78). The three clusters regarding causes of mealtime behavioral problems had the lowest bridging values, which indicates that these are the most defined concepts. *Direct consequences of mealtime behavioral problems* had the highest bridging value, implying that this cluster is not well defined. Overall, three overarching categories can be considered, capturing the management, causes, and expressions and interpretations of mealtime behavioral problems. We initially did not consider solutions with just a few clusters because we anticipated loss of nuance in capturing a complex phenomenon such as mealtime behavior. The 10-cluster solution provided sufficient detail to represent the findings of this study in a final concept map which we regard the main result. Next, we experienced that in grouping clusters to facilitate an integrated discussion, three groups of clusters allowed for a coherent interpretation and discussion. We then decided to empirically test how closely our grouping would resemble the software's 3-cluster solution. It matched fully without any of the statements moving between clusters and this legitimizes visualization of the concept map with 10 clusters within the three larger concepts. We describe these three larger concepts (categories) and their meaning below.

1. Management of mealtime behavioral problems

The clusters *'Approach to mealtime behavioral problems', 'Trying to get a grip on the problem',* and *'Understanding mealtime behavioral problems in a multidisciplinary context'* describe the search for underlying factors and challenges in interpretation of the problems. Several statements illustrate the complexity and considerations in this search, reflected by 'When you stop offering food and drinks' (Statement 28) and 'How I can better understand or reduce the mealtime behavioral problems' (Statement 79). Further, these clusters include personal experiences regarding the management of mealtime behavioral problems, as expressed in statement 49: 'Feeling of helplessness of the person who assists in feeding'. Various statements describe the necessity of multidisciplinary collaboration and involvement of family, such as the consultation of specific discipline(s) (Statement 14), and the importance of identifying the cause of defensive behaviors, as a multidisciplinary team in collaboration with family (Statement 33 and 57). The cluster *understanding mealtime behavioral problems in a multidisciplinary context* was considered of the highest importance by the participants (3.98), as were the individual statements in this cluster (Table 3). On the contrary, the cluster *Trying to get a grip on the problem* was given the lowest importance rating of all clusters (3.07). This cluster also had the second highest bridging value on cluster level (0.76), which means that the statements in this cluster were often linked to other clusters by participants. For example, the statement with the highest individual bridging value (0.97) was Compulsion (Statement 13), which was not only sorted in *Trying to get a grip on the problem,* but also frequently linked to *Mealtime behavioral problems as an expression of control* and *Understanding mealtime behavioral problems in a multidisciplinary context.*

2. Causes of mealtime behavioral problems

Causes related to physical condition and environment, Causes in resident processing of information, and *Seeking causes in not properly attuning care to the resident's preferences* comprise concepts regarding the search for causes and the variety of these causative factors. Participants distinguished between factors that are related closely to the resident such as (*Causes in resident's processing of information),* causes connected to the person who is involved at mealtimes (*Seeking causes in not properly attuning care to the resident's preferences)*, and more indirect factors (*Causes related to physical condition and environment). Causes in resident's processing of information* had the lowest bridging value on cluster level, which indicates a relatively well defined concept and a high level of agreement on the collection of statements in the cluster. These direct causes result from altered stimulus processing and/or functioning due to the dementia, such as inability to clearly articulate opinions or thoughts (Statement 59), not recognizing food or cutlery (Statement 73), or causes such as apraxia (Statement 23). The concept that describes causes in the resident's processing of information was the most defined, which was reflected in the lowest bridging value on both cluster- (0.05) and statement level (0.00-0.13). This indicates that participants consider mealtime behavioral problems resulting from altered stimulus processing and functioning due to dementia a clear concept. Moreover, the other clusters that describe possible causes (*Causes related to physical condition* and *Seeking causes in not properly attuning care to the resident's preferences)* have low bridging values as well, which illustrates that (the search for) the underlying mechanisms of mealtime behavioral problems also is a well-defined concept.

3. Expressions and interpretations of mealtime behavioral problems

Expressions and interpretations of mealtime behavioral problems illustrates various examples of the problems as seen in clinical practice, for example making a gesture of rejection with the hands, such as pushing food, drinks or cutlery away, shoving the plate away or pushing the caregiver's hand away (Statement 41). The bridging values of the statements are relatively low (range 0.22-0.36), which shows agreement of participant on these examples of the behavior as observed in clinical practice. *Direct consequences of mealtime behavioral problems* had the highest bridging value of all clusters (0.87), indicating that the statements in this cluster were linked the most frequently to the other clusters of the concept map. Risk of choking (Statement 44), and discomfort (Statement 31) are examples of statements that are included in the cluster *Anxiety and agitation*. It was mentioned that mealtime behavioral problems imply defensiveness, and not aggression (Statement 71). *Mealtime behavioral problems as an expression of control* includes statements of the resident's autonomy and the question of being in charge. This is visualized in Statement 84, for example, which describes mealtime behavioral problems as a way to retain some sense of control for the resident. Examples of expression of control by the resident are also mentioned in *Seeking causes in not properly tailoring care to the resident's preferences,* reflected by whether there is a desire to not live anymore (statement 7), unwillingness or ignorance (statement 27), and refusing food because the resident does not want to eat (statement 30 and 32). The similarity in examples explains why *mealtime behavioral problems as an expression of control* and *Seeking causes in not properly tailoring care to the resident's preferences* are positioned close together on the concept map. Overall, the bridging values on both cluster and statement level are average (range: 0.54-0.62), implying that expression of control is a somewhat defined concept.

Table 3. Overview of clusters and description of the content including mean bridging and rating values

Cluster label, (bridging value), and description of the content[1]	Statements
Causes in the resident's processing of information (0.05) *Causes of mealtime behavioral problems resulting from altered stimulus processing, and causes resulting from altered functioning due to the dementia.*	23 Apraxia (difficulty performing particular movements, such as using cutlery). 0.00
	56 Not being aware of feeling hungry, not being hungry (anymore). 0.00
	73 That the resident does not recognise the food or cutlery. 0.01
	20 Reduced speed of information processing of the resident. 0.02
	21 That a resident is occupied with something other than eating at mealtime. 0.02
	24 Resident's decreased appetite. 0.05
	59 That the resident with dementia is unable to clearly articulate his/her opinions or thoughts. 0.05
	85 That the resident is too tired to eat. 0.05
	29 Altered sensation in the mouth. Examples: the fork/spoon does not feel comfortable, the resident does not like the consistency of the food. 0.06
	10 Decreased comprehension of the resident with dementia. 0.07
	22 That a resident does not like the smell or taste of the food. 0.10
	6 Depression. 0.13
Causes related to physical condition and environment (0.21) *Causes of mealtime behavioral problems that are medical in nature or stem from an unsuitable environment. These are external to the resident, who has no control over them, but is affected by them.*	19 Physical complaints, such as abdominal pain or nausea 0.08
	43 Oral pain. 0.11
	47 Dental problems. 0.11
	5 Whether the resident is experiencing pain. 0.21
	60 Under-stimulation, for example due to lack of atmosphere and engagement during the meal. 0.24
	17 Swallowing problems. 0.25
	18 The final stage of life, which results in a slow loss of appetite. 0.36
	40 Side effects of medication. Examples: dry mouth, altered taste, fungal infection, or drowsiness. 0.25
	48 Too many stimuli in the environment during mealtimes, causing the resident to, for example, become distracted. 0.28

Table 3. Continued.

Cluster label, (bridging value), and description of the content[1]	Statements
Seeking causes in not properly tailoring care to the resident's preferences (0.24) *Looking for causes of mealtime behavioral problems in how the resident deals with eating and drinking and with the situation at mealtimes, and whether care is properly attuned to the resident's preferences.*	45 Offering food in an unsuitable way. Examples: too fast, at the wrong time, pace too high, the person assisting is not calm enough, style of communication is not in line with resident needs. 0.09 32 Refusing food because the resident does not want to, is unable to or no longer understands how to eat and drink. 0.16 74 Whether the conditions for eating are present, such as whether the resident is awake/rested. 0.16 68 The sitting position. 0.21 70 Whether there is a negative experience with food and drink in general or with a specific dish. 0.23 58 Resident inadequately prepared for the meal, for example, [therefore] incomprehension, no smell of food, [no] quiet environment. 0.24 27 Whether there is unwillingness or ignorance on the part of the resident. 0.36 30 Not wanting to eat anymore. 0.26 69 The entire situation at the mealtime, such as: where does the resident sit in the living room/bedroom, table companions, commotion in the room due to, e.g., radio/TV or people talking. 0.26 67 Whether the resident likes the food. Examples: is this what the resident is used to eating, did he/she like this before, the food is too bland/too heavily seasoned, the resident does not like the consistency. 0.28 7 Whether there is a desire not to live anymore. 0.39
Expressions of mealtime behavioral problems (0.30) *Examples of how mealtime behavioral problems can be expressed by a person with dementia*	54 Anger. 0.22 42 Throwing cutlery or tableware. 0.23 55 Playing with the food. 0.26 83 Agitated behaviour. 0.27 51 Frustration. 0.30 37 Biting off, chewing the food well and then spitting it out. 0.31 39 Turning away or lowering the head when food or drink is offered. 0.32 41 Making a gesture of rejection with the hands, such as pushing food/drink/cutlery away, shoving the plate away or pushing the caregiver's hand away. 0.32 38 Letting food or drink drip from mouth. 0.33 61 Using words/phrases indicating rejection when offered food or drink, such as 'leave me alone'. 0.33 77 Hitting. 0.36 76 Keeping mouth closed when offered food. 0.42

Table 3. Continued.

Cluster label, (bridging value), and description of the content[1]	Statements
Anxiety and agitation (0.33) *Anxiety and agitation related to mealtime behavioral problems resulting in uncomfortable situations*	46 Not calm enough to eat or remain seated at the table, getting up and walking away from the table. 0.19 50 Anxiety. 0.19 31 Discomfort. 0.28 82 That the resident will not accept help. 0.28 71 That it is defensiveness, not aggression. 0.48 44 Risk of choking, with fear of aspiration. 0.58
Approach to mealtime behavioral problems (0.36) *Approach to mealtime behavioral problems from the healthcare professional's perspective, including considerations and policy regarding eating and drinking and involving loved ones / family members*	11 Supporting and providing information to loved ones / family members. 0.23 1 Discussing eating and drinking policies with loved ones / family members. 0.24 36. Discussion about initiating tube feeding. 0.26 28 When you stop offering food and drink. 0.35 34 The need for suggestions to deal with mealtime behavioral problems. 0.35 72 That there is no point in pushing; accept that this is (sometimes) part of it. 0.44 65 Accepting defensive behaviours as the dementia progresses. 0.47 81 That eating and drinking is important for residents with dementia, from every perspective. 0.47 9 Whether there is something to be gained from attention to the way in which food and drink are offered. Examples: presenting multiple choices, patience and time of the person offering, going along with the experience of the resident with dementia. 0.48

Table 3. Continued.

Cluster label, (bridging value), and description of the content[1]	Statements
Understanding mealtime behavioral problems in a multidisciplinary context (0.37) *A multidisciplinary approach to jointly identify the cause of mealtime behavioral problems and use an appropriate intervention within the legal framework.*	15 Multidisciplinary collaboration. 0.26 75 That it is problem behaviour requiring a multidisciplinary approach/analysis based on a biopsychosocial explanatory model. 0.26 14 Consultation of specific discipline(s). 0.27 79 How I can better understand or reduce the defensive behaviour 0.34 57 Identifying the cause, as a multidisciplinary team in collaboration with family. 0.36 33 The importance of finding the cause of defensive behaviours. 0.40 4 A comprehensive analysis of the cause of the resident not eating. Examples: a physical or psychological cause. 0.43 62 What it means when the resident says 'no' when food or drink is offered. 0.44 12 The Compulsory Care Act (Wzd). 0.45 63 That defensive behaviour does not automatically mean someone does not want to eat or drink something. 0.45
Mealtime behavioral problems as an expression of control (0.58) *The resident's degree of control/being in charge and autonomy* .	8 Whether refusing to eat is a conscious choice. 0.54 52 Loss of control and of sense of being in charge. 0.54 26 Resident expresses autonomy. 0.57 53 That a sense of being in charge is important. 0.59 84 That defensive behaviour is a way for the resident to retain some sense of control. 0.60 25 To what extent the resident is in control. 0.62

Table 3. Continued.

Cluster label, (bridging value), and description of the content[1]	**Statements**
Trying to get a grip on the problem (0.76) *Challenges regarding the problem of reduced intake and feelings of not being understood and being powerless on the part of family members/ loved ones and care professionals (do we do something about the behavior itself or about nutrition)*	2 Preventing deficiencies by enriching food. 0.59 3 Thinking about what products a resident does take in. 0.61 78 Family willing to do whatever it takes to stimulate intake 0.66 49 Feeling of helplessness of the person who assists in feeding 0.84 35 Lack of understanding on part of family 0.89 13 Compulsion. 0.97
Direct consequences of mealtime behavioral problems (0.87) *Possible direct consequences of defensive behaviours in the form of reduced intake and resulting weight loss and dehydration*	64 An umbrella term for behaviour resulting in impaired fluid and nutritional intake. 0.68 80 That many residents with dementia eventually show Alzheimer cachexia (extreme emaciation). 0.83 16 Reduced intake that may cause weight loss, inadequate fluid and/or nutritional intake or malnutrition. 0.95 66 Risk of dehydration. 1.00

[1] The clusters and according statements per cluster are arranged in ascending order of bridging values

Discussion

Using the group concept mapping method, this study identified three categories capturing ten concepts that describe mealtime behavioral problems in persons with dementia, 1) management of mealtime behavioral problems; 2) causes of mealtime behavioral problems; and 3) expressions and interpretations of mealtime behavioral problems. The low bridging values of the three clusters about causes of mealtime behavioral problems (category 2) indicate this is a relatively well-defined category, other categories were less well-defined. Statements that refer to ethical factors emerged in all three categories of the concept map; not only in the third category (e.g. Not accepting help), but also in the first (e.g. When you stop offering food and drink), and second category (e.g. Whether there is a desire to not live anymore). This implies that in the reasoning of healthcare professionals these factors tend to be overlooked or not addressed as an important issue of its own. This study provides insight in the way healthcare professionals view the coherence and interplay between factors around mealtime behavioral problems.

Our study emphasizes the complex nature of mealtime behavioral problems, given that the clusters do not all reflect well defined concepts. Mealtime behavioral problems are complex and dynamic, because various factors are interrelated, complicating the analysis of the problems and care demands. Hodiamont et al. confirm this finding, stating that every care situation is unique and requires different knowledge (29). Corazza et al. suggest that a different attitude towards clinical complexity, such as mealtime behavioral problems, is needed. When only separate components of clinical problems are analyzed, the present interactions between factors are not considered, leading to misunderstanding and not properly attuned care. Corazza et al. recommend that both biological and non-biological (e.g. environmental, socioeconomic, cultural and behavioral) factors should be considered in complex clinical problems, so that the interventions are tailored to the resident's needs (30).

The search and considerations to analyze and interpret mealtime behavioral problems and to find a way to manage the problems are reflected in the clusters of the concept map. Several clusters had high bridging values, and therefore were frequently linked to other clusters. A possible explanation could be that participants had some overarching considerations and sorted the statements in the context of linking causes and consequences, rather than labeling it as a separate concept. Although ethical dilemmas were mentioned, like autonomy of the resident and issues regarding treatment decisions, these statements were spread across the concept map and therefore the participants may have considered these dilemmas as part of a more functional problem, rather than an entity of its own. However, it is known that mealtime behavioral problems can affect both healthcare professionals and relatives (31, 32). Prior research mentions distress, anger and depression in relatives of persons with dementia (33, 34). In our study, discussions between healthcare professionals and family about treatment, such as stopping to offer food and drinks or initiating tube feeding, were mentioned. Barrado-Martin et al. confirmed this finding, mentioning that situations around mealtime behavioral problems sometimes even lead to conflicts or disagreement (2). In these situations a moral case deliberation can be helpful to come to a shared decision (35, 36). Moreira et al. (37) found considerable levels of burden, even with a short time of disease and few changes in the resident's diet. Because persons involved consider these problems as challenging and burdensome, this stresses the need to understand and properly manage mealtime behavioral problems in clinical practice.

The presence of three different clusters describing possible causes of mealtime behavioral problems implies that participants think it is important to unravel different types of causes. These findings are supported by previous research that found correlations between environmental factors and cognitive function on food intake difficulties in residents with dementia, such as distraction by a turned on radio or television (38). Jung et al. described in a scoping review that cognitive and physical function, close relationships with family and caregivers, and physical environment are the highest contributing factors to mealtime behavioral problems (3). Similar factors are mentioned by Fostinelli et al., further adding cultural norms and values as an influencing factor (39). The concept *Seeking causes in not properly tailoring care to the resident's preferences* describes how the resident deals with eating, drinking, and the situation at mealtimes, and whether help is properly attuned to the resident's preferences. Every person has unique needs and preferences, and therefore the care provided should be in line with these needs to optimize eating performance (31, 40). Moreover, unraveling the cause(s) is the starting point for further management of problems in clinical practice (41, 42). The focus on unraveling causes can be explained by the fact that the majority of our participants were healthcare professionals. Healthcare professionals are trained to search for underlying causes and to find effective interventions to minimize consequences of problems they encounter in clinical practice (6). The clusters that describe expressions of mealtime behavioral problems and consequences are in line with existing literature (3, 43).

Strengths and limitations

A strength of this study is the diversity in backgrounds of the participating healthcare professionals in all phases of data collection. Also, the participants had experience with mealtime behavioral problems in both younger and older persons with dementia. The final concept map is based on diverse perspectives and therefore reflects a comprehensive picture of the problems as seen in clinical practice. Further, the overall response rates were sufficient and the stress value indicated a high goodness of fit with a value of .26 (average range .21-.37) (23, 26, 27).

Although we included less than the 100 participants we aimed for, the information they provided was rich and therefore the contributions to the final concept map cover a broad range of content. This added to the reliability and validity of this study (27).

This study has some limitations. First, because the majority of participants were healthcare professionals, the perspectives from relatives and researchers may have been underrepresented, despite proactive recruitment of participants. The results should therefore be interpreted in that context, because the adequacy of the content is bounded by the source of input (26).

Second, interpretation of the results may be influenced by variations in cognitive style of the participants. However, this is a common flaw of the method, and integration in the conceptualization process is needed in further development of methods of group concept mapping (28, 44). In group concept mapping, it is unknown to the researchers what the thoughts and interpretations of the participants were during data collection, especially during the sorting activity when they have to conceptualize ideas. This may have resulted in the risk that the research team not accurately reflected the content as seen through the eyes of the participants. On the other hand, Stoyanov et al. (44) suggest that a concept map can be considered as a group's common cognitive contract that can consolidate individual differences and may serve as a tool for managing diversity in a group of participants. Compared with purely qualitative methods, the strength of group concept mapping lies in the combination of a qualitative and quantitative approach, using multivariate statistical analyses to conceptualize generated ideas from relevant stakeholders (28).

In conclusion, this group concept mapping study added to unraveling the complex nature of mealtime behavioral problems, as perceived by healthcare professionals, relatives, and researchers. We conclude that the overall concept cannot be defined easily and the different clusters overlap and interact with each other. The findings from this study indicate that ethical factors should be considered during identifying and management of mealtime behavioral problems. These ethical factors were present across all clusters, and refer to autonomy of the resident but also considerations about when to stop offering food and fluids. These factors are often overlooked, but this study emphasizes the importance. Therefore, it is recommended to comprehensively analyze all components in the management of mealtime behavioral problems, in particular being aware of ethical factors and align the provided care accordingly to residents with dementia. Multidisciplinary teams are advised to explicitly address ethical issues in team meetings when discussing treatment decisions. Based on the findings of this study, we recommend to view a situation from a broad perspective, and to not only focus on the behavior and related solutions, but also reflect on ethical considerations in general and themes such as respect for the autonomy of the resident versus sufficient intake of food and fluids. Further, it is recommended to actively involve family caregivers in the interpretation of behavioral symptoms, and subsequent care goals. With increased awareness of ethical factors, healthcare professionals may be better able to assess situations and to consider a moral deliberation in complicated cases or possible disagreements about the treatment decisions. We recommend further study on ethical factors and how they relate to mealtime behavioral problems. The search for balance between on the one hand autonomy of the resident and quality of life, and on the other hand sufficient nutrition is a continuous search and challenge. We recommend further research that explores the way professionals deal with ethical issues, such as the urge for weight maintenance while not forcing to eat, preserving the quality of life as much as possible while respecting the presumed wishes of the resident. As this study mainly describes the perspectives from healthcare professionals, it is recommended to further investigate the viewpoints of relatives and researchers in future research to further explore whether these views differ.

Declarations

Ethics approval and consent to participate

This study was conducted according to the principles of the Declaration of Helsinki (version 13) (45). The study was declared exempt from the Medical Research Involving Human Subjects Act by the research ethics committee of the Radboud university medical center Nijmegen (File number CMO: 2021-13085). All participants gave their informed consent online after creating an online Groupwisdom account.

Consent for publication

Not applicable.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Authors’ contributions
All authors contributed to the conceptualization and methodology of the study. EvB was responsible for software programming, preparing and executing data collection, and visualization of the data. Data were analyzed by EvB, MP, and JvdS. The original draft was prepared by EvB, MP, and JvdS; CB and RK reviewed and edited the draft. JvdS supervised the research activities and was responsible for the project administration.

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4

Incidence of resistive behavior adversely affecting the intake of food and fluids in younger and older people with dementia

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Abstract

People with dementia can develop resistive behavior that adversely affects the intake of food and fluids. This behavior, including (non-)verbal refusal, such as pushing away cutlery or an assisting person, can lead to malnutrition, dehydration, and increases mortality risk. However, it is unclear how common this behavior is in residents with young-onset dementia (YOD; symptoms under age 65) and how it compares to late-onset dementia (LOD). This study investigated the incidence and characteristics of these behaviors. We conducted a prospective cohort study with a twelve-month follow-up period, including thirty-six care units comprising 424 beds in twelve nursing homes across the Netherlands. Monthly registration of the total number of residents at risk informed the denominator, and the numerator was determined by the number of incident cases. Of forty reported cases, sixteen were incident, resulting in an incidence rate of 32/1000 person-years. The incidence rate was higher in residents with YOD (45/1000 person-years) than in LOD (26/1000 person-years). In all cases, at least two symptoms were observed. In fourteen of sixteen cases there was a prioritized global care goal aimed at providing comfort care and accept persisting resistive behavior. The findings might imply that young residents are at greater risk of developing these behaviors, and professional and informal caregivers should be prepared for the occurrence of specific resistive behaviors in younger residents.

Keywords
Incidence rates, resistive behavior, intake of food and fluids, dementia, young-onset dementia

Introduction

Resistive behavior that adversely affects the intake of food and fluids can occur in persons with dementia. Such behavior may involve verbal or non-verbal refusal of food, including turning away one's head or not opening one's mouth when food is offered. Other symptoms include spitting out food, pushing away help or food, hitting, and walking away from the table (1-4). This behavior can lead to malnutrition, dehydration, and an increased mortality risk (5, 6). Moreover, the behavior can be perceived as burdensome to family and to professional caregivers, even with a short duration of the disease (7-9).

Resistive behavior can occur in all types of dementia and disease stages (4, 6). Research on prevalence and incidence rates of such behavior is scarce, although there are indications that it occurs in over one-third (35.7%) of residents with dementia (4). Most research involves late-onset dementia (LOD), although it is known that neuropsychiatric symptoms such as agitation and apathy are more frequently present in persons with young-onset dementia (YOD; symptoms under age 65) compared to LOD (10-13). Therefore, the aim of this study was to determine the incidence of resistive behavior that adversely affects the intake of food and fluids and describe its characteristics and treatment strategies in nursing home residents with YOD and LOD.

Materials and methods

Design

Prospective cohort study with a twelve-month follow-up period (14).

Population

We needed an estimate for the number of care units to include in our study, regardless of the age of onset. We aimed to include 180 residents from care units for people with LOD and YOD special care units, with on average nine residents with dementia per care unit. This number was estimated based on prior Dutch research in a cohort of older nursing home residents with dementia (15). Although we did not expect the incidence to be lower in YOD, we used the available rate for older persons.

Nursing homes affiliated with either the University Knowledge Network of Old Age Care Nijmegen (UKON) or the Young Onset Dementia Knowledge Center were invited to participate in this study with two LOD care units and, if present, YOD special care units. In this study, we refer to YOD when the first symptoms of dementia occur before the age of 65 (12, 13, 15). We aimed to include an equal number of YOD and LOD care units. To obtain incidence rates, during 12 months, we followed all residents with a dementia diagnosis who resided on the participating care units (Table 1).

Table 1. Monitoring criteria for residents with resistive behavior affecting intake of food and fluids.

Inclusion criteria	Exclusion criteria
The resident has an established diagnosis of dementia	Residents with Huntington Disease, Acquired Brain Injury, Down Syndrome or Korsakov's Disease
One or more of the following behaviors hindering intake of food and fluids: - Turns his/her head away - Refuses to open mouth - Keeps hands in front of mouth - Spits out food - Grabs, hits or bites the nurse - Plays with or throws cutlery / crockery - Bites the cutlery/crockery - Pushes cutlery/crockery/food/nurse away - Throws food - Stands up from the chair or leaves the table - Nods 'no' - Refuses help during mealtime - Refuses food verbally	
The behavior adversely affecting intake of food/fluids occur at least two times a week	
There is a change in behavior regarding intake of food/fluids that leads to a severely diminished or absent intake of food/fluids causing weight loss, dehydration or an increased risk of weight loss or dehydration in the short term. An extra indication is discussing the case during a regular doctor's visit	The behavior is caused by a delirium or obvious physical cause (such as improperly fitting dentures, urinary tract infection, pneumonia, gastroenteritis, pain etc.)

Data collection

The participating care units appointed a contact person prior to data collection, including nursing staff (17), managers (2), support staff (2), psychologists (3) and activities counselors (2). We informed all contact persons from the 36 care units in online meetings and instructed them how to apply the inclusion criteria (Table 1). Team members could also attend. A binder containing study Information regarding the study, including flyers for resident representatives were distributed to each care unit. The contact persons were asked to fill in the SNAQ (16) informing possible weight loss, and a form that captures the intake of food and fluids over the past seven days.

Incidence rates

We monitored the care units from October 2022 until October 2023. We collected baseline information for each care unit and subsequently obtained the relevant data for the incidence rates monthly via the contact persons. The total number of residents per care unit with a dementia diagnosis who were at risk of developing resistive behavior was registered at baseline and subsequently each month to calculate the denominator for the incidence rate. The numerator was determined by the number of incident cases that were included in the study during the follow-up period.

Characteristics of incident cases

Additional descriptive data was registered by the contact person via data entry software (Castor edc 2022.5.0.0 – 2023.4.0.0 and Microsoft Access Database 2019). When a case was identified, patient representatives were asked to provide informed consent (IC) to collect data from the medical record and through observations. If IC was not provided, only anonymous basic information was collected for calculating the incidence rates.

Resistive behavior

We registered the date of onset of the resistive behavior, and whether the resident had experienced prior episodes of similar behavior. Characteristics of the behavior were registered using an observational form that was developed based on a prior study on the topic covering examples of the behavior (17). These characteristics were part of the inclusion criteria (Table 1). The observational form was developed by nursing students, using an existing guideline about resistive behavior as the basis, and a literature study to inform any updates needed, and the raw data of the prior study on the topic. The form was constructed for young- and late onset dementia. It was not formally validated, but the previous version that was part of the guideline had been used in clinical practice. The form was completed using information from an observation, choosing one or more of thirteen pre-structured items regarding the type of behavior and an option to report other behavior.

Residents

Resident characteristics that were collected included diagnosis, age at onset, sex, year of birth, and year of admission to the nursing home.

The contact persons retrieved the following characteristics from the resident's medical record, when IC was provided:

- The dementia type, reported as Alzheimer's dementia, frontotemporal dementia, vascular dementia, dementia with Lewy Bodies (including Parkinson dementia), mixed

dementia of Alzheimer's disease and vascular dementia, other mixed dementia, and other dementia type.
- Comorbidity as classified using part H of the Older Persons and Informal Caregivers Minimum Dataset (TOPICS-MDS) questionnaire;(18)
- The prioritized global care goal, reported as: 1) symptomatic, i.e. aimed at well-being and quality of life, additional prolonging of life undesirable, 2) palliative, i.e. aimed at well-being and quality of life, irrespective of shortening or prolonging of life, 3) curative, i.e. aimed at life prolongation, 4) maintaining function, 5) not (yet) determined, and 6) other. The palliative and symptomatic care goals both represent comfort care goals as they refer to comfort, quality of life and well-being, but differ concerning whether prolongation of life is desirable;
- The treatment decision, categorized using the following options: 1) to no longer stimulate eating/drinking, providing comfort care and acceptance of mealtime behavioral problems, 2) to administer artificial nutrition and hydration, 3) to solely administer artificial hydration, and 4) other.

Dementia severity was classified using the Bedford Alzheimer Nursing-Severity Scale (BANS-S) (19, 20). This scale contains seven items scored 1 to 4 for dressing dependency, sleeping, speech, eating dependency, muscles, mobility, and eye contact. The total score varies from 7 - which indicates no impairment - to 28, with a score of 17 or higher indicating severe dementia.(21) After approximately four weeks, the contact person registered whether the behavioral symptoms were still present, and whether any additional disciplines were involved, such as a speech and language therapist, occupational therapist, dietitian or psychologist.

Data analysis

We calculated incidence rates for the entire group and for YOD and LOD separately. We calculated the denominator for the incidence rates in person-years for the total number of residents at risk per care unit per month. We imputed the data with at-risk numbers in the nearest months in a few cases of missing any monthly at-risk numbers. The numerator was determined by the number of cases of resistive behavior affecting intake of food and fluids which were reported during follow-up time and met our inclusion criteria. We calculated 95% confidence intervals for the incidence rates based on a Poisson distribution and expressed the values in numbers per person-years (22).

Participant characteristics including demographic data and additional data on the characteristics of resistive behavior were described in frequencies and percentages. Descriptive data were compared for the YOD and LOD groups. We did not use formal statistical tests to compare the groups, due to the small group sizes.

Ethical considerations

This study was conducted according to the principles of the Declaration of Helsinki (version 13).(23) The study was declared exempt from the Medical Research Involving Human Subjects Act on August 3, 2021 by the research ethics committee of the Radboud university medical center Nijmegen (File number CMO: 2021-13085). All participants (or patient representatives) provided IC. The protocol of the cohort study was registered at the Open Science Framework platform on October 2, 2022 (14).

Results

A total of 36 dementia long-term special care units were included in this study, comprising seventeen (47%) special care units for residents with YOD, fifteen (42%) special care units for residents with LOD, and four (11%) units with both YOD and LOD residents. We followed a total of 424 residents, including 178 (42%) YOD residents and 246 (58%) LOD residents. During the follow-up period with an average of 13.5 months, resistive behavior adversely affecting the intake of food and fluids was reported 40 times (24 YOD, 16 LOD). This number included four cases with several separate periods of these symptoms in two residents. A total of sixteen cases (9 YOD, 7 LOD) were included, and additional information on the behavioral characteristics was collected (Table 2). We excluded 24 cases (15 YOD, 9 LOD), because these were prevalent cases at baseline (14; 58% of excluded cases), or did not meet our inclusion criteria (10; 42%), referring to no dementia/unknown diagnosis, low frequency of the behavior, or no consequences such as weight loss or (risk of) dehydration.

Incidence of resistive behavior

The incidence was 32/1,000 person-years, with a higher incidence rate in YOD residents (45/1,000 person-years) compared to LOD residents (26/1,000 person-years; Table 2). The 95% confidence intervals overlapped, indicating no significant differences between the incidence rates for YOD (21-85) and LOD (11-54). Cases were reported from all involved facilities, with minimal variation in incidence between the facilities.

Table 2. Incidence rates

	Total	YOD*	LOD†
Number of care beds (percentage)	424	178 (42%)	246 (58%)
Number of bed months	5615,4	2412,9	3201,8
Number of bed months in years	467.9	201.1	266.8
Number of potential new cases (percentage)	40	24 (60%)	16 (40%)
Incidence rates	0.032	0.045	0.026
Incidence rates per 1000 person-years (95% CI)	32 (20-55)	45 (20-85)	26 (6-44)

** Young-onset dementia*
† Late-onset dementia

Characteristics

Among the sixteen incident cases, we received eight full reports of the residents' characteristics and resistive behavior affecting their intake of food and fluids. Data of the remaining cases (N=8) was incomplete due to the type of consent provided. Most reported cases, both LOD and YOD, concerned a female resident (13 of 16 cases; 81%) with an average age of 66 years (range 55-95) compared to a mean age of 63 in men (range 57-69 years). The mean (±SD) age of the residents was 63.2±5.33 years with YOD, and 90.1±6.1 with LOD. All LOD cases were female, and 6 of 9 YOD cases concerned a female as well (67%). Alzheimer's disease was the most common cause of the dementia (9 of 16 cases; 56%). Average dementia severity was 16 (range 11-20) on the BANS-S, with a mean score of 15 for YOD and 17 for LOD. The mean length of stay (±SD), from admission to reported behavior in months, was 16.8±9.44 months with YOD, and 61.29±25.86 with LOD. Comorbidity varied from none, to single, to multiple comorbid diseases.

The characteristics of resistive behavior varied, with 'turning his/her head away', 'pushes cutlery/crockery/food/nurse away', and 'stands up from the chair or leaves the table' being most often reported. These characteristics were similar for YOD and LOD residents, although on average more symptoms were reported for LOD (5 symptoms) compared to YOD residents (2 symptoms) (Table 3).

Table 3. Characteristics of resistive behavior

Age	***Sex***	***Dementia type***	***Severity of dementia*** ***BANS-S (range 7-28)***	***Comorbidity***	***Length of stay (from admission to reported behavior in months)***	***Prior episode of resistive behavior***	***Descriptions of resistive behavior affecting intake of food and fluids***	***Prioritized global care goal and treatment decision****	***Follow-up time (moment of report until end of follow-up)***	***Status at follow-up***
Young-onset dementia										
55	F	Alzheimer's dementia	-†	None	12	Yes (2021)	-	-	11 months and 2 days	*Behavioral problems still present*
57	M	Frontotemporal dementia	-	-	8	No	-	-	3 months and 29 days	*Died*
61	M	Frontotemporal dementia	-	-	-	-	Turns his/her head away Throws food Stands up from the chair or leaves the table	Palliative To no longer stimulate eating/drinking, providing comfort care and acceptance of behavioral problems and to provide an alternative type of food	3 months	*Died*
70	F	Other:: Primary Progressive Aphasia	20	Involuntary urine loss (incontinence) Depression	20	No	Stands up from the chair or leaves the table Other: resident walks or runs away from the living room in case of distraction	Symptomatic Other: consultation of a dietitian for suitable advice on the intake of food and fluids	2 months and 10 days	*Behavioral problems still present*

Table 3. Continued.

Age	***Sex***	***Dementia type***	***Severity of dementia*** ***BANS-S (range 7-28)***	***Comorbidity***	***Length of stay (from admission to reported behavior in months)***	***Prior episode of resistive behavior***	***Descriptions of resistive behavior affecting intake of food and fluids***	***Prioritized global care goal and treatment decision****	***Follow-up time (moment of report until end of follow-up)***	***Status at follow-up***
62	F	Alzheimer's dementia	-	Asthma, chronic bronchitis, emphysema or CARA/COPD Suspected type of cancer or malignant condition	10	No	Pushes cutlery/crockery/food/nurse away Stands up from the chair or leaves the table	Symptomatic	23 days	*Died*
68	F	Alzheimer's dementia	11	Central nervous system disease (Parkinson's' disease, Multiple Sclerosis, epilepsy)	18	Yes (2022)	Pushes cutlery/crockery/food/nurse away Stands up from the chair or leaves the table	Symptomatic	12 months and 20 days	*No behavioral problems*
68	F	Alzheimer's dementia	11	Central nervous system disease (Parkinson's' disease, Multiple Sclerosis, epilepia)	18	Yes (2022)	Pushes cutlery/crockery/food/nurse away Stands up from the chair or leaves the table	Symptomatic	12 months and 20 days	*No behavioral problems*
69	M	Other (not specified)	17	Asthma, chronic bronchitis, emphysema or CARA/COPD	39	No	Turns his/her head away Other: lies down in bed and cuts off contact with nurse	Palliative To no longer stimulate eating/drinking, providing comfort care and acceptance of behavioral problems	5 months and 1 day	*Died*

Table 3. Continued.

Age	*Sex*	*Dementia type*	*Severity of dementia* *BANS-S (range 7-28)*	*Comorbidity*	*Length of stay (from admission to reported behavior in months)*	*Prior episode of resistive behavior*	*Descriptions of resistive behavior affecting intake of food and fluids*	*Prioritized global care goal and treatment decision**	*Follow-up time (moment of report until end of follow-up)*	*Status at follow-up*
59	F	Other: Probable Alzheimer's dementia or frontotemporal dementia	-	-	9	Yes	Turns his/her head away Refuses to open the mouth	Symptomatic	4 months and 17 days	*No behavioral problems*
Late-onset dementia										
81	F	Alzheimer's dementia	16	None	35	No	Turns his/her head away Refuses to open the mouth Spits out food Plays with or throws cutlery/crockery Stands up from the chair or leaves the table Nods 'no' Refuses help during mealtime Refuses verbally	Symptomatic Other: To consult a specific discipline	8 months and 19 days	*No behavioral problems*

Table 3. Continued.

Age	*Sex*	*Dementia type*	*Severity of dementia* *BANS-S (range 7-28)*	*Comorbidity*	*Length of stay (from admission to reported behavior in months)*	*Prior episode of resistive behavior*	*Descriptions of resistive behavior affecting intake of food and fluids*	*Prioritized global care goal and treatment decision**	*Follow-up time (moment of report until end of follow-up)*	*Status at follow-up*
81	F	Alzheimer's dementia	16	None	35	No	Turns his/her head away Refuses to open the mouth Spits out food Plays with or throws cutlery/crockery Stands up from the chair or leaves the table Nods 'no' Refuses help during mealtime Refuses verbally	Symptomatic Other: To consult a specific discipline	8 months and 19 days	*No behavioral problems*
95	F	Alzheimer's dementia	15	Asthma, chronic bronchitis, emphysema or CARA/COPD	49	Yes (2023)	Turns his/her head away Refuses to open the mouth Plays with or throws cutlery/crockery Refuses help during mealtime Refuses verbally Other: plays with clothes, says 'I can do it myself' or 'No, I have had enough'	Symptomatic To no longer stimulate eating/drinking, providing comfort care and acceptance of behavioral problems	4 months and 3 days	*Behavioral problems still present*

Table 3. Continued.

Age	***Sex***	***Dementia type***	***Severity of dementia BANS-S (range 7-28)***	***Comorbidity***	***Length of stay (from admission to reported behavior in months)***	***Prior episode of resistive behavior***	***Descriptions of resistive behavior affecting intake of food and fluids***	***Prioritized global care goal and treatment decision****	***Follow-up time (moment of report until end of follow-up)***	***Status at follow-up***
95	F	Alzheimer's dementia	15	Asthma, chronic bronchitis, emphysema or CARA/COPD	49	Yes (2023)	Turns his/her head away Refuses to open the mouth Plays with or throws cutlery/crockery Refuses help during mealtime Refuses verbally Other: plays with clothes, says 'I can do it myself' or 'No, I have had enough'	Symptomatic To no longer stimulate eating/drinking, providing comfort care and acceptance of behavioral problems	4 months and 3 days	*Behavioral problems still present*
89	F	Alzheimer's dementia	18	Type of cancer (malignant condition) Hearing loss Visual problems	61	No	Turns his/her head away Refuses to open the mouth Refuses verbally	Palliative To no longer stimulate eating/drinking, providing comfort care and acceptance of behavioral problems	1 month and 4 days	*Died*

Table 3. Continued.

Age	***Sex***	***Dementia type***	***Severity of dementia*** ***BANS-S (range 7-28)***	***Comorbidity***	***Length of stay (from admission to reported behavior in months)***	***Prior episode of resistive behavior***	***Descriptions of resistive behavior affecting intake of food and fluids***	***Prioritized global care goal and treatment decision****	***Follow-up time (moment of report until end of follow-up)***	***Status at follow-up***
95	F	Alzheimer's dementia	19	Diabetes Mellitus Heart failure, myocardial infarction or other type of heart disease Joint wear (osteoarthritis, rheumatism) Bone decalcification (osteoporosis)	100	No	Turns his/her head away Refuses to open the mouth Pushes cutlery/crockery/food/nurse away	Symptomatic To no longer stimulate eating/drinking, providing comfort care and acceptance of behavioral problems	10 months and 29 days	*No behavioral problems*
95	F	Alzheimer's dementia	19	Diabetes Mellitus Heart failure, myocardial infarction or other type of heart disease Joint wear (osteoarthritis, rheumatism) Bone decalcification (osteoporosis)	100	No	Turns his/her head away Refuses to open the mouth Pushes cutlery/crockery/food/nurse away	Symptomatic To no longer stimulate eating/drinking, providing comfort care and acceptance of behavioral problems	10 months and 29 days	*No behavioral problems*

* Palliative and symptomatic treatment goals represent comfort care goals that both refer to comfort, quality of life and well-being, but differ as to whether prolongation of life is desirable.

† Missing value due the type of informed consent (-)

Among the sixteen incident cases, three residents had prior episodes of resistive behavior, and two experienced multiple episodes during the follow-up period. In fourteen of sixteen cases there was a prioritized global care goal aimed at providing comfort care (3 palliative, 11 symptomatic goals), and in two cases this was unknown. The most frequently reported treatment decisions (7 of 16 cases; data on treatment decisions not available in six cases) were: to no longer stimulate eating/drinking, along with providing comfort care and accepting the behavioral problems and possible negative consequences. Other reported treatment decisions were to consult a specific discipline (3 of 16 cases). In none of the cases it was decided to administer artificial nutrition or hydration. At follow-up, five residents had died, four still had behavioral symptoms, and seven no longer experienced problems.

Discussion

This is the first study to investigate the incidence of resistive behavior that adversely affects the intake of food and fluids in nursing home residents with LOD and with YOD. The overall incidence rate was 32/1,000 person-years, with higher rates for residents with YOD (45/1,000 person-years) compared to those with LOD (26/1,000 person-years).

The behavioral symptoms that were reported most often in our study, both for residents with LOD and YOD, were 'turning one's head away'; 'pushes cutlery/crockery/food/nurse away'; and 'stands up from the chair or leaves the table. The types of behavioral symptoms have also been reported in prior research (24-27). Resistive behavior, such as turning one's head away or not opening one's mouth, has been observed more in residents who need full assistance.(4, 28-30) In our study, only one resident was able to eat independently, while all others needed partial or full assistance. Resistive behavior in such cases may reflect a desire to remain independent, with refusal of help as a result (31-34). Although residents with LOD showed more behavioral symptoms, the types of symptoms were similar for both groups. Further, in most cases the behavioral symptoms did not persist, although two residents experienced multiple episodes during follow-up. This suggests that early identification of behavioral symptoms is crucial and that it is necessary to monitor the situation over an extended period. In this way, potential serious consequences and the escalation of the behavior can be minimized. As described in previous research (3), there is no linear behavior-consequence relationship when it comes to eating and drinking problems; rather, various factors play a role and this differs per situation. Therefore, it is important to remain alert regarding these factors.

In this study, the most frequently reported global care goals were aimed at prioritizing comfort care. In most of these cases, orders were developed to no longer stimulate eating and drinking and to accept persisting resistive behavior and possible negative consequences. This also entailed that in none of the cases artificial food or fluids were considered and thus not provided. This reluctance aligns with prior research which emphasizes negative outcomes related to artificial food and fluids (35).”

Prior studies primarily focused on behavior in residents with LOD and did not aim at obtaining incidence figures. The outcomes from this study suggest a higher incidence of resistive behavior affecting intake of food and fluids in residents with YOD. The higher incidence may relate to a greater frequency of neuropsychiatric symptoms in general in YOD residents, and appetite and eating changes being common in YOD residents (36-40). The low overall incidence that we found might be explained by the definition we used that not only included the resistive behavior but also the negative consequences such as weight loss and dehydration. The relatively low incidence of resistive behavior with negative consequences may indicate that the management of these behaviors in Dutch nursing homes is effective, at least in preventing serious consequences, such as weight loss and dehydration.

Strengths and limitations

An important potential limitation of this study could be contact persons under reporting cases with resistive behavior, resulting in underestimating the incidence rate. We mitigated this risk through close monitoring, with monthly communication with the assigned contact persons who were locally overseeing data collection. Further, we received cases from all twelve participating nursing homes. Minimal variation in incidence between facilities; therefore, comparable low rates across facilities, increases our confidence in the procedures and reporting. Moreover, more cases were reported than we would include in the study based on the criteria.

Conclusions and implications

The overall incidence of resistive behavior adversely affecting the intake of food and fluids with impact such as weight loss and dehydration in Dutch nursing homes was low, with a higher incidence for residents with YOD compared to LOD. These findings might imply that young residents are at greater risk of developing these behaviors, and therefore, professional and informal caregivers should be more aware of the risk of occurrence of these symptoms in younger residents. Further research on the incidence of resistive behavior should include monitoring larger samples of residents with YOD and LOD to allow for statistical testing of possible differences. In-depth monitoring of minor and major symptoms over time and a long follow-up of outcomes is recommended, to explore possible targets for timely interventions, and to limit possible negative consequences and escalation. In this study, we focused on cases of severe resistive behavior requiring at least two symptoms. We recommend to consider intervening when observing a single symptom to prevent escalation. Given the potential for resistive behavior to persist and the complexity of factors contributing to eating and drinking problems, it is recommended to integrate preventive strategies and tailored management approaches into conceptual models. This could improve both the identification and management of resistive behavior, ultimately enhancing care and outcomes for persons with dementia.

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Declaration of interest statement

The authors report no conflicts of interest.

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5

Navigating resistive behavior that adversely affects the intake of food and fluids in people living with dementia: a multiple case study

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Abstract

Background
People living with dementia can develop resistive behavior during eating and drinking, complicating food and fluid intake.

Objective
This study aimed to explore how relatives and healthcare professionals navigate care decisions, and to identify possible ethical dilemmas related to decision making and the impact on all involved.

Methods
A qualitative multiple case study was conducted, nested in a prospective study. We identified cases where resistive behavior was observed in a person with dementia. We aimed at interviewing at least one relative and three healthcare professionals closely involved with a specific case. The interviews were transcribed verbatim and analyzed thematically.

Results
A total of sixteen cases were eligible, of which five cases were included. Four cases concerned people residing in a nursing home, and one person was living at home. Three themes were identified from a total of sixteen interviews: 1) fundamental tension between autonomy and adequate nutrition, 2) understanding the person with dementia and the resistive behavior, and 3) solutions: searching for a personalized approach. This study contributes to the understanding of decision making in situations involving resistive behavior that adversely affects the intake of food and fluids.

Conclusions
The findings emphasize the importance of a personalized approach that balances autonomy, quality of life, and adequate nutrition to provide the best care for people with dementia. The perspectives elicited in this study can help multidisciplinary teams to navigate this complex decision-making process.

Keywords
Behavioral and psychological symptoms of dementia; Dementia; Alzheimer’s Disease; Young-Onset Dementia

Introduction

People living with dementia can develop resistive behavior affecting the intake of food and fluids. These behaviors include verbal and non-verbal behaviors, such as walking away or throwing with food or cutlery. Such behavior can have serious consequences, for example malnutrition, dehydration, and weight loss (1-4). Causes of resistive behavior during eating and drinking may relate to a variety of factors. Due to cognitive decline, persons may have trouble understanding how to eat or be less able to eat independently. For some, resisting help during mealtimes may reflect an attempt to maintain autonomy. Dealing with such situations presents significant challenges for both relatives and healthcare professionals and can lead to ethical dilemmas concerning decision-making around food and fluid intake (5, 6).

Towards the end of life, decreased oral intake can result in a variety of reactions from relatives. Some may accept the decrease in oral intake, while others view continued intake as part of the "battle against the disease" (6, 7). In these situations, the two main options are to either accept the consequences of reduced intake and focus on comfort care or to administer artificial nutrition and hydration. However, the administration of artificial nutrition and hydration is not recommended in guidelines, because it does not necessarily prolong life (8, 9). Moreover, it may also result in a decreased sense of comfort during the palliative phase, which in turn may lead to ethical challenges (1, 10-15). Relatives often feel that it is important to explore the different options, because for some, withholding nutrition and hydration can be difficult to accept. Not providing food and fluids can be experienced as giving up on the person with dementia, and relatives sometimes want to be sure that every available option has been tried (1, 16, 17). Furthermore, relatives may experience not providing artificial nutrition and hydration as taking someone's life (1). This may be the case in cultures where the provision of food and fluids is an expression of love and care or is related to religious beliefs (16-18).

Decision making regarding treatment options is often complicated when there is a discrepancy between the views of relatives and those of healthcare professionals. This can be related to the grief experienced by relatives, who may struggle to accept the nearing end of life. These differing views can lead to disagreement between relatives and healthcare professionals,(14, 19-21) complicating the decision-making process and increasing burden already experienced by relatives. To support achieving consensus about decisions regarding end-of-life care in complex cases, a moral case deliberation can be helpful because it provides a structured approach in which all perspectives are considered (6, 22).

So far, the way sensitive decisions are being made remains unclear, as are the ways in which persons involved deal with possible ethical dilemmas surrounding resistive behavior that adversely affects the intake of food and fluids. The aim of the present study was to explore how relatives and healthcare professionals navigate treatment and care decisions in persons with dementia whose behavior complicates the intake of food and fluids. We aimed to identify possible ethical dilemmas related to the decision making and the impact on all involved.

Methods

Study design

A qualitative multiple case study design with an explorative approach was chosen nested in a larger study on resistive behavior affecting the intake of food and fluids in dementia. We aimed to include six different cases, to describe a diverse range of situations related to resistive behavior that adversely affects intake of food and fluids. Individual interviews were conducted with involved relatives and healthcare professionals. The findings are presented in accordance with the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist (23) (supplementary material A).

Population

A total of 36 care units in 12 Dutch nursing homes were monitored for a period of 12 months. Residents were recruited from 17 special care units for younger persons with dementia, 15 special care units for older persons with dementia, and four mixed care units for both younger and older persons with dementia. The persons residing on the care units were monitored from October 2022 to October 2023. The nursing homes were in various regions of the Netherlands and were affiliated with the University Knowledge Network of Old Age Care Nijmegen (UKON) or the Young-Onset Knowledge Center. Each incident case was considered for inclusion in the current multiple case study. A contact person was appointed at each participating care unit during the follow-up period. The contact person screened cases following the inclusion criteria, and discussed eligibility of the case with the researcher EVB. The potential interviewees were recruited and invited after selection of an eligible case.

Cases

Cases were deemed eligible for inclusion when a dementia diagnosis had been established. Additional inclusion criteria were the presence of one or more behavioral symptoms adversely affecting the intake of food or fluids, including verbal and non-verbal behaviors, such as walking away or throwing with food or cutlery. Further, the behaviors occur at least twice a week, and result in significant consequences such as weight loss or dehydration. In this study, we considered decision making as a broad concept including “small” decisions such as whether or not to adjust the approach of the person with dementia during mealtime, in addition to major decision such as considering to administer artificial nutrition and hydration.

Further, purposeful sampling was aimed for achieving a diversity of cases based on the following criteria:

- ethnic minority;
- age at first dementia symptoms onset, referring to young-onset dementia (YOD) or late-onset dementia (LOD);
- whether artificial nutrition and hydration was provided or considered;
- level of agreement on treatment decision among professionals;
- level of agreement on treatment decision between relatives and healthcare professionals;
- a moral case deliberation to gain consensus about the treatment decision.

Participants

Candidate participants closely involved with the specific case in question were selected and invited for a one-time individual interview by the researcher EVB. Eligible participants were relatives, physicians, nurses, psychologists, occupational therapists, dietitians or speech and language therapists. The contact person of the care unit informed the person with dementia and their representative about the study and invited them to join. In addition, the involved (elderly) care physician or psychologist assessed the appropriateness of also inviting the person with dementia for an interview. Exclusion criteria for relatives were limited communication skills or a high level of caregiver burden. When a relative or healthcare professional agreed to participate, the researcher (EvB or AvD) contacted the participant by e-mail or telephone and scheduled a date, time and location for the interview. Healthcare professionals were only invited for an interview when the person with dementia and their representative agreed to join the study. Prior to the interview, the participant was informed, verbally and in writing, about the study and asked to sign the informed consent form. The researcher co-signed the form to confirm having provided adequate information to the participant. Participants were assured that they would be unrecognizable in publications, and they were permitted to withdraw their consent at any time. Persons with dementia who had the capacity to do so gave their informed consent on their own behalf.

Data collection

Semi-structured interviews with relatives and healthcare professionals were conducted by researchers EvB or AvD. The time and location of the interview were agreed upon with the participant. At the time of the study, AvD was working as an (elderly) care physician in training, EvB was a PhD candidate. Neither researcher had any prior relationship with participants. Only the researchers and participants were present during the interviews, and field notes were made after the interviews. The interviews were audio-recorded. The interviews were conducted using a topic guide, which was not pilot tested before data collection (supplementary material B). The participants were offered the transcripts to provide feedback. None of them had additional comments.

Data analysis

The audio recordings of the interviews were transcribed verbatim. Thematic content analysis was used and supported by Atlas.ti 9.1.6.(24). The researchers moved back and forth between data collection and analysis. The data were analyzed by researchers EvB and AvD, both trained in the basics of conducting qualitative research, while the research team's expertise covered extensive qualitative research. EvB and AvD independently coded five interviews, and a comparison of the codes in Atlas.ti showed sufficient consensus. EvB subsequently coded the other interviews independently based on the preliminary codebook. Data analysis started with an open coding process in which new codes were identified inductively, and the preliminary codes were subsequently discussed by AvD, EvB and MP. Next, EvB, AvD and MP formulated categories and finally themes. These were discussed by EvB, AvD, MP en JvdS until consensus was reached, and subsequently discussed with RK and CB as well. With backgrounds as general practitioner and methodologist, MP and JvdS are experienced dementia care researchers with experience in qualitative research.

Ethical considerations

This study was approved by the research ethics committee of the Radboud university medical center Nijmegen (file number CMO: 2021-13085) on March 22, 2022.

Results

A total of 16 cases were eligible for inclusion, in five of which consent was provided. This resulted in 16 interviews with one person with dementia, five relatives and eleven healthcare professionals involved in these cases. In consultation with the contact person of the care unit, we decided that some relatives were not eligible as participation was estimated as too burdensome. For example, in cases when the person with dementia recently died. Other candidate participants involved with the eligible cases did not want to participate in the study. The cases were drawn from three different nursing homes, with one case involving a person with dementia living at home. The interviews were conducted between June 2023 and June 2024 and lasted 20 to 50 minutes. Interview locations included quiet spaces in nursing homes (n=5), participants' home (n=3), general practices (n=2), and online via Microsoft Teams (n=6). A detailed overview of the cases and participants is provided in Table 1.

Table 1. Description of the included cases and participants.

	Sex	YOD/LOD	Ethnic minority	Behavioral symptoms	ANH considered or provided*	Moral case deliberation	Agreement on treatment decisions	Description of the situation	Interviewees
Case 1	F	LOD	Yes	Refuses food verbally Stands up from the chair or leaves the table	No	No	Yes	This lady lost weight, and was offered a personal preference diet. After three months, she stopped losing weight, stopped refusing meals, and looked much more fit and alert.	Relatives: *Niece*
Case 2	F	YOD	Yes	Turns her head away Stands up from the chair or leaves the table	No	No	Yes	This person had multiple episodes of resistive behavior. In 2022, she first exhibited resistive behavior. She started to eat and drink again after receiving specific medication (stomach protection). In 2023, the case was reported again, because she started refusing food again. This time, she exhibited the same symptoms, but experienced increased difficulty with focusing on meals, and did not accept help easily. Effective communication was limited due to a language barrier (Dutch was her second language).	Relatives: *Husband* Healthcare professionals: *Nursing staff (2)* *Healthcare psychologist* *Nurse practitioner*

Table 1. Continued.

	Sex	YOD/LOD	Ethnic minority	Behavioral symptoms	ANH considered or provided*	Moral case deliberation	Agreement on treatment decisions	Description of the situation	Interviewees
Case 3	M	YOD	No	Refuses food verbally Turns his head away	No	No	Yes	Signs of resistive behavior had been present for two weeks when the case was reported. He lost about 1 kilogram of weight per week. He died after 4 months.	Relatives: *Son* Healthcare professionals: *Healthcare psychologist* *Nurse practitioner*
Case 4	F	LOD	No	Refuses help during mealtime	No	No	Yes	Signs of resistive behavior for over 2 years. She wanted to be in control but did not understand how to eat anymore.	Relatives: *Sister* Healthcare professionals: *Nursing staff (2)*
Case 5	F	LOD	No	Refuses food verbally	No	Yes	No	This case involved a woman with advanced dementia who lived at home with her husband. In 2023, a moral case deliberation was held to come to agreement how to approach the situation around intake of food and fluids. She lost approximately 30 kilograms of weight over the course of 5-6 years. She did not accept that she had a diagnosis of dementia.	Person with dementia Relatives: *Husband* Healthcare professionals: *General practice-based assistant practitioner* *General practitioner* *(Elderly) care physician*

*ANH refers to artificial nutrition and hydration

Thematic analysis resulted in three themes, capturing the dynamics surrounding resistive behavior in persons with dementia. These themes are 1) fundamental tension between autonomy and adequate nutrition, 2) understanding the person with dementia and the resistive behavior, and 3) solutions: searching for a personalized approach (table 2). The first theme covers contemplation and considerations around doing good, while the searching for concrete causes and interpretations in the second theme provide directions for an individual approach. The decision-making process around these situations reflects a search as well, and the findings from this study indicate an implicit approach. The third theme finally focuses on practical solutions - what to do during mealtimes to help the person with dementia eat and drink in the best possible way.

Table 2. Hierarchy of themes and categories describing resistive behavior around eating and drinking

Theme 1. Fundamental tension between autonomy and balanced nutrition	Shared urgency about maintaining weight and adequate nutrition
	Accept consequences when eating and drinking is no longer possible, or the resident continues to refuse
	Considerations regarding eating and drinking policy aimed at quality of life
	Coercion is counterproductive
	Emotional involvement of healthcare professionals and relatives
Theme 2. Understanding the person with dementia and the resistive behavior	What does eating and drinking mean to the person with dementia?
	What role does autonomy play for this person?
	What does the resistive behavior look like?
	What are the possible causes of resistive behavior in the person?
Theme 3. Solutions: searching for a personalized approach around eating and drinking	Eating as a positive experience and a solution
	Deliberate consideration by healthcare professional of which intervention to use with the individual person
	Influence of type of assistance and who assists with meals
	Negative impact of understaffing and staff changes
	Effective communication between the healthcare professional and the person with dementia

Fundamental tension between autonomy and balanced nutrition

The first theme illustrates tensions between autonomy and adequate nutrition, including considerations around the right treatment and whether to accept the resistive behavior including its consequences. Both relatives and healthcare professionals felt a tension between respecting someone’s autonomy and ensuring adequate nutrition. The participants expressed concern about maintaining and monitoring adequate nutritional intake and weight. Relatives emphasized the importance of balanced nutrition while recognizing the probable limited effects of intervening. For some relatives, the tension arose from wanting their relative to be healthy on the one hand, and how to help to eat and drink without forcing someone. This was discussed with healthcare professionals in most cases, and they made mutual agreements about the treatment plan, taking autonomy of the person with dementia into account. At the same time, relatives and healthcare professionals felt that forcing the resident with dementia to eat would be counterproductive. Such approaches were viewed as distressing and would exacerbate the resistive behavior.

> *"Forcing him to eat and drink doesn't help. It only backfires. To begin with, that's not something I want for him." (relative 3)*

Participants mentioned the emotional challenges of accepting low oral intake, especially in cases where persons with dementia explicitly refused to eat or drink or when a lot of interventions were tried without being effective. The participants highlighted the importance of reaching a shared understanding of the treatment plan, considering the quality of life of the person with dementia and their previously expressed wishes.

> *"If giving someone food and drink does not improve their quality of life, then the absence of it is better than adding stress." (Healthcare psychologist 1)*

Although most participants found a treatment plan essential, most relatives mentioned that they preferred to wait for a problem to occur and subsequently discuss it with healthcare professionals.

> *"I find that very upsetting, because it's someone else's life and then I have to decide what we're going to do (…) Yes, I feel when the moment is there, then I may decide." (Relative 1)*

The acceptance of limited oral intake while resistive behavior persists, was described as difficult by both relatives and healthcare professionals. One of the relatives described:

> *"I am wondering where this may lead, when she continues to lose weight, and her life may come to an end"*

While the initial stages were described as emotionally challenging for relatives, relatives felt that with the progression of time they were able to also gradually adjust to the situation. They reported that in due time, they managed to emotionally distance themselves from the situation, allowing for greater acceptance of the consequences of decreasing oral intake.

> *"Yes, well, the first year was really tough. But now I am better able to look at things from a distance." (relative 2)*

Then, with further progression of dementia, relatives found it easier to make decisions such as stopping with actively providing food and drinks. The involved relatives and healthcare professionals felt that the focus of care shifted from ensuring adequate nutrition to prioritizing comfort and enjoyment during mealtimes. Further, healthcare professionals found it easier to maintain an emotional distance, although some of them experienced feelings of frustration or helplessness, especially in cases where communication with the person with dementia was no longer possible.

> *"If she could clearly say, 'If I don't eat, I'll die', that's fine, then it's a different story. But if you can't talk to someone about it at all, you are left feeling powerless." ((elderly) care physician 1)*

Although accepting the situation became more easy over time, in one of the cases the situation had negative consequences for the health of the relative themselves, who was eating less, was having a one-sided diet, and became less active.

Upon asking, the healthcare professionals and relatives expressed reluctance to provide artificial nutrition and hydration, in situations of a person continuously refusing to eat and drink. The reluctance reflected ethical and personal views. Healthcare professionals mentioned that they sometimes raised this treatment option, but after explaining and discussing, families do not want to start with artificial nutrition and hydration. Most healthcare professionals felt that artificial nutrition and hydration was not a suitable option for treatment of persons with dementia. Even persons with dementia themselves were reported opposed to such interventions when oral intake would be no longer possible, affirming their autonomy in end-of-life decisions, and the person with dementia in our study replied:

> *"No, I am not going to do that (referring to agreeing on placement of a nasogastric tube). I'm telling you. If you (husband) make me do that, I'll put you on a feeding tube forever" (person with dementia 1)*

In one of the cases, the healthcare professionals and relatives organized a moral case deliberation, to discuss the treatment plan regarding resistive behavior. This was experienced as being helpful by all involved persons.

> *"Clarifying the situation and getting everyone on the same page really brought peace of mind" (General Practitioner 1)*

Understanding the resident with dementia and the resistive behavior
The second theme describes the need to understand the person with dementia and the mealtime context, including what eating and drinking means to someone.

Various examples of resistive behavior were described by participants, such as verbal refusal or non-verbal behavior such as keeping their mouth closed, be distracted, or walking away from the table in the dining room. The frequency of the behavior varied. Participants mentioned that in some situations there can be relatively good days when someone eats an acceptable amount of food, while he refuses everything that is offered the next day, resulting in low overall oral intake.

> *"He had this period. It really was unpredictable. Because just three weeks ago when I went on holiday, he wanted to stay in bed all the time. And now I've just arrived here and I see him sitting in the living room happily talking, which he hasn't done in almost 2 years. So, it's really in spurts and phases. (…) He pushes the plate away. (…) The moment you want to give him a bite, he will just turn his head or keeps his mouth closed." (relative 3)*

Both healthcare professionals and relatives emphasized the need to continuously search for underlying causes of the resistive behavior, including physical factors to psychological factors. This continuous search was obvious through reporting on details of potentially relevant observations, and people wondering, for example, whether the person could be bothered by toothache or has difficulty to concentrate on a meal. Another possible underlying factor mentioned was the influence of culture, including knowing what eating and drinking means to the person with dementia. Awareness of these factors and individual preferences were described as essential for interpreting the behavior and tailoring the care to the someone's needs.

> *"My aunt is from (a different culture) and they are, well… they are used to a different kind of food. It's not that the other food turns them off or anything, they just like their own food better." (relative 1)*

Searching for an underlying cause and understanding the person, it was mentioned that resistive behavior could also be an expression of autonomy. Healthcare professionals asked themselves to what extent a person can be autonomous, and from what moment on they had to decide for them. Examples of expressions of autonomy related to the problem were mentioned by healthcare professionals, relatives and persons with dementia. For example, it can indicate a diminished will to live, as described by one of the participants:

> *“Six months ago, a year ago my father explicitly told my wife that he doesn’t really see the point anymore. That he wouldn’t mind if it all ends.” (relative 3)*

Solutions; searching for a personalizedapproach around eating and drinking

The third theme captures the considerations and concrete examples of positive or negative effects of interventions. Understanding the behavior was intertwined with searching for solutions. Creating positive eating experiences was said to be important, and something that someone could enjoy. This was more important than the amount of food and drinks persons consume. In addition, offering the kind of food a person enjoys can facilitate higher nutritional intake.

> *“Yes, well, after all she is 94 years old now, and well, if she only wants to eat what she likes; and if the nursing home goes along with it, yes, then I’m fine with it. (…) Snacks are important to her. When I visit her and she polishes off a whole bag of chips or prawn crackers, I’m like ‘okay, she’s doing well’.” (relative 1)*

Individual preferences regarding type of food, as well as the amount and type of assistance were mentioned as important information for providing personalized care. Healthcare professionals described continuously adjusting their approach to the person with dementia, carefully considering what to do or not to do and what intervention to user or not use at any given moment.

> *“Yes, and also being alert, I have noticed this, that and that. And that you can share that with your colleagues so that they can also use it. (…) Sometimes I compare it with a backpack. As long as you have plenty tools in your backpack, you can take out something different every time. And there will probably be something there that suits the specific situation.” (Healthcare psychologist 1)*

Moreover, participants mentioned that in some situations, the person who assisted during mealtimes made a big difference. For example, the overall oral intake of some persons with dementia was higher when a relative was present during mealtimes. In addition, a link between the type of approach and the amount of intake was mentioned. Making contact with someone and proper communication were examples of factors influencing oral intake. A language barrier was experienced as problematic by most participants.

> *"She is originally, she's from (a distant country with a different culture and language). When she was admitted (to the nursing home) in 2021, she still spoke Dutch fairly well. That is practically gone now. And she only uses Spanish or French. That makes communication so difficult. The staff does not understand Spanish and she can't explain very well in Spanish or Dutch what she wants, how she feels." (relative 2)*

Familiarity was important in searching for solutions. The identity of the person who is assisting, the approach to the person with dementia while helping, and therefore familiarity, was mentioned to have a significant impact on oral intake. Participants expressed concern about the impact of lack of continuity in care units, in terms of staff-turnover and reliance on temporary workers, which negatively impact previously established agreements. In some situations, this also led to less communication between the multidisciplinary team and the relatives, and consequently insufficient attention for the person with dementia.

Discussion

This study explored the decision making and impact of resistive behavior in persons with dementia that adversely affects food and fluid intake. Three main themes were identified: 1) a fundamental tension between autonomy and adequate nutrition, 2) understanding the person with dementia and the resistive behavior, and 3) solutions: searching for a personalized approach. The findings contribute to a deeper understanding of care decisions, possible ethical dilemmas and the impact of resistive behavior.

In this study, balancing autonomy and adequate nutrition presented ethical and emotional challenges for the persons involved. Self-determination, choice and control are fundamental to self-worth, and this remains true for people with dementia (25, 26). The tension we identified between respecting autonomy and ensuring adequate nutrition represents tensions in doing good, and indicates that finding a balance that alleviates this tension remains a key challenge in daily clinical practice. Healthcare professionals and relatives continuously sought ways to navigate this tension, mentioning autonomy and quality of life as key considerations in the decision-making process. These findings are consistent with prior research (1, 27).

Despite the recognized importance of shared decision-making, most participants in this study had not actively discussed advance care planning regarding the situation of resistive behavior. Instead, relatives tended to postpone discussions about treatment plans until a critical event occurred, such as pneumonia or a near-total loss of oral intake of food and fluids. Prior research found that while relatives may be prepared for their role as decision makers, they may struggle to make decisions on behalf of their loved ones and tend to focus on the present (27-29). In this study, decision making did not emerge as a prominent theme and was not generally perceived as challenging. Instead, it was viewed as an ongoing process of identifying actions that aligned with the needs and preferences of the person with dementia while remaining acceptable to those involved.

Although decision making itself was not a prominent theme in our study, one case illustrated that moral deliberation was necessary to reach consensus on a treatment plan. The complexity of this case was likely due to the specific context of living at home with dementia. The other cases in our study concerned the nursing home setting. In the home care setting, the burden of managing resistive behavior and implementing interventions falls primarily on family and 24-hour care is not available. In contrast, nursing home settings provide structured care with close collaboration among healthcare professionals. Additionally, in this case, the burden of daily caregiving had significant health consequences for the primary caregiver. These findings suggest that resistive behavior may pose greater challenges in home care settings, where families bear primary responsibility, compared to institutional settings with multidisciplinary support. A study in the home care setting in Singapore indicated high levels of caregiver burden and increased risk of depression, especially in situations involving neuropsychiatric symptoms such as resistive behavior (30).

As dementia progressed, the focus of care in this study shifted from ensuring adequate nutrition to prioritizing comfort and enjoyment during mealtimes. Relatives in our study reported that such shift alleviates the burden of decision making and reduce its emotional impact on the persons involved. However, accepting the resistive behavior - such as agreeing on no longer offering food and drinks when the behavior persisted - remained challenging for relatives. In addition, the overall impact of resistive behavior on relatives and healthcare professionals evolved over time. Relatives reported that the situation was particularly challenging when the resistive behavior first emerged but became easier to deal with over time and as the dementia progressed. This is in line with prior research (31). In our study, healthcare professionals also experienced feelings of frustration and helplessness, particularly when the resistive behavior persisted and oral intake decreased. These findings highlight that resistive behavior affects both relatives and healthcare professionals, although the latter are generally more emotionally detached than relatives. A review indicated that healthcare professionals can experience a considerable amount of distress related to caring for persons with dementia, which is even greater in situations with resistive behavior (32). Most participants ultimately accepted the situation and prioritized comfort care and dignity over life-prolonging interventions such as artificial nutrition and hydration, even when this potentially shortened the life expectancy of the person with dementia. However, the ethical and emotional impact of withholding food and fluids, especially near the end of life, remained significant for both relatives and healthcare professionals.

While artificial nutrition and hydration was discussed in some cases, it was never administered. Participants expressed reluctance regarding such interventions because they wanted to respect their relative's possible autonomous decision and did not want to potentially exacerbate resistive behavior. Research has highlighted negative outcomes of artificial nutrition and hydration, such as higher risk of pneumonia and higher mortality rates in people with advanced dementia with tube feeding compared to people with dementia who did not receive tube feeding (15, 33, 34). However, in some countries, artificial nutrition and hydration are commonly administered or even considered care by default for people with advanced dementia, indicating cultural differences regarding such interventions (35-37).

The second theme of this study highlights the dynamic nature of resistive behavior. Understanding the person with dementia – their personal background, preferences, and the possible causes of resistive behavior – is essential for developing effective interventions. Assessing each person and situation individually allows healthcare professionals to determine whether the resistive behavior stems from physical discomfort or other underlying causes. In addition to the physical and psychological factors, resistive behavior may reflect a diminished will to live. While voluntarily stopping eating and drinking did not occur in our study, it can present significant ethical dilemmas for all involved (38, 39). The search for underlying causes can be challenging. We know from prior research that many factors can influence mealtimes, such as environmental, interpersonal and intrapersonal factors. At the same time, eating experiences are highly individualized, emphasizing the need for a personalized approach (40). The importance of adaptive, personalized care was also emphasized in the third theme. This involves flexible, individualized strategies to support nutritional intake while respecting autonomy. It emphasizes the need for personalized interventions to address the complexity of resistive behavior (41). Mealtime assistance should be continuously adjusted to meet the individual needs to ensure a continued balance between interventions and respect for autonomy. These findings resonate with earlier studies highlighting the need for flexible care that prioritizes individual needs (42). Furthermore, a personalized approach is consistent with the preferences of persons with dementia, who value care that upholds their dignity and individuality (43). Healthcare professionals play a crucial role in understanding the goals and values previously expressed by the person with dementia and in guiding relatives to make treatment decisions in line with these preferences (44, 45).

Strengths & limitations

The main strength of this study is the diversity of participants, including not only relatives and healthcare professionals, but also a person with dementia. The qualitative design provides a rich and in-depth view from all persons involved in situations of resistive behavior. Although we initially aimed to include six different situations, the five cases that could be included describe a broad variety in terms of age of onset, ethnic minority, sex, and setting. The heterogeneity of the sample allowed a variety of experiences and perceptions to be captured. The views of a person with dementia and of relatives provide a unique insight into their experiences of dealing with a complex situation, which to date have been underexplored in research.

One limitation of this study is that not all contact persons at the participating care units were equally active in identifying and referring potential cases, although we contacted them every month to monitor inclusion. This may have resulted in a lower number of potentially relevant cases. In addition, for ethical reasons we did not contact relatives of persons who had recently died or when the contact person indicated that the situation had too much impact on the people involved. This may have resulted in potentially more complex cases not being captured. However, we were able to include one complex case in which moral case deliberation was required to reach agreements on the treatment plan, and thus shed light on dilemmas that may be involved in the decision-making process in similar cases.

Another limitation concerns data saturation. Since the last case still yielded new codes and code groups, theoretical and inductive thematic saturation may not have been reached. Notably, this particular case was the only one in which the person with dementia lived at home, unlike the other four cases in a nursing home setting. This may explain the refinement of codes in the fifth case. Regarding data triangulation, we lacked input from some relevant healthcare professionals (e.g. speech and language therapists, dietitians, and occupational therapists). However, we were able to explore the perspectives of the professionals who were most actively involved in each case, and we therefore captured the majority of valuable perspectives from those close to the person.

Conclusion

In conclusion, this study contributes to a deeper understanding of care decisions, possible ethical dilemmas and the impact of situations of resistive behavior in people with dementia. Both relatives and healthcare professionals are advised to continuously balance striving for adequate nutrition without forcing someone to eat and drink. Healthcare professionals are recommended to proactively navigate decision-making, as clear solutions are often not obvious and continue to require time, effort and adjustment from all involved. Open discussion and shared decision making are critical to developing treatment plans that respect the autonomy and preferences of the person with dementia while also considering the needs and well-being of their relatives. When perspective differ and reaching a consensus on the treatment plan appears challenging, a moral case deliberation may be helpful. Regarding advance care planning, healthcare professionals can provide information and guidance to relatives to help them prepare for potential events, such as developing pneumonia or a hip fracture, which become more common as dementia progresses. Tools such as conversation starters or worksheets can support conversations about preferences and wishes for future treatment plans (46).

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Author Contributions

EVB, JVDS, CB, RK, and MP contributed to the conception, design and interpretation of the work and to funding acquisition. EVB and AVD contributed to the acquisition of data and drafted the manuscript. EVB, JVDS, AVD and MP contributed to data analysis. JVDS, CB, RK and MP revised the manuscript and provided final approval of the version submitted.

Statements and declarations

Ethical Considerations

This study was approved by the research ethics committee of the Radboud university medical center Nijmegen (file number CMO: 2021-13085) on March 22, 2022.

Consent to participate

All participants provided informed consent prior to participating in this study. Written informed consent was obtained from a legally authorized representative for anonymized patient information to be published in this article.

Consent for publication

All participants or their legally authorized representatives provided informed consent for publication.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Data Availability Statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Supplementary material A. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	4
Occupation	3	What was their occupation at the time of the study?	4
Gender	4	Was the researcher male or female?	4
Experience and training	5	What experience or training did the researcher have?	4
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	4
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	2
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	3
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	3
Sample size	12	How many participants were in the study?	4
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	4
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	5,6

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	4
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	4
Field notes	20	Were field notes made during and/or after the interview or focus group?	4
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	13
Transcripts returned	23	Were transcripts returned to participants for comment and/or	4
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many coders coded the data?	4
Description of the coding tree	25	Did authors provide a description of the coding tree?	6
Derivation of themes	26	Were themes identified in advance or derived from the data?	4
Software	27	What software, if applicable, was used to manage the data?	4
Participant checking	28	Did participants provide feedback on the findings?	4
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? E.g. participant number?	7-10
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7-10
Clarity of major themes	31	Were major themes clearly presented in the findings?	7-10
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	10-13

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Supplementary Material B Topic List

Topic	Sub-topic
Decision-making	***General questions*** - *What agreements have been made regarding how to handle the resistive behavior*?* - *What kind of assistance do you provide your relative with eating and drinking? (Can you describe your role?)* - *What do you think of the agreements that have been made regarding resistive behavior during eating and drinking?* **align with the interviewee's own terminology* ***Type of agreements*** - *What kind of care does your relative currently receive for [the resistive behavior]*? Has this changed?* - *Have you discussed with healthcare professionals what should happen next?* ***Process (progress so far, changes in agreements)*** - *How do you think the agreements have worked so far? Have they changed?* - *Looking at the agreements that were made, would you want anything to be different? (If yes, what? If no, why not?)* ***Advance directive*** - *Does your relative have an advance directive? Can you tell us about it?* - *Can you share anything about your relative's wishes—what they would or wouldn't have wanted in this situation?* ***Considerations*** - *What factors were important to you when making agreements? What considerations did you take into account?* ***Opinion on treatment decisions*** - *What was your relative's behavior around eating and drinking like, and how did it affect you as a caregiver?* - *What strategies were considered, attempted, and decided upon to improve eating behavior and intake? How did the* decision-making process go? Did you feel supported by healthcare professionals? - *How were previously discussed treatment wishes and boundaries incorporated into decision-making?* - *What led to the moral deliberation meeting? What considerations were discussed, and what was decided?* - *Looking back, how do you feel about the whole process? What are you satisfied with, and what would you have wanted to be different?*
Moral dilemmas	*What did you find difficult or easy when making agreements?*

Topic	Sub-topic
Symbolic meaning of eating and drinking	***Norms and values*** - *How does your relative view eating? What aspects of food and drink are important to them? And how about for you?* ***Religious/cultural aspects*** - *Are there any religious or cultural factors that play a role for your relative when it comes to eating and drinking?*
Communication	***Contact with healthcare professionals*** - *What do you think of the communication with healthcare professionals?* ***Guidance from healthcare professionals*** - *What do you think of the support your relative receives?* ***Differences of opinion*** - *Have there been any disagreements between you and healthcare professionals so far?*
Impact of resistive behavior	- *To what extent does the resistive behavior occupy your thoughts?* - *Is there anything else you would like to share that we haven't discussed?*

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General discussion

This thesis reports on a research project about younger and older persons with dementia and resistive behavior that adversely affects the intake of food and fluids. The main goal of this project was to better understand the behavior and the impact on persons with dementia, involved relatives and healthcare professionals. In this chapter, the main findings are presented answering the research questions as described in the general introduction, as well as the implications of the findings for clinical practice, research, and education.

Summary of the main findings

The first research question of this thesis was *'How can we describe and define mealtime behavioral problems and related complex issues in nursing home residents with dementia?'* Chapter 2 shows how we adapted an existing conceptual model about nutritional problems in general in persons with dementia based on focus group interviews with various healthcare professionals working in nursing homes. We identified interprofessional collaboration and ethical factors as two new themes, additional to the existing four themes corresponding with the models of Chang and Roberts (1) and Aselage and Amella (2) (observing and analyzing nutritional problems; consequences of nutritional problems; functioning of the person with dementia; environmental factors). Our thematic analyses indicated complex bidirectional relationships within and between themes regarding nutritional problems. All aspects should be taken into account to minimize the consequences of nutritional problems for persons with dementia. These findings underline the complexity of nutritional problems in daily clinical practice. As such, this study links theory around nutritional problems in persons with dementia to daily clinical practice in nursing homes.

In chapter 3, the concept of resistive behavior around eating and drinking was examined in-depth. We used a mixed-method Group Concept Mapping approach and data was collected online with a panel of 67 healthcare professionals, researchers and relatives. The participants contributed to the generation of ideas, sorting, and rating of the ideas regarding resistive behavior. Multidimensional scaling and hierarchical cluster analysis resulted in a concept map, visualizing the coherence and importance of ideas. The final concept map showed three categories capturing ten clusters which describe expressions and interpretations, causes, and the management of resistive behavior adversely affecting intake of food and fluids. The three clusters about causes of resistive behavior formed a relatively well-defined concept, in contrast to the other clusters. Further, the ideas that referred to ethical factors emerged in all three categories of the concept map. This implies that in the reasoning of healthcare professionals, these factors tend to be overlooked or not addressed as an important issue of its own. This study provides insight into the way healthcare professionals view the coherence and interplay between factors around resistive behavior.

The second research question (‘*What is the incidence of resistive behavior that adversely affects the intake of food and fluids in younger and older persons with dementia and what are the characteristics of this behavior?’)* was addressed in chapter 4 through a prospective incidence study. We followed a group of 424 younger and older residents with dementia for 12 months and monthly registered the total number of residents at risk and the number of incident cases. Of forty reported cases, sixteen were incident cases meeting the inclusion criteria, resulting in an incidence rate of 32/1000 person-years. The incidence rate was higher in residents with YOD (45/1000 person-years) than in residents with LOD (26/1000 person-years). In all cases, at least two symptoms were observed, with ‘turning one’s head away’, ‘pushes cutlery/crockery/food/nurse away’, and ‘stands up from the chair or leaves the table’ most frequently reported. At follow-up, five had died, four still had behavioral symptoms, and seven residents no longer experienced problems. These findings might imply that young residents are at greater risk of developing these behaviors, and healthcare professionals and relatives should be prepared for the occurrence of specific resistive behaviors in younger residents.

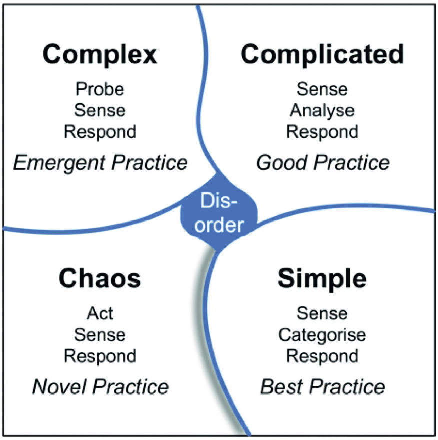
The third and last research question was ‘*How do relatives and healthcare professionals navigate treatment and care decisions and what are possible ethical dilemmas related to decision-making?’* Chapter 5 presents a multiple case study that explored the decision-making process and impact of situations with resistive behavior on relatives and healthcare professionals. We included five cases, of which four concerned persons with dementia residing in a nursing home and one person living at home. In each case, we interviewed professionals and the primary informal caregiver. Three themes were identified from a total of 16 interviews: 1) tension between residents’ autonomy and adequate nutrition; 2) understanding the resident with dementia and the resistive behavior; and 3) the search for a personal approach around food and drinks. This study showed that dealing with situations around resistive behavior is a continuous search for a person-centered approach, driven by connecting to the person with dementia. Constant tension is felt between autonomy and adequate nutrition, considering preservation of the quality of life of the person with dementia. The perspectives elicited in this study can help multidisciplinary teams to cope with, and navigate these complex decision-making processes.

Discussion of the main findings

The complex nature of resistive behavior adversely affecting intake of food and fluids

The studies in this thesis demonstrate that situations involving resistive behavior in persons with dementia are complex and multifactorial in nature. As addressed in Chapters 2 and 3, a variety of factors can influence situations with resistive behavior, and these factors may interact with each other in dynamic and unpredictable ways. This resonates with the principles of the biopsychosocial model that is widely used in healthcare to approach health problems not only in terms of *health and illness,* referring to the biomedical model, historically the dominant model of medicine, but also includes dynamic interactions among social, psychological and behavioral factors (3, 4). Although the biopsychosocial model is frequently applied in healthcare, including in nursing homes, health problems are often still approached in a one-dimensional way, such as resistive behavior (problem) leading to dehydration (consequence). This one-dimensional approach is also described in chapter 2, when referring to the original models on nutritional problems. However, possible interactions between factors risk being missed, whilst the expanded theoretical model in chapter 2 emphasizes complex non-linear, dynamic relations between factors. Given the complex nature of resistive behavior, it may be appropriate to consider resistive behavior through the lens of *complexity science.* Closely related theories include *complexity theory*, and *complex adaptive systems.* The Cynefin framework draws on research from these theories, and focuses on how people perceive and interpret situations in order to make decisions (5). Although originally developed in business contexts, the framework is applicable in other areas as well, including healthcare settings such as nursing homes (6-8). The framework contains five contexts: clear, complicated, complex, chaotic, and a center of disorder. When a healthcare issue, such as resistive behavior, involves multiple contributing factors and numerous interactions among these factors, these are considered to behave as complex systems. The multilayered nature of persons combined with the many interactions between different factors imply that physiological and behavioral patterns do not follow a linear or predictable course. These are important characteristics of complex systems. Identifying and understanding such complexity in clinical practice becomes easier when complex systems are distinguished from simple, complicated, and chaotic systems.

The Cynefin framework allows problems to be addressed in relation to their level of complexity. Simple problems may benefit from current know-how, but more complex problems require questioning the way of working to allow for improvements (7). Situations with resistive behavior can be categorized as *complex,* meaning there are *not known unknowns,* and therefore the outcomes are unpredictable. Snowden and Boone advise for these situations to probe, sense, and respond, in order to find out what works for the specific situation. This differs from complicated problems, which ask for specialized knowledge, such as the treatment of infections or trauma management. In these situations, guidelines and protocols can be followed. In addition, chaotic problems ask for a rapid response, as this refers to acute situations such as accidents with multiple victims, or crisis situations. Lastly, medical problems that have elements from several of the other domains are in the disorder zone. An example of the disorder zone could be a person living at home, being admitted to the hospital with a hip fracture after falling down the stairs, while the police comes into action because of suspected abuse. However, the partner has dementia and cannot stay at home alone to take care of himself (8).



Snowden & Boone, 2007

The framework can be applied to the situations in this thesis as follows. For example: probing a specific approach during mealtime when assisting a person exhibiting resistive behavior, sense whether it is effective or not, and respond to it and ask yourself if you need to try out an alternative intervention or whether the current action suffices for that moment. As described in theme 3 of chapter 5, this probing, sensing, and responding was mentioned by the participants in their search for the underlying causes and subsequent solutions. Healthcare professionals described continuously adapting their approach and interventions to the person with dementia, carefully considering what to do or not at any given moment. The group concept mapping study in Chapter 3 highlights this ongoing search as well, as participants frequently made connections between identifying the underlying cause of resistive behavior and determining which treatment or approach would be most appropriate.

Defining resistive behavior

The complex nature of resistive behavior makes it challenging to define these situations clearly and comprehensively. However, it is necessary to find underlying triggers and possible causes of the behavior, in order to understand a situation and find a tailored intervention. The underlying causes or triggers of resistive behavior may result from a personal factor, such as a strong wish to be in control, as is described in chapters 3 and 5. Simultaneously, an inappropriate approach, such as the use of touch or being too speedy while assisting during mealtimes, may trigger the person with dementia to resist as well and further complicate mealtimes (9). In this example, personal and environmental factors, as well as social interactions, are intertwined. This complexity challenges healthcare professionals in defining resistive behavior, identifying underlying causes and determining appropriate and effective interventions to manage the behavior and limit adverse consequences. Prior research resonates with these findings as well, and has also indicated that resistive behavior in dementia is rarely attributable to a single cause (10-14).

Various terms are used in this thesis to refer to the situations with resistive behavior that adversely affects the intake of food and fluids. The different terminology is due to its complexity which implies that there is no single comprehensive definition that captures the various foci and situations we studied in this thesis. In chapter 2, the situations are referred to as *nutritional problems*. We chose this term because this study describes a broad concept of eating and drinking problems not limited to resistive behavior, but including any problem occurring during eating and drinking that causes inadequate intake of food and fluids (15). Chapter 3 describes situations with explicit resistive behavior, and therefore the terms *mealtime behavioral problems* was used. Chapters 4 and 5 focus on situations of serious resistive behavior, including negative health outcomes such as weight loss and dehydration. In these studies the term *resistive behavior that adversely affects the intake of food and fluids* was used. These differences in terminology reflect the complex nature of resistive behavior. Prior research refers to these situations in different terms as well, and different operational definitions are often used in clinical studies to describe these situations. Other related terms include eating ability, mealtime behaviors, feeding difficulty, challenging behavior, or mixed behavior, which also refer to different underlying concepts (14, 16-18). These variations in terms and assessment methods hinder not only the understanding of resistive behavior, but also the development of possible effective interventions. As the research project progressed, we adapted phrasing in order to frame these situations in the most suitable way. Of these formulations, *resistive behavior that adversely affects the intake of food and fluids* was considered the most concrete and comprehensive option, because it includes both the behavior and the consequences. In order to operational define this behavior in the studies in chapters 4 and 5, rather narrow inclusion criteria were formulated. Given the complex and unpredictable nature of resistive behavior, the findings in chapter 2 and 3 imply that it may be impossible to develop a conclusive definition that is applicable to all situations with resistive behavior. Following the principles of complexity science in order to be able to interpret the behavior and subsequently provide tailored care, can be a suitable approach instead. For research, a pragmatic approach is recommended; for example, opting for either a broad or narrow definition, including or not including consequences, as appropriate to address the research questions.

Issues concerning autonomy

In situations with resistive behavior, multiple issues regarding autonomy can play a role. For some persons with dementia, the behavior may be an expression of autonomy. In persons with dementia, being independent and able to make their own choices as an autonomous person changes over time when the disease progresses and skills decrease (Anselmo et al., 2025; Delineau et al., 2025; Moutran Barroso, 2024). At a certain point, persons with dementia may not be able to articulate their needs and preferences, and become more dependent on others, such as relatives and healthcare professionals (van der Steen et al., 2024; van der Weide et al., 2023; Wolfe et al., 2021). Chapter 5 indicates that persons with dementia may resist food and drinks because they find it difficult to accept help. Prior research found a high association between dependence in care actions, such as mealtimes, and the level of resistance (19-22). Further, refusing food and fluids may stem from a wish to die, as described in chapter 5. Whether the behavior is an expression of autonomy can be difficult to determine for healthcare professionals. In addition, the behavior might be an expression of feelings that autonomy is disrespected, rather than an expression of a wish to die.

Chapters 3 and 5 show that healthcare professionals indicated the necessity to understand the person with dementia, to be able to interpret the underlying triggers or causes of resistive behavior, such as autonomy related factors. They indicated a continuous search for balance between on the one hand, respecting the autonomy of the person with dementia, and on the other hand, providing the best possible care focused on maintaining adequate nutritional intake. These findings align with prior research, emphasizing the need for a person-centered approach and indicating that care should be adapted to the circumstances (23-26). This approach, which emphasizes understanding and responding to individual needs and preferences, supports the observed benefits in managing resistive behavior during mealtimes (27). Further, the findings highlight the necessity for healthcare professionals and relatives to interpret the symptoms of resistive behavior, and to respond to these situations with empathy and flexibility. However, in practice, flexible directly responding to care needs is not always feasible, due to limited time and staffing (26).

Ethical dilemmas in decision making

When resistive behavior persists, ethical factors other than autonomy become relevant and weighing those may expose ethical dilemmas. It is essential to come to an agreement on the treatment plan with other stakeholders involved. Treatment decisions such as whether or not to continue with providing food and fluids may pose ethical dilemmas for both healthcare professionals and relatives who make these decisions for the person with dementia, as reflected in both chapter 2 and 5. Differences in norms and values and the influence of culture or religion were perceived as influential in decision making, sometimes resulting in struggles or even in moral dilemmas, as described in chapter 2. Although ethical factors were mentioned by various participants in the studies in chapters 2, 3, and 5, these factors were spread across the concept map in chapter 3. This may imply that ethical factors are not actively considered, although healthcare professionals and relatives are aware of them.

Chapter 3 added to these findings the considerations about when to stop providing food and fluids, considering what is the best care for a person with care needs resisting that care. Chapter 5 describes these considerations about the right treatment and whether to accept the resistive behavior including its consequences. This study also highlighted that forcing a person with dementia to eat or drink should be avoided. This corresponds with prior research, describing that possible damage due to forced care are higher than the risks of missed healthcare (26, 28-30). However, this may pose dilemmas as well, because no oral intake leads to consequences such as weight loss and ultimately death (31).

Another option instead of stopping provision of food and fluids is to consider artificial nutrition and hydration, when the behavior persists or when oral intake becomes unsafe and may lead to complications such as aspiration pneumonia (32). Artificial nutrition and hydration were sometimes considered by healthcare professionals and relatives, as described in chapter 5, but never administered in the cases we studied. This reluctance toward artificial nutrition and hydration was driven by personal and ethical views, because they wanted to respect the person's possible autonomous decision and did not want to potentially exacerbate the resistive behavior. Chapter 2, however, describes that healthcare professionals struggled with end-of-life decisions, when their views differed from those of relatives. A study from Singapore found that this can be the case for relatives as well, as they may experience feelings of making a 'wrong' decision on behalf of their loved one (33). The reluctance toward considering artificial nutrition and hydration is a widely supported view, because it may reduce the experienced quality of life and lead to complications in the end-of-life phase (32, 34-37). However, artificial nutrition and hydration is administered to persons with advanced dementia in some countries, especially when driven by religious views (38).

The impact of resistive behavior on relatives and healthcare professionals

Although severe resistive behavior appears to be relatively rare, as described in Chapter 4, its impact on both relatives and healthcare professionals can be considerable, particularly in the early stages of its emergence. Research has indicated that a high rate of neuropsychiatric symptoms is associated with large burden for the involved (39). However, relatives in the study of chapter 5 mentioned that they were able to gradually adjust to the situation and become emotionally more detached, allowing for a greater acceptance of the consequences of decreasing oral intake. With further progression of the dementia, relatives also found it easier to make decisions. In contrast, in prior research in early stages but also when nearing the end-of-life phase including in the Netherlands describes difficulty and frustration in relatives who are involved in decision-making conversations regarding nutrition and hydration (40, 41).

Older vs younger persons with dementia

In the studies in this thesis, we focused not only on older persons with dementia, but also on younger persons. Although recently more research has been conducted that includes younger persons, the majority of studies exclusively concern older persons with dementia. Until now, younger persons have been under researched, and therefore a lot is still unknown about possible differences and similarities. Chapter 4 indicates that situations with resistive behavior are more frequently seen in younger persons compared to older persons with dementia.

Although the small sample in chapter 4 did not provide direct evidence to support this hypothesis, it remains a relevant consideration. Younger persons with dementia may be physically more fit, enabling them to leave a table more easily or express more forceful behavior compared to persons with significant comorbidities who are wheelchair bound. Moreover, there are differences in the types of resistive behavior observed, and consequently in the perceived impact on those involved (42-45). These differences in behavior may be syndrome specific, given the wide variety of dementia syndromes, and could occur more frequently in younger persons with dementia (46, 47). Even though this was not the case in the study of chapter 5, relatives of younger persons with dementia may be less prepared for situations with resistive behavior, which may influence their perception and experienced impact of the behavior. Prior research indicated that the emotional impact can be greater at a younger age in general, because of responsibilities regarding holding down a job or taking care of children (47, 48).

Methodological considerations

Some methodological considerations regarding the studies should be mentioned.

First, the unavailability of a comprehensive definition of resistive behavior was of influence on the studies in this thesis. It is known from prior research on comparable concepts, such as challenging behavior and frailty, that complex concepts are difficult to demarcate and define (49, 50) resulting in the use of many different measurement instruments. In the group concept mapping study in chapter 3, we tried to develop a definition ourselves. However, this study also indicated the diversity of factors and complex nature of resistive behavior, and therefore we were not able to do so. We then carefully considered how we could define situations with resistive behavior and how to operationalize these in our different studies.

Second, in the studies presented in chapters 4 and 5, we attempted to specify the characteristics of severe situations with resistive behavior by narrow inclusion criteria. However, this may have resulted in missing situations without consequences such as weight loss or dehydration. Weight loss, however, occurs over time, so it is possible that we missed relevant cases in the incidence study as there may have been no noticeable weight loss yet at the time the contact person reported the case. If we had included prevalent cases, this may have resulted in additional relevant findings. For example, there can be multiple episodes of resistive behavior and the behavior can be recurrent as well, as shown by the results in chapter 4. By focusing on incident cases, we can only speculate about the specific moment of onset of potentially repetitive episodes of resistive behavior or less obvious lingering behavior. Moreover, we did not record the cause of death, so based on the findings of the incidence study we are unable to assess whether death was due to the resistive behavior. In retrospect, an admission cohort may have been more suitable than the fixed cohort which was more feasible.

Third, one of the strengths of this research project is that it applied a variety of study designs, including qualitative, quantitative, and mixed-method designs. This resulted in an in-depth understanding of situations with resistive behavior.

Fourth, the trustworthiness of the results of the qualitative studies in chapters 2 and 5 is high due to including a variety of participants, resulting in multiple perspectives and rich data. This also applies to the qualitative data of the group concept mapping study in chapter 3. However, in the studies of chapter 2 and 3 it appeared difficult to include relatives, and their perspectives may therefore have been underexposed. In the qualitative studies, a member check was performed; the interviewees could check the transcripts.

Further, the interviewers did not have a professional relationship with the participants, and multiple experienced researchers with different backgrounds were involved in data analysis. This has enhanced the credibility and confirmability of both studies. The findings from both studies are internationally applicable in long-term care settings, but also in the home setting, which enhances transferability.

Implications and recommendations for clinical practice, education, and research

Clinical practice

The findings in this thesis have important clinical implications for the daily care of persons with dementia with resistive behavior that adversely affects the intake of nutrition and hydration. The following recommendations should be considered in clinical practice.

First, because this thesis highlights the complex nature of situations with resistive behavior, it is recommended to approach these situations following the framework of complexity science. Healthcare professionals are advised to approach these situations by applying emergent practice. Emergent practice means that there are no right answers, and a protocol or one-size-fits-all intervention is unlikely to work, because this does not take personal beliefs and preferences into account (8). Healthcare professionals are advised to try out a specific intervention, reflect on it, and adapt when it is ineffective. This may involve changing the mealtime environment, such as reducing sensory stimuli, or shifting the approach when assisting a person with eating and drinking. The unpredictable nature of resistive behavior asks for such a strategy that allows to probe, sense, and respond (figure 1). This adaptive approach encourages experimentation and discovery (7, 51), allowing responses to emerge through experimenting with different interventions, so the involved persons are learning by doing.

This thesis has shown that determining what is effective can vary depending on the person and the specific moment or situation. Therefore, factors related to the individual, including autonomy and preferences, but also the behavior including the observed symptoms should be considered. Additional factors to consider are environmental and interpersonal factors, such as the relationship between the person with dementia and the assisting caregiver. Then, a well-considered choice for an intervention, such as a specific approach or intervention, can be made. After applying the intervention, it is recommended to reflect on the effectiveness, both individually and with the multidisciplinary team. Team meetings or peer-to-peer intervision can be used to discuss these situations, and if necessary, to adapt the approach or try out a different intervention (51).

Second, the findings in this thesis indicate that ethical factors are omnipresent yet risk being overlooked. When discussing and establishing treatment plans, it is essential to actively consider any ethical factors that may underlay or affect the resistive behavior and potential solutions. Such factors, including personal values, cultural background, and religious beliefs, not only influence persons with dementia but should also be acknowledged in the self-awareness of healthcare professionals. It is particularly important to consider the identity and personality of persons exhibiting resistive behavior, as the behavior may reflect an expression of autonomy, such as a desire to remain independent relating to difficulty accepting help, or expressions of a despair or a wish to die. Because persons with dementia may not always be able to articulate their wishes, it is crucial that healthcare professionals and relatives engage in careful deliberation and shared decision-making. In addition, reflecting on situations with the multidisciplinary team is recommended, with joint considering of moral issues such as how to balance divergent values at stake when developing treatment plans. Further, it may be helpful to use tools that are developed to support advance care planning, such as conversation guides or digital tools (52-54). In the Netherlands, these tools are also recommended by a national care standard for dementia (55). Examples of tools that support conversation about wishes and preferences for the future are 'Gesprekskaart' (56) and a toolbox that focuses on shared decision-making in long-term care 'Toolbox Samen Beslissen' (57). When it is hard to reach consensus on the treatment plan or when ethical dilemmas arise, it is recommended to use the stepwise procedure of a moral case deliberation, as this considers all perspectives and provides directions for a mutual agreement on the treatment plan (58).

Third, given the impact of resistive behavior on involved persons, support should be accessible for both relatives as well as healthcare professionals. In situations involving resistive behavior, the healthcare professionals should be alert to the potential emotional impact on relatives. As this study found that the emotional burden is particularly high for relatives at the onset of resistive behavior, a proactive attitude is recommended in the early stage when these behaviors emerge. There are numerous instruments, such as self-report instruments and questionnaires, that can be used to estimate caregiver burden (59). When signs of emotional distress are present, it may be appropriate to initiate a dialogue, possibly in a multidisciplinary context, or to involve a psychologist or spiritual counselor to provide psychosocial support (60, 61). Depending on the needs of the caregiver, or when the specific needs are not clear after a dialogue, questionnaires such as the Caregiver Strain Index can be used to find directions to guide further actions.

Education

To improve the timely recognition of any signs of resistive behavior, healthcare professionals could benefit from knowledge on the symptoms of the behavior and support in how to detect and manage this behavior. Healthcare professionals must be equipped with the necessary knowledge when to communicate signs with the multidisciplinary team rather than taking gradual or subtle changes in the course of the dementia for granted. The acquisition and development of knowledge and skills begins during formal education. To ensure that healthcare professionals in training are well-prepared for clinical practice, it is essential that specific knowledge and skills are incorporated into the curricula of their educational programs. It is recommended that such training not only includes theoretical instructions but also focuses on the development of practical skills that include observing, but also sensing, probing, and reflective capacity. Given the complexity of and large variability in situations involving resistive behavior, awareness to detect symptoms and estimate the effectivity of a specific intervention, and reflective capacity are crucial for managing these situations effectively. Simulated practice of such scenarios is advisable, as it can help students to develop a sense of familiarity with this specific type of behavior in a safe learning environment with the opportunity to receive constructive feedback. In addition, the use of training on the job, blended-learning, peer support, and qualified trainers are considered the most effective strategies to improve knowledge of healthcare professionals in the nursing home setting (62).

These recommendations apply to nursing assistants as well as registered nurses, but also to other healthcare professionals such as speech and language therapists, occupational therapists, dietitians, healthcare psychologists, and elderly care physicians. It is further recommended to set up these educational programs in an interprofessional way, as the findings of this study highlight the importance of multidisciplinary collaboration and communication in effectively managing resistive behavior. Research indicates that interprofessional education has a positive impact on improving the knowledge, skills, and attitudes about collaborative teamwork (63). Moreover, it is shown to improve the team-based approach, which in turn improves patient outcomes as well (64). Particular emphasis should be placed on recognizing symptoms of resistive behavior explicitly and comprehensively in the curricula of programs for nursing assistants and registered nurses, as they represent a consistent presence on nursing home care units and thus play a primary role in the early detection of situations with resistive behavior.

Research

This thesis provides some recommendations for future research as well. As the results of this thesis show, complex concepts such as resistive behavior are difficult to demarcate and define. It is known from related complex concepts, such as challenging behavior and frailty, that this is hard and can result in broad and rather vague definitions (49). Because behavior is dynamic and can be influenced by many triggers and underlying causes, it is impossible to capture this in a single, ambiguous definition. Although a definition is developed on frailty, for example, there are still sub-type definitions necessary that address each frailty dimension (65). Further, these differences make it hard to compare studies and interpret the findings. Hence, a complex concept cannot easily be captured by one definition that comprises the whole concept. The first recommendation is therefore to consider to stop efforts to develop a single definition of resistive behavior. It is recommended to clearly describe the exact behavior and characteristics that are studied in future research, to facilitate the interpretation of the findings and comparison between studies that focus on the same behavior.

Further, it is recommended to conduct an international study on the incidence of resistive behavior. In this thesis, the sample included in the incidence study was rather small and was conducted only in the Netherlands. It may be interesting to find out whether the incidence of resistive behavior is lower, higher or comparable in other countries. It is known that there are large differences and care gaps in dementia care in European countries, such as access to care, nationwide care plans, dementia specific services, and the participation of persons with dementia and their relatives in research (66). In addition, it is advisable to record whether the behavior may have been the cause of death, as this provides more detailed information on the course of resistive behavior. Also, finding possible explanations for potential differences in occurrence provides more insight into situations with resistive behavior and can provide directions to more effectively manage these situations. Further, larger studies may provide additional and more detailed insight into the clinical course of the behavior (67). It is also recommended to not only focus on the incidence, but also on the prevalence of resistive behavior. Including the less serious situations, or without severe consequences such as dehydration or weight loss, may also provide more insight in different situations and potential differences in the course of the behavior. Lastly, including younger persons with dementia in future studies on the subject is recommended, to confirm or disprove that resistive behavior around eating and drinking is more common in this population compared to older persons with dementia, as this thesis indicated. Larger studies that include both younger and older persons may provide more insight into the potential similarities and differences regarding symptoms, clinical course, and may guide future interventions to manage resistive behavior in the most effective way.

Guidelines

The last recommendation is to include the findings from this thesis into relevant national and international guidelines, such as the Dutch ‘Richtlijn Dementie (68), ‘Probleemgedrag bij dementie’ (69), but also into guidelines such as ESPEN on nutrition and hydration in dementia (35). Further, it is advised to include the findings and materials from this thesis into protocols that concern decision making regarding situations with resistive behavior around eating and drinking.

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A

Appendices

Samenvatting (summary in Dutch)

Inleiding

In **hoofdstuk 1** van dit proefschrift wordt uitgelegd wat **afweergedrag** bij eten en drinken is. Afweergedrag betekent elk gedrag tijdens het eten en drinken waardoor iemand geen eten of drinken binnenkrijgt. Bijvoorbeeld: een helpende hand wegduwen, ‘nee’ zeggen, slaan of met een bord gooien. Mensen met dementie kunnen om verschillende redenen afweergedrag laten zien. Het is vaak moeilijk om precies te weten waarom. Toch is het heel belangrijk om de oorzaak te vinden, omdat pas dan een passende behandeling gestart kan worden. Met een goede behandeling kunnen de gevolgen zoveel mogelijk worden beperkt. Afweergedrag kan ernstige gevolgen hebben. Als iemand lange tijd weinig of niets eet en drinkt, kan dat leiden tot gewichtsverlies, uitdroging en zelfs de dood.

Wat het lastig maakt, is dat mensen met dementie vaak zelf niet goed kunnen uitleggen waarom ze afweren. Dit komt door problemen met praten of begrijpen door de dementie. Daardoor is het moeilijk om afweergedrag goed te begrijpen. Afweergedrag kan een manier zijn om zelf de **controle** te houden. Maar het kan ook zo zijn dat iemand niet goed meer kan eten of drinken, bijvoorbeeld omdat het lichamelijk niet lukt of omdat hij of zij niet begrijpt wat er van hem verwacht wordt.

Mensen met dementie zijn steeds meer afhankelijk van anderen, zoals naasten en zorgprofessionals. Als het afweergedrag blijft bestaan, moeten zij samen een besluit nemen over wat ze gaan doen. Dit kan soms zorgen voor ingewikkelde situaties, met ook moeilijke keuzes. Bijvoorbeeld als naasten kunstmatig voeding of vocht wil geven (via een sonde of infuus), maar het zorgteam hier niet achter staat. Ook verschillen in normen en waarden, het accepteren van achteruitgang, en de betekenis van eten en drinken spelen mee. Er is nog weinig bekend over hoe deze beslissingen worden genomen, wat het effect van afweergedrag is op betrokkenen, en hoe vaak ernstige situaties voorkomen.

Dit proefschrift heeft daarom onderzocht 1) wat afweergedrag precies is, 2) hoe vaak afweergedrag voorkomt bij mensen met dementie en 3) hoe beslissingen worden genomen en wat het effect is op zorgprofessionals en naasten van mensen met dementie.

Belangrijkste bevindingen

In **hoofdstuk 2** zijn **drie groepsinterviews** gehouden met in totaal 20 zorgprofessionals uit verpleeghuizen. Zij kennen problemen met eten en drinken bij mensen met dementie goed. De vragen die gesteld werden tijdens de interviews kwamen uit bestaande modellen uit de literatuur. De zorgprofessionals deelden hun ideeën over wat eet- en drinkproblemen zijn, de oorzaken, gevolgen en hoe ze samenwerken. Uit het onderzoek kwamen twee nieuwe, belangrijke factoren: **'samenwerken tussen verschillende disciplines'** en **'ethische factoren'**. Deze zijn toegevoegd aan een nieuw ontwikkeld model.

Hoofdstuk 3 onderzoekt wat afweergedrag precies is. Dit gebeurde in zes stappen. De eerste stap was de voorbereiding van het onderzoek, waarbij goed is nagedacht over wat precies de vraag aan de deelnemers moest worden. Een groep van 67 naasten, zorgprofessionals en onderzoekers hebben in een brainstormsessie in stap 2 allerlei ideeën gedeeld over afweergedrag. Hierna hebben zij in stap 3 deze 85 ideeën gesorteerd en een cijfer gegeven van 1 (helemaal niet belangrijk) tot 5 (heel belangrijk). Hierna heeft het onderzoeksteam in stap 4 de bevindingen geanalyseerd en is in stap 5 een **'begrippenkaart'** ontwikkeld. Op de begrippenkaart staan 10 groepen ideeën, samengevat in 3 thema's. Dat zijn 1) het behandelen van afweergedrag, 2) de oorzaken van afweergedrag, en 3) de vormen van afweergedrag en hoe ze te begrijpen zijn. Dit laat zien dat afweergedrag heel ingewikkeld is. Het is daarom aan te raden om aan **alle** verschillende factoren te denken bij het zoeken naar de oorzaak van afweergedrag. Vooral ethische factoren, zoals het starten met kustmatige voeding of vocht, of juist stoppen met het aanbieden van eten en drinken, zijn erg belangrijk maar worden niet altijd als apart punt gezien.

Hoofdstuk 4 kijkt hoe vaak **ernstige situaties** met afweergedrag voorkomen. Hierbij werden 424 mensen met dementie in 12 verpleeghuizen een jaar lang gevolgd. Dit waren 178 mensen met dementie op jongere leeftijd (jonger dan 65 jaar toen de eerste symptomen begonnen) en 246 mensen met dementie op oudere leeftijd. Een contactpersoon per afdeling meldde situaties met afweergedrag. Er werd gekeken naar **nieuwe gevallen** van ernstig afweergedrag, dat minstens twee dagen per week voorkwam en leidde tot problemen zoals gewichtsverlies of uitdroging. Ook moesten de mensen een diagnose dementie hebben en moesten er één of meer symptomen van afweergedrag gezien worden. Er werden 40 situaties gemeld, waarvan 16 echt voldeden aan de criteria. Afweergedrag kwam iets vaker voor bij jongere mensen met dementie (45 nieuwe gevallen per 1000 bewoners per jaar) dan bij oudere (26 gevallen per 1000). Dit aantal was relatief laag, wat kan betekenen dat zorgprofessionals vaak goed kunnen ingrijpen om erger te voorkomen. Symptomen zoals het hoofd wegdraaien, bestek of bord wegduwen, en van tafel opstaan en weglopen werden het meest gezien.

Hoofdstuk 5 onderzoekt hoe beslissingen over afweergedrag worden genomen en wat het effect is op betrokkenen. Tijdens het jaar dat de mensen met dementie in hoofdstuk 4 gevolgd werden, werd gekeken welke situaties hier geschikt voor waren. In totaal waren 16 situaties geschikt, waarvan er 5 diepgaand zijn bestudeerd. Er zijn **interviews** gehouden met naasten en zorgprofessionals die betrokken waren bij een van de 5 situaties. Uit de interviews kwamen drie belangrijke thema's: 1) spanningsveld tussen de zelfstandigheid van de persoon en zorgen voor goede voeding, 2) het begrijpen van de persoon met dementie en het afweergedrag en 3) het zoeken naar zorg die past bij de persoon. Het onderzoek laat zien dat een **persoonlijke aanpak** nodig is, waarbij iemands zelfstandigheid, kwaliteit van leven en goede voeding centraal staan. Deze inzichten kunnen zorgteams helpen om moeilijke beslissingen beter te nemen, zowel in verpleeghuizen als thuis.

Conclusie

Dit proefschrift geeft meer duidelijkheid over afweergedrag bij eten en drinken en helpt om de zorg en kwaliteit van leven van mensen met dementie te verbeteren. Afweergedrag is complex, omdat er veel factoren kunnen meespelen en er geen standaard oplossing is. Daarom is het belangrijk om per maaltijd en persoon te kijken wat werkt. Het is aan te raden om de benadering en de manier van helpen per moment af te stemmen op de situatie. Ethische zaken, zoals normen en waarden, cultuur en religie moeten ook aandacht krijgen in de besluitvorming. Dit gebeurt nu niet altijd, maar is wel belangrijk. Open gesprekken tussen zorgprofessionals en naasten zijn hierbij heel belangrijk. Ook is het goed om op tijd te zien wat het effect van afweergedrag is en daar iets aan te doen, zodat de emotionele last voor iedereen minder wordt. Verder onderzoek met een grotere groep mensen met dementie wordt aanbevolen om nog meer inzicht te krijgen in afweergedrag bij jongere en oudere mensen met dementie.

Toepassing

De uitkomsten van dit proefschrift zijn verwerkt in praktische hulpmiddelen voor de praktijk. Dit zijn een handreiking, een observatieformulier, een poster voor het zorgteam, een folder voor naasten en een korte kennisclip over afweergedrag bij eten en drinken.

ALS ETEN EN DRINKEN NIET GOED GAAT

Informatie voor naasten
van mensen met dementie

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Datamanagement

Ethics and privacy

This thesis is based on the results of research involving human participants, which were conducted in accordance with Dutch Law and the Declaration of Helsinki (1). Data storage was guided by the Findable, Accessible, Interoperable and Reusable (FAIR) principles (2).

The institutional ethical review committee CMO Radboudumc, Nijmegen, the Netherlands has given approval to conduct these studies (CMO Radboudumc dossier number: 2021-13085). The research project did not fall under the remit of the Dutch Medical Research Involving Human Subjects Act (WMO).

The studies in **Chapters 2, 3, 4, and 5** are based on data from human participants. The studies in **Chapters 2 and 3** included mostly healthcare professionals, but also relatives of persons with dementia and **Chapter 3** included researchers as well. Written informed consent was obtained from all participants to collect and process their data for this research project. Consent was not obtained for sharing and reuse of the (pseudonymized) data for future research. The studies in **Chapters 4 and 5** included data from persons with dementia, in addition to data from healthcare professionals and relatives of persons with dementia. Written informed consent was obtained from the legal representatives of the persons with dementia to collect and analyze the data. Consent was not obtained for sharing and reuse of the (pseudonymized) data for future research. According to Dutch legislation, data from electronic health records we collected in **Chapter 4** was collected by personnel with a treatment relationship with the persons with dementia (contact persons) who worked at the care units in the nursing homes that participated in this study. We asked the legal representatives of the persons with dementia explicitly for permission to obtain information on characteristics of resistive behavior from the electronic health records, as well as for a short observation at the care unit, and asked them to fill in a questionnaire. For **Chapter 5**, we asked the person with dementia to provide informed consent on their own behalf, if estimated by the contact person, elderly care physician or psychologist they had the capacity to do so. The privacy of the participants involved in **Chapters 4 and 5** was protected by the use of pseudonymization via a pseudonymization key. This key was stored on a secured network drive that was only accessible to members of the project with authorized access in the context of their role within the project (researcher and research assistant). The pseudonymization key was stored separately from the research data.

Data collection and storage

The data in **Chapter 2** concerned focus group discussions by a single researcher (Eline van Buuren). The discussions were video recorded and transcribed verbatim in Microsoft

Word. The video records were destroyed after transcription. The transcripts were entered into Atlas.ti for data analysis. The raw data and informed consents are stored in a secured locker for 15 years at the department of rehabilitation at the Radboudumc, and only accessible by dr. J.G. Kalf.

Data for **Chapter 3** were collected by using Groupwisdom® (Concept Systems Inc.). The participants had a personal account, and the raw data was exported from the online platform into Microsoft Excel and Microsoft Word. Data were analyzed via Groupwisdom and Microsoft Excel.

The data on characteristics of persons with dementia in **Chapter 4** were collected through Castor EDC, using electronic case report forms (e-CRF) and questionnaires. Data were exported to Microsoft Excel. In addition, data on incident numbers and a log with additional information (e.g. reasons for inclusion or exclusion, and practical information) of the participating care units were kept in Microsoft Access.

The interviews in **Chapter 5** were tape-recorded and transcribed verbatim using Microsoft Word by two researchers (Eline van Buuren and Anouk van Dartel). The tape records were destroyed, and the transcripts were imported in Atlas.ti for data analysis.

All digital data is stored at the H-station of the department of Primary and Community Care. The data is only accessible to employees of the Radboudumc who are responsible for archiving. Data are anonymized and stored for 15 years. After this period the project leader (dr. Jenny van der Steen) will decide whether the data can be destroyed or have to be stored for an additional period.

Data sharing according to the FAIR principles

The studies in **Chapters 2 and 3** are published open access. Chapters 4 and 5 are submitted for publication. The data underlying chapter 2 are not suitable for reuse because the participants did not provide informed consent to do so. The data will be archived with closed access for 15 years in a DAC of the Radboud Data Repository (DOI 10.34973/843j-qk02).

The data used for **Chapter 3** are not suitable for reuse because the participants did not provide informed consent to do so. The data will be archived with closed access for 15 years in a DAC of the Radboud Data Repository (DOI 10.34973/843j-qk02).

The data underlying **Chapters 4 and 5** are not suitable for reuse because because the participants did not provide consent for this. The data from these chapters will be archived with **closed access** for 15 years in a DAC of the Radboud Data Repository after termination of the study (DOI 10.34973/843j-qk02).

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Raymond, ik weet nog goed dat jij me ooit de vraag stelde of ik wilde promoveren en dat ik in lachen uitbarstte. Ik had op dat moment niet gedacht dat het sparren over de inhoud en meeschrijven aan een subsidieaanvraag vanuit onze rollen in de wetenschapscommissie tot dit proefschrift zou leiden, maar het is toch gebeurd! Heel erg bedankt voor je vertrouwen en de potentie die jij in mij zag als onderzoeker. Ik waardeer jouw gedrevenheid en hart voor de zorg voor kwetsbare mensen, en voel me vereerd dat ik onder jouw zeer ervaren en kundige begeleiding mocht groeien als onderzoeker. Ook al ben je (allang) met emeritaat, het weerhoudt jou er niet van om nog altijd erg betrokken te zijn; dat zegt heel erg veel vind ik. Dank!

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Marieke, dankjewel voor jouw begeleiding. Samen met Jenny was jij mijn dagelijks begeleider en wat heb ik daar ontzettend veel aan gehad. Jouw aandeel was ontzettend waardevol wanneer wij als team dreigden af te dwalen bij de opzet van een onderzoek, reviewer commentaar, noem maar op. Jij hebt als geen ander een helicopterview en kan dat ook nog eens combineren met een zeer kundige, maar ook pragmatische aanpak. Het was heel fijn om even goed te kunnen sparren, spuien of gewoon even een koffietje of biertje te drinken!

Jenny, jij bent het meest intensief betrokken geweest bij mijn onderzoek. Dankjewel voor jouw begeleiding, ik heb heel erg veel van jou geleerd! Niets was jou teveel. Ook al zat je in het buitenland of had je anderszins een driedubbele planning, dan zag je alsnog de kans om naar stukken te kijken of mij artikelen te mailen die misschien wel interessant voor me waren én tijd te maken voor de talloze 1-2'tjes die we hebben gehad. Hoe je het doet is mij een raadsel, maar voor mij was dat heel erg fijn. Dankjewel!

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Hanneke, het is al even geleden, maar via deze weg nogmaals bedankt voor je begeleiding tijdens mijn masteronderzoek! Wat mooi dat dit alsnog een wetenschappelijk artikel is geworden én ook nog eens het eerste onderzoekshoofdstuk van dit proefschrift met ons beiden als auteur. Ik weet hoe zeer jij je hard maakt voor meer wetenschap in de logopedie en daar kan ik me helemaal in vinden. Dank voor alle inhoudelijke discussies, talloze kopjes (dubbele zwarte!) koffie en jouw scherpe blik en expertise. Dat we nog maar lang als collega logopedist en -onderzoeker mogen optrekken!

Mariëlle, ook wij gaan 'way back'. Allebei logopedist, allebei promotieonderzoek naar dementie, allebei science practitioner in het verpleeghuis. Ik weet nog goed dat je mij belde omdat je het even niet meer wist en zei: ‘jij snapt het, want je bent precies zoals ik’. Dankjewel voor het uitwisselen van tips en ervaringen, samen thuis werken, het meeschrijven aan het eerste artikel, en natuurlijk alle gezellige momenten!

Anouk, jij kwam in beeld bij de multiple case studie. Een academic traineeship leek je wel leuk en Marieke koppelde jou aan mij. Er bleek toch even een iets langere adem voor nodig dan gepland, maar je hebt je er goed doorheen geslagen. Heel erg bedankt dat je mijn co-interviewer was, mee hebt gecodeerd en hebt meegeschreven aan het artikel!

Collega’s van het UKON, het gaat te ver om iedereen hier persoonlijk te noemen, want ik ben veel te bang dat ik iemand vergeet. Collega promovendi, dank jullie wel voor de inhoudelijke gesprekken, de journal clubs, promovendi bijeenkomsten, congresreizen en natuurlijk de gezellige momenten waarop we net iets te lang bij de koffieautomaat bleven hangen (of in de Aesculaaf belandden). Charlotte, jij in het bijzonder bedankt voor je hulp bij het ontwikkelen van het materiaal voor de toolkit!

Science practitioner collega’s, ik wil jullie bedanken voor de fijne samenwerking in de afgelopen jaren. Als we elkaar zien is dat altijd inspirerend. Jullie betrokkenheid heeft ervoor gezorgd dat er makkelijk lijntjes te leggen waren in de diverse organisaties, dank daarvoor! Een aantal van jullie was ook contactpersoon, heel erg fijn!

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Caroline, de andere helft van het praktijkonderzoekersduo. We horen vaak dat we zo verschillend zijn, maar ik ben ervan overtuigd dat dat júist maakt dat we elkaar mooi aanvullen en slagvaardig zijn. Dankjewel voor de samenwerking en je interesse in mijn onderzoek (en dat je me aanspoort om de toolkit fatsoenlijk te implementeren;-)). Ook bedankt voor het meelezen en je suggesties voor de Nederlandse samenvatting. We hebben al ontzettend mooie dingen opgebouwd binnen De Waalboog rondom onderzoek en ik hoop dat we dat nog lang samen kunnen blijven doen!

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Irene, we kennen elkaar sinds de opleiding en onze gezamenlijke liefde voor persiflage en gekke stemmetjes bestaat tot op de dag van vandaag. Beroepsdeformatie of niet, het heeft voor vele slappe lach momenten gezorgd. Dankjewel voor alle diepgaande gesprekken en bijklets-sessies in de afgelopen jaren.

Eliza, my oldest friend, zoals we elkaar noemen. Sinds onze puberjaren zijn we bevriend en ook al wonen we niet bij elkaar om de hoek, we zorgen dat we in elkaars leven blijven. Jij kan als geen ander mij laten inzien dat dit een hele knappe prestatie is en dat ik daar niet te snel overheen moet stappen maar ook echt trots kan zijn op mezelf. Dankjewel voor je vriendschap!

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Team GEMS van RV De Waal: Merel, Jaako, Serge, Dirk en Marjanne, het was heerlijk om na een lange dag van onderzoek doen even met jullie uit te waaien op het water! Serge, ik wens jou succes met het afronden van jouw promotietraject, dat gaat je zeker lukken!

En dan jij, Paul. De laatste woorden van mijn proefschrift zijn voor jou. Jij kent me niet anders dan dat ik bezig ben met ‘het onderzoek’. Dankjewel dat je er voor me was op de momenten dat ik het even niet meer zo goed trok, jij weet me altijd op te fleuren en op te beuren. Gelukkig kunnen we ook mijlpalen samen goed vieren, soms zelfs iets te goed;-) Op naar nog heel veel mooie avonturen samen, ik hou van jou!

PhD portfolio

Name: C.P. (Eline) van Buuren
Department: Primary and community care
PhD period: 15/3/2021 to 15/12/2024
PhD supervisor: prof. dr. R.T.C.M. Koopmans
PhD co-supervisors: dr. ir. J.T. van der Steen, dr. M. Perry, prof. dr. C. Bakker

Training activities	**Year**	**Hours**
Donders Center for Medical Neuroscience (DCMN) introduction day	2021	7.00
Radboudumc introduction day	2021	9.00
Donders Graduate School (DGS) - Graduate School Day 1	2021	7.00
An introduction to Group Concept Mapping and Groupwisdom™	2021	1.00
Library introduction for PhD’s and postdocs	2021	1.00
Online Endnote Instruction and Pubmed Workshop	2021	2.00
Workshop literature review for your PhD	2021	4.00
Basis Course for clinical investigators (BROK)	2021	42.00
How to write a medical scientific paper	2021	4.00
Achieving your goals and performing more successfully in your PhD	2021	42.00
Project management for PhD candidates	2021	56.00
Effective writing strategies	2021	84.00
Writing scientific articles	2022	96.00
DCMN - Scientific Integrity Course	2022	7.00
DGS - Graduate School Day 2	2022	7.00
Cursus Qualitative interviewing	2023	16.00
DGS - Graduate School Day 3	2023	7.00
Active Bystander Training	2023	2.00
The art of finishing up	2024	10.00
Career development for PhD candidates & postdocs “The next step in my career”	2024	24.00
		428 hours

Conferences

Mix&Match network meeting Alzheimer Nederland/ Memorabel (Online)	2021	7.00
UKON Symposium (’s Hertogenbosch)	2021	7.00
SANO Wetenschapsdag (Leiden), poster presentation	2022	7.00
Mix&Match (Utrecht)	2022	7.00
Dag van de Logopediewetenschap (Utrecht)	2022	4.00
Care Days (Eindhoven)	2023	14.00
UKON Symposium (’s Hertogenbosch), oral presentation	2023	7.00
SANO Wetenschapsdag (Amsterdam)	2023	7.00
Alzheimer Europe (Helsinki), poster presentation	2023	32.00
Kennisplein De Waalboog (Nijmegen), poster presentation	2023	4.00
Odisee International conference on young-onset dementia (Brussels), oral presentation	2024	20.00
Alzheimer Europe (Geneva), poster presentation	2024	32.00
Landelijk congres Probleemgedrag bij dementie (Amsterdam), oral presentation	2024	6.00
		154 hours

Teaching activities

Lecturing

Guest lecture minor oropharyngeal dysphagia, Bachelor Speech and Language Therapy, Hogeschool van Arnhem en Nijmegen (Nijmegen)	2022	12.00
Lunch meeting, department primary and community care, line of research ‘palliative care’ (Nijmegen)	2022	4.00
Workshop science day, Tante Louise (Steenbergen)	2022	12.00
Network meeting Gerodontology/Geriatric Dentistry (Amersfoort)	2023	8.00
Annual meeting for dieticians working in geriatric care (DGO) (Veenendaal)	2023	7.00
Meet the Author, Logoscientia (Online)	2024	8.00
V&V Knowledge Hub (‘s Hertogenbosch)	2024	12.00

Supervision of internships

Bachelor nursing students, development of the observational form for the incidence study	2021	32.00
Anouk van Dartel (Elderly care physician in training)	2023	32.00
		127 hours

Other

Co-author of the book ‘Probleemgeoriënteerd denken in de palliatieve zorg’, Chapter ‘Dementie’), second edition	2023	6.00
Guideline oral care, commentary (2023)	2023	4.00
Member of the Journal Club, department of primary and community care (2022- 2024)	2022-2024	24.00
‘Consult your researcher’, advisory role for science practitioners affiliated with UKON (2023-2024)	2023-2024	12.00
		46 hours
		755 hours

Over de auteur (about the author in Dutch)

Eline van Buuren werd op 11 februari 1988 geboren in Gorinchem. Ze behaalde haar HAVO-diploma in 2005 aan het Van Lodenstein College in Amersfoort. Eline ging daarna logopedie studeren aan de Hogeschool van Arnhem en Nijmegen (HAN) in Nijmegen, waar zij haar diploma behaalde in 2011 (Bachelor of Science).

Sindsdien is zij met veel plezier werkzaam als logopedist bij De Waalboog in Nijmegen, waar zij mensen behandelt met diverse problematiek op het gebied van communicatie en eten en drinken. In 2015 startte Eline met de master Klinische Gezondheidswetenschappen aan de Universiteit Utrecht, waar zij in 2019 haar diploma behaalde (Master of Science). Haar afstudeeronderzoek betrof eet- en drinkproblematiek bij mensen met dementie en heeft geresulteerd in een wetenschappelijk artikel – hoofdstuk 2 van dit proefschrift. Na het behalen van haar masterdiploma is Eline haar werk als logopedist bij De Waalboog gaan combineren met de functie van praktijkonderzoeker. In deze functie werkt zij als bruggenbouwer tussen de wetenschap en de praktijk van de dagelijkse zorg en is zij verbonden aan het Universitair Kennisnetwerk Ouderenzorg Nijmegen (UKON). In 2021 is Eline gestart met haar promotietraject bij de afdeling Eerstelijnsgeneeskunde van het Radboudumc, waarnaast zij bleef werken als praktijkonderzoeker. Het promotieonderzoek richtte zich op situaties waarbij jonge en oudere mensen met dementie afweren bij eten en drinken. Gedurende haar promotieonderzoek heeft Eline studenten begeleid van de opleidingen verpleegkunde en arts in opleiding tot specialist ouderengeneeskunde. Ze heeft bijdragen geleverd aan verschillende (inter)nationale congressen en presentaties en scholingen gegeven aan collega's van diverse disciplines.

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