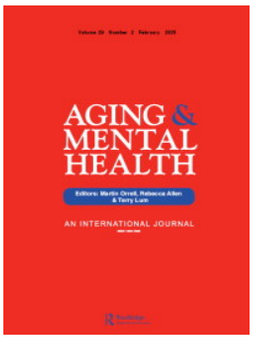

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Patient characteristics, behavior, and discharge locations of patients with dementia and very severe challenging behavior

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ABSTRACT

Objectives: To gain insights into the characteristics, behavior, and discharge location of patients with dementia and very severe challenging behavior admitted to highly specialized units that are specialized in the diagnostics and treatment of this patient group.

Method: In this observational study, 11 units participated from 2020 - 2023. Measurements included demographics; dementia type; severity of cognitive decline; presence of delirium; location before admission; compulsory admission; medical history; drug use; and behavior during the first 2 weeks of admission, assessed by the Cohen-Mansfield Agitation Inventory and the Neuropsychiatric Inventory Questionnaire.

Results: 127 patients (67.7% males) participated. Nine in ten patients had moderately severe or severe cognitive decline. Behavior was rather heterogeneous, with agitation, general restlessness and verbal aggression present in 70% or more. Agitation was severely or extremely distressful for nursing staff in relation to one in four patients. Half of the patients were discharged to a regular dementia special care unit (DSCU), one in ten could not be discharged, and one-third died during their stay.

Conclusions: Despite heterogenous and highly prevalent behaviors of patients, about half of the patients could be discharged to DSCUs after treatment in a highly specialized unit. Future studies should explore whether and how treatment is effective.

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Agitation; behavioral and psychological symptoms of dementia (BSPD); neuropsychiatric symptoms

Introduction

Challenging behavior in persons with dementia has a significant impact on themselves, their caregivers, and society. It is associated with a diminished quality of life in persons with dementia (Henskens et al., 2019; Livingston et al., 2017; Majer et al., 2020), increased distress in formal and family caregivers (Black & Almeida, 2004; Brites et al., 2020; van Duinen-van den et al., 2018; Majer et al., 2020; Svendsboe et al., 2016; Zwijsen et al., 2014), and increased health care costs (Buylova Gola et al., 2020). While the perception of behavior as challenging is context-dependent, challenging behavior is very common in persons with dementia (Selbæk et al., 2013) with a small proportion having very severe to extreme challenging behaviors (Brodaty et al., 2003). The prevalence rate of extremely challenging behavior in long-term care settings is approximately 6.3% when defined as severe agitation, and 7.4%, 2.2%, and 11.5%, respectively, when defined as very frequent agitation, physical aggression, and vocalizations (Palm et al., 2018; Veldwijk-Rouwenhorst et al., 2017, 2021). These patients with very severe challenging behavior are younger and have more advanced stages of dementia compared to patients without such behavior (Palm et al., 2018; Veldwijk-Rouwenhorst et al., 2017).

Highly specialized units for the diagnostics and treatment of patients with dementia and very severe to extreme challenging behavior—"very severe challenging behavior" hereafter—have been established in the Netherlands (Koopmans et al., 2022; van Voorden et al., 2024). These highly specialized units are pioneering in the diagnostics and treatment of these patients, and they are part of an organization for long-term care, mental health care or a collaboration of both. Patients can be admitted when a stay in a regular DSCU is no longer possible due to the severity of the challenging behavior (Verhees et al., 2024). Among highly specialized units differences in methodological work-up were found, but also similarities in emphasis on observation with an open attitude, a key role of nursing staff, and attention to sensory stimuli (van Voorden et al., 2024). Patients are discharged from these highly specialized units when there is insight into the background of the behavior and a behavioral approach can be applied that is manageable in these dementia special care units (DSCUs) (van Voorden et al., 2024). Units comparable to these highly specialized units also exist in Australia and the United Kingdom (Gresham et al., 2021; Jones et al., 2023). In the

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Netherlands, people with dementia can be admitted to these units when residence in a regular DSCU (Verbeek et al., 2009) is no longer possible due the severity of the challenging behavior. Several developments might have contributed to the need for these units. First, the number of people with dementia is increasing (van Bussel et al., 2017; Nichols et al., 2022). Second, the number of inpatient psychiatric beds within the Dutch mental health care sector has been systematically reduced over recent years (Kroon et al.,, 2021). Finally, older people are living at home longer and moving to nursing home settings when they are in more advanced stages of dementia, when they often have more challenging behaviors (Gaugler et al., 2009; Verbeek-Oudijk & Koper, 2021). Concerns have been reported about the care for people with dementia and very severe challenging behavior in regular nursing home settings by the Dutch health care inspectorate (Health and Youth Care Inspectorate, 2020).

Given that little is known about the patient characteristics, the nature of the very severe challenging behavior, and the discharge locations of patients admitted to these highly specialized units, this study aims to investigate these features.

Methods

Study design

Design

This observational study took place from December 2020 until December 2022, with a follow-up taking place in September 2023. For newly admitted patients, we collected data on their demographics, clinical characteristics, behavior during the first 2 weeks of admission, and discharge locations or death.

Setting

Units where patients with dementia were temporarily admitted due to severe challenging behavior were asked to participate. These highly specialized units (Koopmans et al., 2022) were identified and recruited by six academic networks of long-term care (Koopmans et al., 2013). Of the 15 identified units, 11 gave consent to participate. Unit sizes ranged from 7 to 28 (see Table S1 in the Supplementary materials).

Participants

Patients were included when they met the following inclusion criteria: (1) dementia or suspected dementia, and (2) severe challenging behavior such as verbal and/or physical aggression, agitation, vocally disruptive behavior "*associated with suffering or danger to the person with [suspected] dementia or people in his or her environment*" (Zuidema et al., 2018). Exclusion criteria were: (1) acquired brain injury without (suspected) dementia, and (2) a life expectancy of less than 2 weeks. Criteria for eligibility were considered by the treating physician, who received an online instruction from the research team and could discuss with them when eligibility was in doubt.

Data sources and data collection

Castor EDC (https://www.castoredc.com/) was used for data management. The treating physician was instructed to register all patients admitted to the unit during the study. They also provided details about the demographics, dementia type, severity of cognitive decline, delirium, location before admission, compulsory admission, medical—including psychiatric—history, and (psychotropic) drug use of patients who gave informed consent (see ethics statement below). Psychiatric diagnoses and dementia type were recorded as registered in the medical file at admission. Physicians were instructed in an online training session about the study and about how to complete assessments send as digital questionnaires to them after inclusion.

Two weeks after admission, a nursing staff member with experience in the care for the participant during this period completed a digital questionnaire about challenging behavior using validated instruments (see below). Nursing staff members were trained using an online training with information about the study and instruction about the behavioral assessment scales. Details about discharge date and location or death were obtained from a staff member. For the participants who were still at the unit at the end of the data collection period, a follow-up was conducted nine months later (September 2023). The treating physician completed questions about discharge date and location or death in this follow-up contact with participating units.

Assessments

For dementia type, the chart diagnosis was registered, except for participants with a high suspicion of dementia on admission. The severity of the cognitive decline was assessed using the Global Deterioration Scale, which ranges from no dementia (stage 1) to very severe dementia (stage 7) (Reisberg et al., 1982). The presence of delirium or possible delirium at admission was assessed with the diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013). Medical history was categorized into 56 chronic somatic disorders, which could be grouped into sixteen overarching chapters using the International Statistical Classification of Diseases and Related Health Problems Tenth Revision (ICD-10) (World Health Organization, 2015). Any psychiatric diagnoses were registered separately. Regular psychotropic drug use was classified by using the Anatomical Therapeutical Chemical Classification (WHO Collaborating Centre for Drug Statistics Methodology, 2022) and categorized into antiepileptics, antipsychotics, anxiolytic drugs, hypnotics and sedatives, antidepressants, anti-dementia drugs, and other psychotropic drugs.

Cohen-Mansfield Agitation Inventory

The Dutch version of the Cohen-Mansfield Agitation Inventory (CMAI) was used in the digital questionnaire to be completed by a nursing staff member (de Jonghe & Kat, 1996). The CMAI comprises 29 items rated on a seven-point scale (1–7) ranging from "never" to "several times an hour" (Cohen-Mansfield et al., 1989). The CMAI has good reliability among people with Alzheimer's dementia (Koss et al., 1997), and older people admitted to a Dutch geriatric psychiatry unit (de Jonghe & Kat, 1996). The content validity has been demonstrated to be good (de Jonghe & Kat, 1996; Miller et al., 1995). In addition to the CMAI total score, three factor scores can be calculated representing physically aggressive behavior, physically nonaggressive behavior, and verbally agitated behavior (Zuidema et al., 2007).

Neuropsychiatric Inventory Questionnaire

The Dutch version of the Neuropsychiatric Inventory Questionnaire (NPI-Q) was also used (de Jonghe et al., 2003). De NPI-Q includes 12 neuropsychiatric symptoms: delusions, hallucinations, agitation, depression/dysphoria, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability, aberrant motor behavior, nighttime behaviors, and appetite/eating change. The severity of each symptom is rated on a three-point (1–3) Likert scale ranging from mild to severe, and the emotional distress for the nursing staff member on a six-point (0–5) Likert scale ranging from not distressing at all to extremely distressing (de Jonghe et al., 2003). The NPI-Q has good item internal consistency and item reliability in hospitalized older adults (Resnick et al., 2023), and content validity of the Dutch version has been found to be reasonable among people with dementia (de Jonghe et al., 2003).

Analysis

Data were analyzed using descriptive statistics, with statistical analysis carried out using SPSS version 29.

Ethics statement

Informed consent was obtained by the treating physician. The physician was trained online and was formally assigned this role by the study team. The patients' capacity to consider participation in the study was assessed by this physician. Written informed consent was obtained from participants with full capacity to consent ($n = 1$) or proxy consent from their legal representative ($n = 126$). Patients who had no full capacity to consent were informed by the physician according to the patient's level of understanding. Physicians were instructed to stop participation when behavior of the participant could be interpreted as resistance against participation in this observational study. The study was conducted in accordance with the Declaration of Helsinki as well as the Dutch legislation. The local Medical Ethics Review Committee—CMO region Arnhem-Nijmegen located at Radboud University Medical Center—reviewed the study, stating that the Medical Research Involving Human Subjects Act (WMO) does not apply to this study and that their official approval is not required (reference number 2020-6979).

Results

Of the 11 participating units (range: 7–28 beds), one unit withdrew participation after two inclusions due to organizational problems, and one unit started 1 year later. The median participation rate of all admitted patients was 30% (range: 4–78%), resulting in a sample size of 127 patients (see Table S1 in the Supplementary materials).

Patient characteristics

Participants were on average 78.5 years, two-thirds were male, about four in ten had Alzheimer's dementia, and about nine in ten had moderately severe or severe cognitive decline. About six in ten were admitted from a regular DSCU, and about half of them were admitted on a compulsory basis (for details, see Table 1).

Comorbidity

About one in six participants had (possible) delirium, and about one-third had a psychiatric history. The median number of chronic somatic conditions was three, and the median number of regular non-psychotropic drugs at admission was four. About two-thirds had a chronic somatic disorder of the circulatory system (for details, see Table 1).

Psychotropic drug use

The median number of regular psychotropic drugs at admission was two. About three in five patients were prescribed two or more psychotropic drugs, with antipsychotics and anxiolytics being most prevalent (for details, see Table 2).

Behavior

Agitation

Participants had a median of ten items present out of the 29 items measuring agitated behavior, and a median of three items were present several times a day or an hour (for details, see Table 2). About three-quarters of the participants had at least one item that occurred several times a day or more, and one-third had behavior in the factor of physically aggressive behavior that occurred once a day or more.

The five most prevalent behaviors were general restlessness (85.7%), cursing/verbal aggression (76.8%), pacing/aimless wandering (71.4%), repetitive sentences/questions (68.8%), and constant unwarranted request for attention/help (67.0%). The five most prevalent items that were present several times a day or an hour were general restlessness (47.3%), pacing/aimless wandering (45.5%), repetitive sentences/questions (37.5%), constant unwarranted request for attention/help (34.8%), and trying to get to a different place (24.1%). In 20.5% of participants, cursing/verbal aggression was present several times a day or more.

Neuropsychiatric symptoms

Six or more out of twelve neuropsychiatric symptoms were present in half of the participants (interquartile range 3–7). Agitation was regarded as severe in one-third of the patients, and irritability and disinhibition in one in five. The three highest scoring symptoms for severe or extreme emotional distress in nursing staff were agitation, irritability, and disinhibition, with severe or extreme distress experienced in one in four or five of the participants (for details, see Table 3).

Discharge location and mortality

Over half of the participants were discharged to a DSCU, one in ten was still waiting for this at the follow-up, and one-third died during their stay (for details, see Table 4). The median length of stay was 122 days for patients who were discharged. Among participants who died during their stay, the median length of stay was 84 days. Patients who died during stay were significantly older.

Discussion

This is the first study to describe the characteristics and discharge locations of patients admitted to highly specialized units

Table 1. Patient characteristics and comorbidity ($n = 127$).

Age	78.5 Years (SD 8.8)
Sex, man	67.7% (86)
Dementia type	*n* (%)
Suspected dementia	*5* (3.9%)
Alzheimer's dementia	53 (41.7%)
Vascular dementia	26 (20.5%)
Mixed type (Alzheimer's and vascular)	15 (11.8%)
Lewy Body dementia	2 (1.6%)
Parkinson's dementia	2 (1.6%)
Frontotemporal dementia	10 (7.9%)
Alcohol-related dementia	2 (1.6%)
Not specified	12 (9.4%)
Severity of cognitive decline (GDS)a	*n* (%)
Stage 2–4 (very mild to moderate)	10 (7.9%)
Stage 5 (moderately severe)	50 (39.4%)
Stage 6 (severe)	61 (48%)
Stage 7 (very severe)	5 (3.9%)
Location before admission	*n* (%)
Regular DSCU in a nursing home	71 (55.9%)
Home	33 (26.0%)
Regular somatic care unit in a nursing home	2 (1.6%)
Other nursing home unitb	10 (7.9%)
Residential home	5 (3.9%)
Mental health care admission unit	2 (1.6%)
Hospital	4 (3.1%)
Compulsory admission	*n* (%)
Compulsory admission	65 (51.2%)
Delirium at admission	*n* (%)
Yes	7 (5.5%)
Possibly	10 (7.9%)
Psychiatric history	*n* (%)
Psychiatric history (one or more diagnoses)c	41 (32.3%)
Comorbidity	Median (IQR)
Number of chronic somatic disorders[c]	3.0 (2.0–5.0)
Number of regular non-psychotropic drugs at admissiond	4.0 (2.0–6.3)
Patients with (one or more) chronic somatic disorders present in this chapter (ICD-10)[c]	*n* (%)
Diseases of the circulatory system	86 (67.7%)
Diseases of the musculoskeletal system and connective tissue	42 (33.1%)
Endocrine, nutritional and metabolic diseases	42 (33.1%)
Diseases of the genitourinary system	26 (20.5%)
Diseases of the nervous system	17 (13.4%)
Diseases of the eye and adnexa	17 (13.4%)
Diseases of the respiratory system	14 (11.0%)
Diseases of the digestive system	14 (11.0%)
Diseases of the ear and mastoid process	13 (10.2%)
Diseases of the skin and subcutaneous tissue	12 (9.4%)
Neoplasms	5 (3.9%)
Injury, poisoning, and certain other consequences of external causes	5 (3.9%)
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	4 (3.1%)
Other (congenital, symptoms not elsewhere classified)	2 (1.6%)
Infectious and parasitic diseases	1 (0.8%)

SD, standard deviation, IQR, interquartile range.
[a]1 Stage 5 or 6.
[b]Namely: so-called admission DSCU ($n = 3$), specialized DSCU ($n = 3$), long-term psychiatric institution ($n = 1$), geriatric rehabilitation ($n = 1$), "*care center*" with no more information ($n = 1$) or private care home ($n = 1$).
[c]Two missing in psychiatric history and chronic somatic disorders.
[d]A total of 13 missing in non-psychotropic drug use.

for temporary treatment of very severe challenging behavior in dementia in the Netherlands. We found heterogeneity in the behavior of patients, relatively high psychotropic drug use, and severe or extreme emotional distress for the nursing staff in about one in four patients. About half of the patients were discharged to a DSCU and one-third died during admission.

Heterogeneity behavior

We found a high level of heterogeneity in behavior among individual patients. Despite this, agitation, general restlessness, and verbal aggression were present in 70% or more of the participants according to the CMAI. Most patients had five or six neuropsychiatric symptoms as measured with the NPI-Q present at the same time, similar to the number reported in specialized units in Australia (Djekovic et al., 2022). This highlights that care and treatment might be demanding because staff need to adapt well and cope with the different types of behavior that are simultaneously present.

Psychotropic drug use

Psychotropic drug use was relatively high, but similar rates were found in other studies that included people with dementia and very severe challenging behavior (Djekovic et al., 2022; Veldwijk-Rouwenhorst et al., 2017). Psychotropic drug use was very high

Table 2. Psychotropic drug use and behavior by CMAI ($n = 127$).

Psychotropic drug usea	Median (IQR)
Number of regular psychotropic drugs at admission	2.0 (IQR 1.0–3.0)
Regular use (one or more) psychotropic drugs per category	*n* (%)
Antiepileptics	10 (8.8%)
Antipsychotics	66 (57.9%)
Anxiolytics	53 (46.5%)
Hypnotics	26 (22.8%)
Antidepressants	41 (36.0%)
Anti-dementia drugs	9 (7.9%)
Other psychotropic drugs	2 (1.8%)
Proportion of patients per number of psychotropic drugs	
No psychotropic drugs	17 (14.9%)
One psychotropic drug	25 (21.9%)
Two psychotropic drugs	36 (31.6%)
Three psychotropic drugs	19 (16.7%)
Four or more psychotropic drugs	17 (14.9%)
Behavior by CMAIb	Median (IQR)
Total score CMAI, range: 29–203 points	63.5 (50.0–77.8)
CMAI factor score	
Physically aggressive, range: 9–63 points	15.0 (11.0-20.8)
Physically nonaggressive, range: 6–42 points	18.0 (11.3–26.0)
Verbally agitated, range: 5–35 points	13.5 (9.0–21.0)
No. of items present, range: 0–29 items	10.0 (8.0–13.0)
No. of items per CMAI factor present	
Physically aggressive, range: 0–9 items	3.0 (1.0–5.0)
Physically nonaggressive, range: 0–6 items	4.0 (2.0–5.0)
Verbally agitated, range: 0-5 items	3.0 (1.0–4.0)
No. of items present several times a day or an hour, range: 0–29 items	3.0 (1.0–6.0)
Items present several times a day or an hour	
Physically aggressive, range: 0–9 items	0.0 (0.0–1.0)
Physically nonaggressive, range: 0–6 items	1.0 (0.0–3.0)
Verbally agitated, range: 0–5 items	1.0 (0.0–3.0)

IQR, interquartile range.
[a]A total of 13 missing in psychotropic drug use.
[b]A total of 15 missing in CMAI.

compared to people with dementia living in regular settings in the Netherlands. For example, antipsychotic use was threefold higher than in a regular setting, and for anxiolytic use this was fivefold higher (Smeets et al., 2018). These high prescription rates are not in line with the guidelines for challenging behavior in the Netherlands (Zuidema et al., 2018) and highlight the complex background of the challenging behavior (Veldwijk-Rouwenhorst et al., 2022). Psychotropic drug use is known to lead to a spectrum of adverse events such as falls, sleepiness, balance problems, and confusion (McInerney et al., 2024). Antipsychotic use is associated with several adverse outcomes like stroke and death (Mok et al., 2024; Mühlbauer et al., 2021).

Emotional distress nursing staff

We found severe or extreme emotional distress of agitation experienced by nursing staff members in relation to one in four participants. In research on the reasons for admission of patients from DSCUs to these highly specialized units, one of the main processes leading to admission was the staff of the DSCU experiencing an increasing burden of the challenging behavior, together with an increase in severity of the challenging behavior, and an increasing realization that the patients' needs could be met, together leading to the nursing staff reaching their limits (Verhees et al., 2024). Therefore, we believe that the emotional distress in nursing staff members is lower than for nursing staff caring for these patients with very severe challenging behavior in these admitting DSCUs (Schmidt et al., 2012; Zwijsen et al., 2014). We hypothesize that this can be—partly—explained by the fact that staff members in these units experience less emotional distress when facing the same or even higher levels of challenging behavior. This might be explained by the fact that team members in these units have an open attitude toward the behavior (van Voorden et al., 2023) and more suitable attitudes toward aggressive behavior (Geoffrion et al., 2020). For future studies, it would be relevant to compare emotional distress among nursing staff members in these settings and what influences this distress, given that severe or extreme emotional distress related to every fourth patient is still burdensome.

Length of stay and discharge

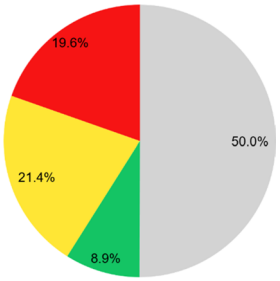
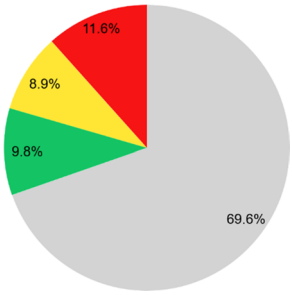
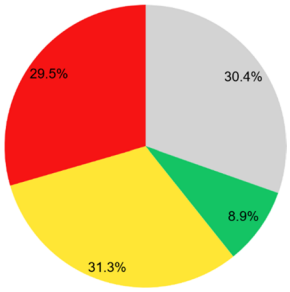
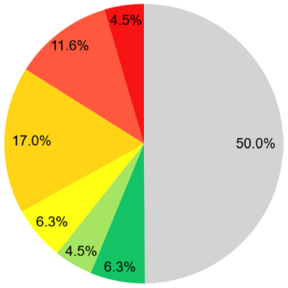
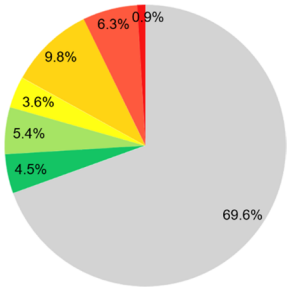
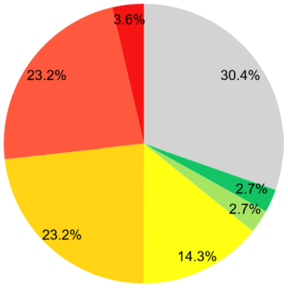
One in three patients died, about half were discharged to a DSCU, and about one in ten could not be discharged (yet) during the study and follow-up. Agitated behaviors as assessed by the NPI might be persistent in DSCUs (Selbæk et al., 2013), which suggests that this behavior among the large majority of patients with very severe challenging behavior will probably also be persistent. However, our findings suggest that in half of the patients with very severe challenging behavior it was possible to understand the background of the behavior and apply a behavioral approach to a manageable extent in DSCUs. About one in ten could not yet be discharged, and the reasons for this might be that no specific DSCU—i.e., suiting the specific needs of the patients—could be found to date (van Voorden et al., 2024). Further insights are necessary into the qualities of the regular DSCU that are needed to ensure successful discharge.

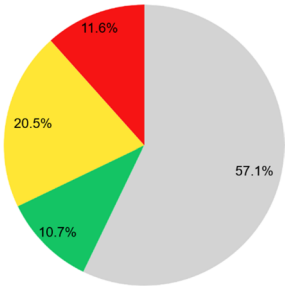
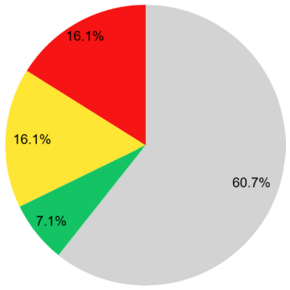
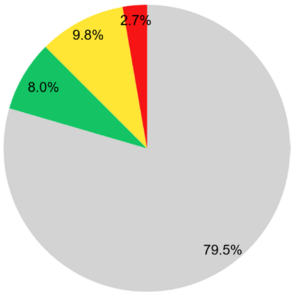
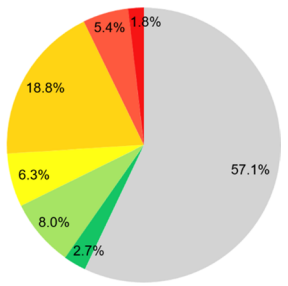
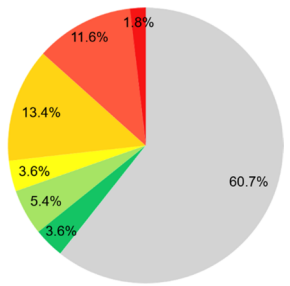
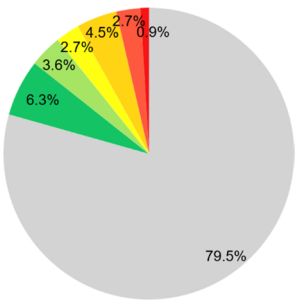
Finally, one out of three patients died during their stay. This might be explained by the fact that very severe challenging behavior could also be a sign that patients are approaching their end of life (Vandervoort et al., 2013) and the behavior may be interpreted as a form of terminal agitation for the patients that died within a few weeks after admission to a highly specialized unit (Jennes et al., 2024). This underlines the need for timely terminal palliative care, even though providing appropriate palliative care with these behaviors is challenging.

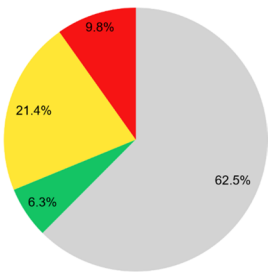
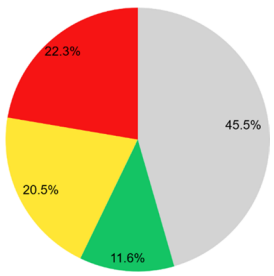
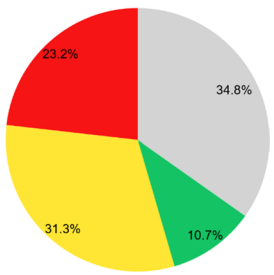
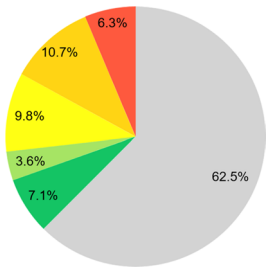
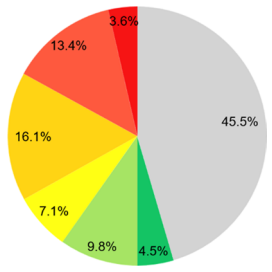
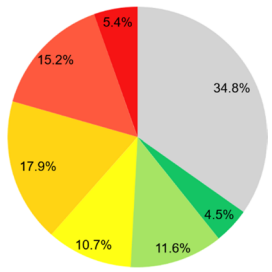
Limitations

Concerning our data collection, one limitation is that we were unable to quantify the number of patients admitted to these units who did not meet the inclusion criteria, did not gave consent or were not asked for participation. Despite this, we were able to provide the total participation rate of all admissions with data obtained from the management. Considering the reasons for the lack of such data—i.e. organizational problems, other patient groups, and the workload, holiday and sick leave of treating physicians—we expect any selection bias of patients to be limited irrespective of the relatively low participation rate. Furthermore, we included patients admitted to highly specialized units with dementia and very severe challenging behavior which is a broad term. In the future a clear conceptual and operational definition is needed to provide for better understanding of who these patients are and comparison within future research. Lastly, we believe that hearing problems might have been under registered as we only used chart diagnoses here, despite knowing that hearing loss can interfere with cognition and dementia (Loughrey et al., 2018; Roets-Merken et al., 2014; Roth et al., 2011).

Table 3. Behavior with NPI-Q ($n = 112$)a.

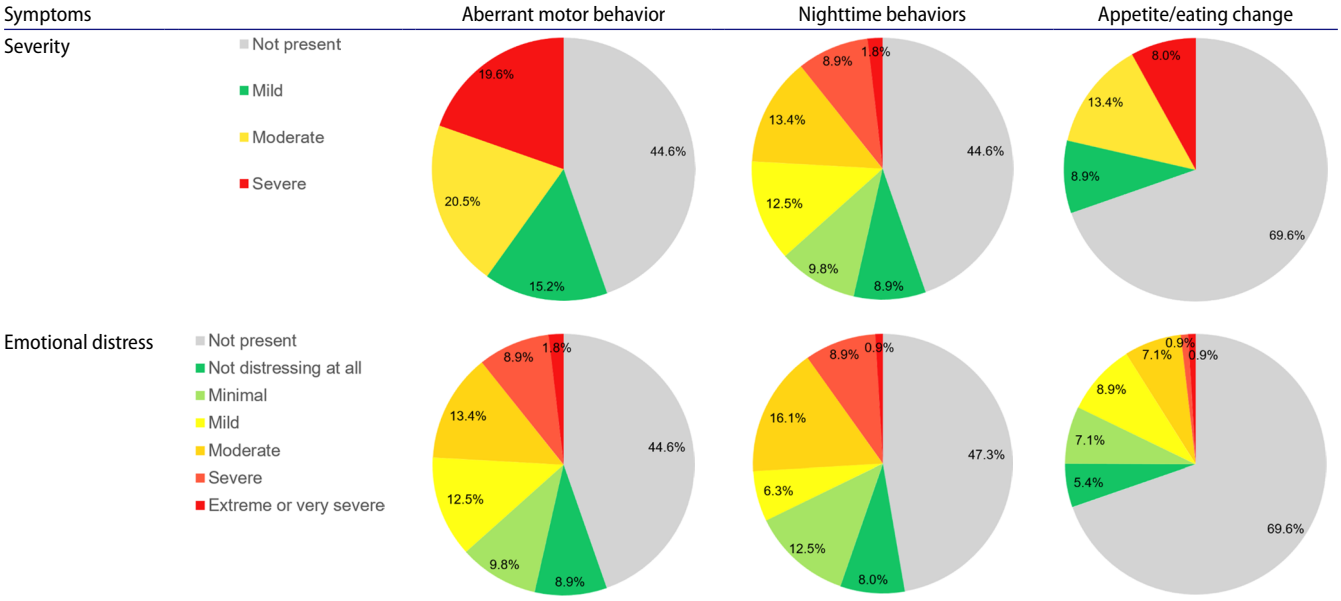
Symptoms		Delusions	Hallucinations	Agitation
Severity	Not present Mild Moderate Severe			
Emotional distress	Not present Not distressing at all Minimal Mild Moderate Severe Extreme or very severe			

Symptoms		Depression/dysphoria	Anxiety	Euphoria/elation
Severity	Not present Mild Moderate Severe			
Emotional distress	Not present Not distressing at all Minimal Mild Moderate Severe Extreme or very severe			

Symptoms		Apathy/indifference	Disinhibition	Irritability
Severity	Not present Mild Moderate Severe			
Emotional distress	Not present Not distressing at all Minimal Mild Moderate Severe Extreme or very severe			

(*Continued*)

Table 3. Continued.



[a]A total of 15 missing in NPI-Q among the total of 127 participants.

Table 4. Discharge location and mortality ($n = 127$).

Mortality	*n* (%)
Death during stay	40 (31.5%)
Discharge	71 (55.9%)
DSCU	63 (49.6%)
Other[a]	4 (3.1%)
Home	2 (1.6%)
Other highly specialized unit	2 (1.6%)
No discharge yet	15 (11.8%)
Unknown whether dischargeb	1 (0.8%)
Length of stay[b,c]	Median (IQR)
Deceased patients ($n = 40$)	84 days (57–195)
Discharged patients ($n = 69$)d	122 days (59–224)
Not (yet) discharged patients ($n = 15$)	493 days (412–616)

[a]Namely: somatic nursing home unit, hospice, mental health care admission unit, acquired brain injury unit.
[b]Unknown for one withdrawn consent.
[c]In testing for differences among these groups for sex, severity of cognitive decline, age, number of chronic somatic disorders, and number of psychotropic drugs, for age a statistically significant difference ($p < .05$) was found: patients who died were significantly older.
[d]Two missing discharge dates.

Implications

Our data suggest that a reasonable proportion of half of the patients admitted to these highly specialized units benefited in the sense that they could be discharged to a DSCU, and about one-third died during admission. About half of the patients had mild to moderately severe cognitive decline, and only a few had very severe cognitive decline, that is, late dementia (Reisberg et al., 1982). This implies that these units also provide treatment for a group of patients with relatively mild dementia. Moreover, we cannot explain why the group of patients with very severe cognitive decline is small. Possible explanations could be selection, that is, most patients with dementia die before the last stage (van der Steen et al., 2014), or behavior being more manageable in this stage for more patients in this stage lack mobility (Reisberg et al., 1982). But more insight into the severity of cognitive decline and the relationship with challenging behavior is needed. In the future, more insight is needed into patient characteristics, the severe challenging behavior before admission, and context characteristics to better select patients who are likely to benefit from this treatment, as well as exploring whether impending death can be recognized to provide timely terminal palliative care. This touches upon the indication for admission to these units and thus the group definition, which is a relevant research question in the recent research agenda of such units (D-zep kennisnetwerk, 2023). Furthermore, as also stated in this agenda (D-zep kennisnetwerk, 2023), more insights are needed into the effectiveness of interventions—e.g. behavioral change, change in the well-being of all involved and whether the manageability of the behavior in DSCUs lasts after discharge—is needed, which should take into account the complexity of this subject (Skivington et al. 2021).

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Richard C. Oude Voshaar: Conceptualization, methodology, formal analysis, writing - reviewing and editing.

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Disclosure statement

The authors report there are no competing interests to declare.

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