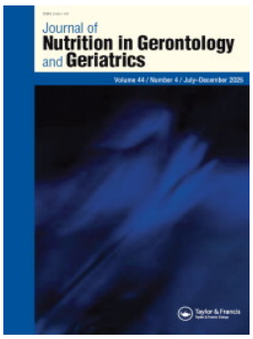

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ORIGINAL RESEARCH

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

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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).

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

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.)

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.

Characteristics

Among the sixteen incident cases, we received eight full reports of the residents' characteristics and resistive behavior affecting their intake of food

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.

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).

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

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*
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*

(*Continued*)

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
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*
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*
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*

(*Continued*)

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*
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*
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*

(*Continued*)

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*

*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 (-).

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.

Take away points

- The overall incidence of resistive behavior affecting the intake of food and fluids was higher among residents with young-onset dementia compared to residents with late-onset dementia.
- The low overall incidence might indicate that healthcare professionals in nursing homes are often able to effectively anticipate and manage at risk situations, which could prevent escalation to the serious behaviors.
- 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.

In fourteen of sixteen cases there was a prioritized global care goal aimed at providing comfort care (3 palliative, 11 symptomatic goals) and the most

frequently reported treatment decisions were to no longer stimulate eating/drinking, along with providing comfort care and accepting the behavioral problems and possible negative consequences.

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Disclosure statement

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Data availability statement

The data that support the findings of this study are available from the corresponding author, [EvB], upon reasonable request.

References

1. Kimura A, Sugimoto T, Kitamori K, et al. Malnutrition is associated with behavioral and psychiatric symptoms of dementia in older women with mild cognitive impairment and early-stage Alzheimer's disease. *Nutrients*. 2019;*11*(8):1951. doi:10.3390/nu11081951.
2. Liu W, Galik E, Boltz M, Nahm ES, Resnick B. Optimizing eating performance for older adults with dementia living in long-term care: a systematic review. *Worldviews Evid Based Nurs*. 2015;*12*(4):228–235. doi:10.1111/wvn.12100.
3. van Buuren CP, van der Steen JT, Olthof-Nefkens M, et al. The complexity of nutritional problems in persons with dementia: expanding a theoretical model. *J Alzheimers Dis*. 2023;*96*(1):183–192. doi:10.3233/JAD-230135.
4. Liu W, Perkhounkova Y, Williams K, Batchelor M, Hein M. Mealtime nonverbal behaviors in nursing home staff and residents with dementia: Behavioral analyses of videotaped observations. *Geriatr Nurs*. 2022;*44*:112–124. doi:10.1016/j.gerinurse.2022.01.009.

5. Barrado-Martín Y, Hatter L, Moore KJ, et al. Nutrition and hydration for people living with dementia near the end of life: A qualitative systematic review. *J Adv Nurs*. 2021;*77*(2):664–680. doi:10.1111/jan.14654.
6. Jiang J, Wang A, Shi H, et al. Clinical and neuroimaging association between neuropsychiatric symptoms and nutritional status across the Alzheimer's disease continuum: a longitudinal cohort study. *J Nutr Health Aging*. 2024;*28*(3):100182. doi:10.1016/j.jnha.2024.100182.
7. Moreira VS, Chaves MLF, de Castilhos RM, Olchik MR. Caregiver burden related to feeding process in Alzheimer's disease. *Dement Neuropsychol*. 2023;*17*:e20220092. doi:10.1590/1980-5764-DN-2022-0092.
8. Farina N, Page TE, Daley S, et al. Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimers Dement*. 2017;*13*(5):572–581. doi:10.1016/j.jalz.2016.12.010.
9. Arjama A-L, Suhonen R, Kangasniemi M. Ethical issues in long-term care settings: Care workers' lived experiences. *Nurs Ethics*. 2024;*31*(2-3):213–226. doi:10.1177/09697330231191277.
10. Ryan B, Martinez Ruiz A, Rivera-Rodriguez C, Curtis M, Cheung G. Sociodemographic and clinical characteristics of 1350 patients with young onset dementia. *Alzheimer Dis Assoc Disord*. 2021;*35*(3):200–207. doi:10.1097/WAD.0000000000000435.
11. Baillon S, Gasper A, Wilson-Morkeh F, Pritchard M, Jesu A, Velayudhan L. Prevalence and Severity of Neuropsychiatric Symptoms in Early- Versus Late-Onset Alzheimer's Disease. *Am J Alzheimers Dis Other Demen*. 2019;*34*(7-8):433–438. doi:10.1177/1533317519841191.
12. van de Veen D, Bakker C, Peetoom K, et al. Provisional consensus on the nomenclature and operational definition of dementia at a young age, a Delphi study. *Int J Geriatr Psychiatry*. 2022;*37*(3):1–11. doi:10.1002/gps.5691.
13. van de Veen D, Bakker C, Peetoom K, et al. An integrative literature review on the nomenclature and definition of dementia at a young age. *J Alzheimers Dis*. 2021;*83*:1891–1916.
14. van Buuren CP, van der Steen JT, Koopmans RTCM, Bakker C, Perry M. Behavior complicating intake of food or fluids in younger and older persons with dementia - a cohort study. 2022.
15. Hendriks SA, Smalbrugge M, van Gageldonk-Lafeber AB, et al. Pneumonia, intake problems and survival among nursing home residents with variable stages of dementia in the Netherlands. *Alzheimer Dis Assoc Disord*. 2016;*00*:1–9.
16. Kruizenga HM, Seidell JC, de Vet HC, Wierdsma NJ, van Bokhorst-de van der Schueren MA. Development and validation of a hospital screening tool for malnutrition: the short nutritional assessment questionnaire (SNAQ). *Clin Nutr*. 2005;*24*(1):75–82. doi:10.1016/j.clnu.2004.07.015.
17. van Buuren ECP, Perry M, Bakker C, Koopmans R, van der Steen JT. Understanding mealtime behavioral problems in nursing home residents living with dementia: a group concept mapping approach. *BMC Geriatr*. 2024;*24*(1):843. doi:10.1186/s12877-024-05420-4.
18. Geriatrics DAfC. TOPICS-MDS short form. 2017.
19. Galindo-Garre F, Hendriks SA, Volicer L, Smalbrugge M, Hertogh CM, van der Steen JT. The Bedford Alzheimer nursing-severity scale to assess dementia severity in advanced dementia: a nonparametric item response analysis and a study of its psychometric characteristics. *Am J Alzheimers Dis Other Demen*. 2014;*29*(1):84–89. doi:10.1177/1533317513506777.
20. Volicer L, Hurley AC, Lathi DC, Kowall NW. Measurement of severity in advanced Alzheimer's disease. *J Gerontol*. 1994;*49*:223–226.
21. van der Steen JT, Volicer L, Gerritsen DL, Kruse RL, Ribbe MW, Mehr DR. Defining severe dementia with the Minimum Data Set. *Int J Geriatr Psychiatry*. 2006;*21*(11):1099–1106. doi:10.1002/gps.1618.

22. Grobbee DE, Hoes AW. *Clinical Epidemiology: Principles, Methods, and Applications for Clinical Research*. 2nd ed. Burlington, MA, USA: Jones & Bartlett Learning, 2015.
23. Association WM. Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects. World Medical Association, 2013.
24. Jung D, Lee K, De Gagne JC, et al. Eating difficulties among older adults with dementia in long-term care facilities: a scoping review. *Int J Environ Res Public Health*. 2021;*18*(19):10109. doi:10.3390/ijerph181910109.
25. Jung D, Choi E, Yoo L, Lee H. Development of mealtime difficulty scale for older adults with dementia in long-term care facilities. *BMC Geriatr*. 2022;*22*(1):518. doi:10.1186/s12877-022-03224-y.
26. Aselage MB, Amella EJ. An evolutionary analysis of mealtime difficulties in older adults with dementia. *J Clin Nurs*. 2010;*19*(1-2):33–41. doi:10.1111/j.1365-2702.2009.02969.x.
27. Liu W, Perkhounkova Y, Hein M, Bakeman R. Temporal relationships between nursing home staff care approaches and behaviors of residents with dementia during mealtimes: a sequential analysis. *Innov Aging*. 2023;*7*(5):igad061. doi:10.1093/geroni/igad061.
28. Chang CC, Lin YF, Chiu CH, et al. Prevalence and factors associated with food intake difficulties among residents with dementia. *PLoS One*. 2017;*12*(2):e0171770. doi:10.1371/journal.pone.0171770.
29. Lee JY, Lee KH, McConnell ES. Mealtime caregiving approaches and behavioral symptoms in persons living with dementia: a longitudinal, observational study. *BMC Nurs*. 2021;*20*(1):104. doi:10.1186/s12912-021-00621-3.
30. Lin PH, Ataiza C, Ho MH, Chung YV, Sharp L, Chang HR. A cross-sectional, observational study of nutritional status and eating behaviours in people living with dementia in acute care settings. *J Clin Nurs*. 2023;*32*(15-16):5028–5036. doi:10.1111/jocn.16729.
31. Wright JL, Jaggard PM, Holahan T, Ethics Subcommittee of A-TSfP-A, Long-Term C. Stopping eating and drinking by advance directives (SED by AD) in assisted living and nursing homes. *J Am Med Dir Assoc*. 2019;*20*(11):1362–1366. doi:10.1016/j.jamda.2019.07.026.
32. Nygaard A, Halvorsrud L, Grov EK, Bergland A. What matters to you?'-a qualitative study on the views of nursing home residents with dementia regarding the health care they receive. *J Clin Nurs*. 2022;*31*(1-2):262–274. doi:10.1111/jocn.15904.
33. Schou-Juul F, Norgaard S, Lauridsen SMR. Ethical issues in dementia guidelines for people with dementia and informal caregivers in Denmark: A qualitative thematic synthesis. *Dementia (London)*. 2023;*22*(1):28–45. doi:10.1177/14713012221131856.
34. Wang ZL, McHale JR, Belza B, Sonney J. Eating experiences in people living with dementia: A concept analysis using Rodgers's methodology. *J Adv Nurs*. 2024;*80*(11):4461–4475. doi:10.1111/jan.16191.
35. Lee Y-F, Hsu T-W, Liang C-S, et al. The efficacy and safety of tube feeding in advanced dementia patients: A systemic review and meta-analysis study. *J Am Med Dir Assoc*. 2021;*22*(2):357–363. doi:10.1016/j.jamda.2020.06.035.
36. Falgas N, Allen IE, Spina S, et al. The severity of neuropsychiatric symptoms is higher in early-onset than late-onset Alzheimer's disease. *Eur J Neurol*. 2022;*29*:957–967.
37. Mendez MF. Managing the behavioral and psychological symptoms of dementia. *Curr Treat Options Neurol*. 2022;*24*(5):183–201. doi:10.1007/s11940-022-00715-6.
38. Altomari N, Bruno F, Laganà V, et al. A comparison of Behavioral and Psychological Symptoms of Dementia (BPSD) and BPSD sub-syndromes in early-onset and late-onset Alzheimer's disease. *J Alzheimers Dis*. 2022;*85*(2):691–699. doi:10.3233/JAD-215061.
39. Polsinelli AJ, Johnson S, Crouch A, et al. Neuropsychiatric symptom burden in early-onset and late-onset Alzheimer's disease as a function of age. *Alzheimers Dement*. 2024;*20*(8):5481–5491.
40. Cadwallader CJ, Velakoulis D, Loi SM. Post-diagnostic support for behaviour changes in young-onset dementia in Australia. *Brain Sci*. 2023;*13*(11):1529. doi:10.3390/brainsci13111529.