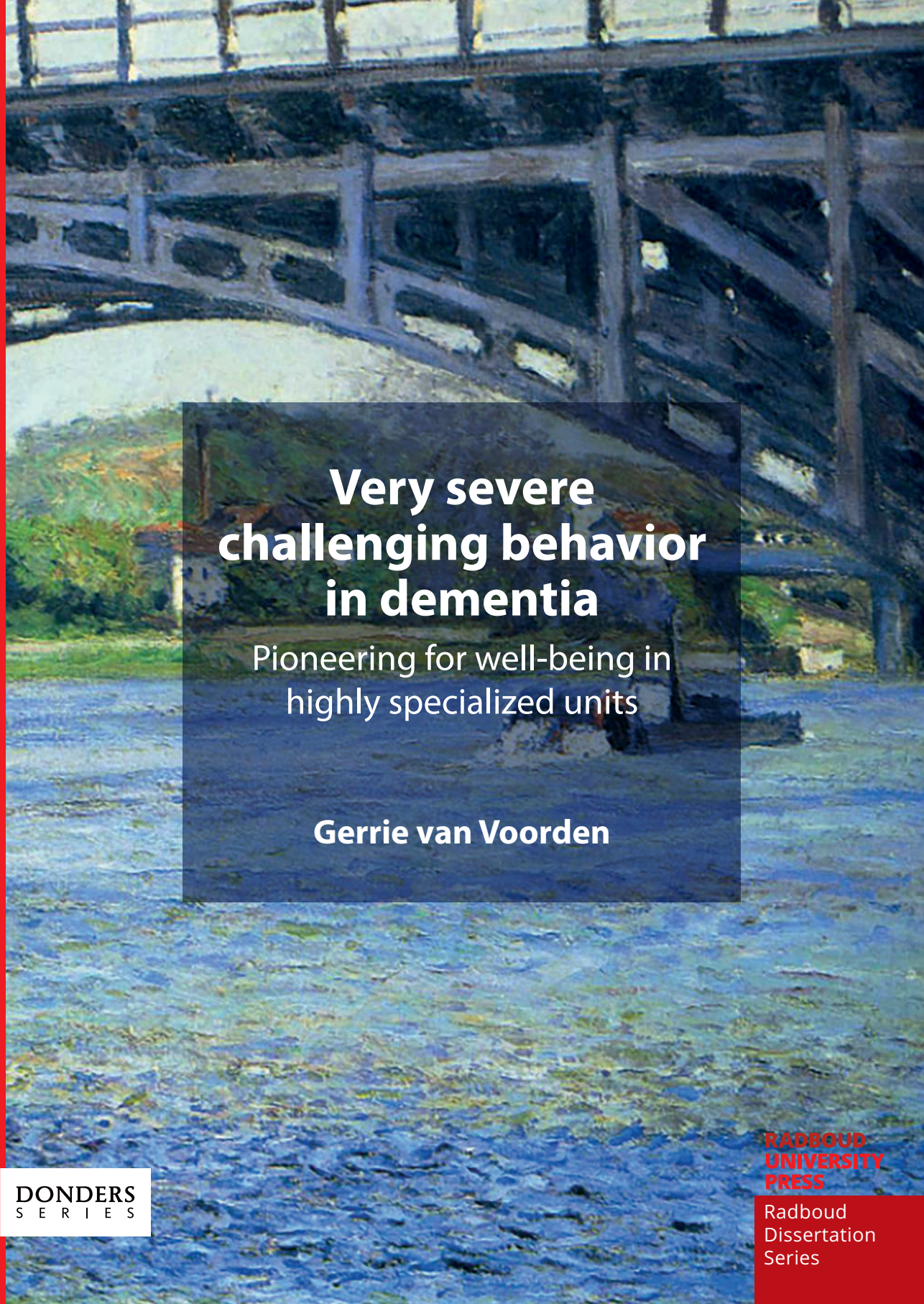

Very severe challenging behavior in dementia

Pioneering for well-being in highly specialized units

Gerrie van Voorden

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Contents

Chapter 1. General introduction

The number of persons[1] with dementia is increasing both in the Netherlands and worldwide (Nichols et al., 2022; van Bussel et al., 2017). Up to 90% of persons with dementia develop behavioral symptoms at some point during the disease (Hongisto et al., 2018; Ismail et al., 2016). This has a huge impact on the well-being of these persons and their social environment (Arthur et al., 2018; de Vugt et al., 2003; Hongisto et al., 2018; Hurt et al., 2008; Isik et al., 2019). Persons with advanced dementia and/or behavioral symptoms are also more likely to be admitted to a dementia special care unit (DSCU) (Gaugler et al., 2009). Some persons develop very severe challenging behavior, which DSCUs often struggle to manage (Brodaty et al., 2003; Palm et al., 2018; Veldwijk-Rouwenhorst et al., 2017). In the Netherlands, these persons can nowadays be temporarily admitted to highly specialized units for treatment, which form the scope of this thesis. The following section provides background information on challenging behavior in dementia, characteristics of regular DSCUs, and highly specialized units for treating persons with dementia and severe challenging behavior in the Netherlands. This chapter will conclude with an outline of the thesis's aims.

Challenging behavior in dementia

Challenging behavior in dementia is an umbrella term encompassing different behaviors, which can also vary in severity, frequency, and impact. Challenging behavior in dementia is more common in advanced stages of dementia (Borsje et al., 2019; Palm et al., 2018; Veldwijk-Rouwenhorst et al., 2017) and predicts nursing home admission (Gaugler et al., 2009). Prevalence rates are up to 80% among persons with dementia in nursing homes (Selbaek et al., 2013). While this behavior is often persistent (Selbaek et al., 2013), multidisciplinary interventions have proven effective in the nursing home setting (Bakker et al., 2011; Pieper et al., 2016; Zwijsen et al., 2014).

Several alternatives to the umbrella term of 'challenging behavior in dementia' are used in the literature, which can be described in three groups (Gerritsen et al., 2019). Challenging behavior is an example of the first group, which concentrates on the behavior of persons with dementia, and sometimes on its consequences. For instance, terms such as agitated behavior (Cohen-Mansfield et al., 1989) only describe the behavior that is exhibited. 'Challenging behavior' (Leontjevas et al., 2024) or 'disruptive behavior' refer to the consequence of the behavior in that it is challenging or disruptive for those involved. Second, in behavior-symptom approaches, behavior is seen as a direct result of dementia. This approach uses terms such as behavioral and

1. The term patients will be used when related to the treatment of very severe challenging behavior in dementia in highly specialized units.

psychological symptoms of dementia (Finkel, 2002) or neuropsychiatric symptoms (Kaufer, 2000). Third, function-focused approaches consider behavior as functional, for instance a way of coping or a way of making sense of the world and thus an indirect consequence of dementia. Examples of these approaches include the unmet-needs approach (Algase et al., 1996) and the lowered-threshold theory (Richards & Beck, 2004). Terms used in this approach often include 'behavior' (Wolverson et al., 2022) or terms such as 'distress' (Thompson et al., 2025).

This thesis uses the term "challenging behavior", and this refers to the definition of the Dutch guideline: *"… all behavior associated with suffering or danger to the person with dementia or people in his or her environment"* (Zuidema et al., 2018). As noted, challenging behavior in dementia differs in severity, frequency, and impact, whereby this thesis focuses on the most extreme cases noted as very severe challenging behavior. The occurrence of very severe challenging behavior might be related to characteristics of the person with dementia and result from the interaction with their social and physical environment. For the analysis of the behavior, guidelines advise including the multidimensional nature of challenging behavior (Watt et al., 2019). In cases of very severe challenging behavior, guideline-informed analysis and treatment generally fail.

Regular DSCUs

In the Netherlands, most persons with dementia who can no longer live independently are admitted to a DSCU (Verbeek et al., 2009). Recent data in the Netherlands shows that over half of the persons with dementia live for shorter than two years in these units (van der Schot, 2020). In the Netherlands, DSCUs commonly have a multidisciplinary team available comprising an elderly care physician, nurse practitioner or physician assistant, a (health care) psychologist, and a nursing staff member, often an certified nursing assistant, which can be extended with therapists, i.e. recreational therapists, physiotherapists, occupational therapists, speech therapists, and dieticians, when indicated (Backhaus et al., 2018; Koopmans et al., 2017; Zwijsen et al., 2014). Sometimes other disciplines can also be involved, such as music therapists or psychomotor therapists. From an international perspective, DSCUs have varying characteristics, although common elements include the expertise of trained staff and activities that meet the needs of persons with dementia in a tailored environment (Bergmann et al., 2023; Joyce et al., 2018), which support social interactions, activities, and relaxation (Laura Adlbrecht et al., 2021; L. Adlbrecht et al., 2021). Nursing home placement is generally associated with a higher quality of life and a better functional status, but also increased agitation (Kok et al., 2013).

Highly specialized units

When care and treatment in a regular DSCU is no longer possible due to very severe challenging behavior, these patients can be temporarily admitted to highly specialized units. Examples where treatment in a regular DSCU is no longer possible include situations where the behavior poses a danger to oneself and/or others in the direct environment, or where it represents an ongoing severe burden for the person and/or those in the direct environment. These units aim to discharge back to a regular DSCU when the behavior is regarded as manageable in a DSCU. Several developments have led to the recent establishment of these units in the Netherlands and some other countries, such as Australia. First, the number of people with dementia is increasing (Nichols et al., 2022; van Bussel et al., 2017). Second, the number of inpatient psychiatric beds within Dutch mental health care for such patients has been reduced (Kroon, 2021). Third, persons with dementia live at home longer and move to nursing home settings in more advanced stages of dementia, often with more challenging behaviors (Gaugler et al., 2009; Palm et al., 2018; Veldwijk-Rouwenhorst et al., 2017; Verbeek-Oudijk & Koper, 2021). Since these units are newly established, little is known about the patients admitted to these units. Acquiring more knowledge about these patients holds utmost relevance for several reasons. First, with these units being a new phenomenon, organizational and treatment aspects might differ among units. Second, given that guideline-informed treatment of patients referred has generally failed, knowledge on treatment strategies and effectiveness in these specialized settings is largely unknown. Finally, challenging behavior in dementia is known to be related to higher mortality (Bränsvik et al., 2021; Hapca et al., 2018).

Aims and research questions

This thesis describes the WAALBED (WAAL Behavior in Dementia)-IV study. This thesis aims to provide insights into the treatment of patients with dementia and severe challenging behavior. Furthermore, insights into organization of highly specialized units, patient characteristics, treatment, and treatment outcomes—i.e., discharge location and mortality—will be described.

These aims were operationalized into the following research questions:

1. What are the organizational characteristics of these units regarding admission and discharge, staffing, and the physical environment?
2. What characterizes the management of severe challenging behavior in these units?
3. How do experienced professionals conceptualize successful treatment in severe challenging behavior in dementia?

4. What are the patient characteristics—including behavioral characteristics and discharge locations—of patients admitted to highly specialized units?
5. What are the causes of death of patients admitted to these units?
6. What regular determinants of mortality in dementia can predict mortality in these patients?
7. Are specific subtypes of very severe challenging behavior associated with mortality during stay in these units?

Outline of this thesis

To answer the first and second research questions, **Chapter 2** describes a study in thirteen highly specialized units. Three data collection methods were used: a digital questionnaire completed by the unit manager, an interview with the physician responsible for medical care and often another practitioner, and an observation of the physical environment. Descriptive analysis was used for quantitative data and thematic analysis for qualitative data.

In **Chapter 3**, the third research question is answered by a concept mapping study in which 82 experts in dementia care participated. The study followed two phases of data collection: an online brainstorm where participants completed the focus prompt: *'I consider the treatment of people with severe challenging behavior in dementia successful if...',* and individual sorting and rating of the collected statements. This was followed by data analysis using multidimensional scaling and hierarchical cluster analysis, resulting in a concept map.

Chapters 4 and **5** describe an observational study in which eleven highly specialized units participated. Newly admitted patients (n=127) were included and baseline characteristics were collected, i.e. demographics, presence of a delirium, severity of the cognitive decline, comorbidity, (psychotropic) drug use, behavior during the first weeks of admission, and discharge location or mortality of patients admitted to these highly specialized units. In **Chapter 4**, research question 4 is answered, and in **Chapter 5** research questions 5, 6, and 7 are answered with a description of causes of death, and explorative Cox models are used to answer research questions 6 and 7.

Finally, in **Chapter 6**, the main findings are summarized and discussed. Furthermore, some methodological considerations are discussed, and implications for practice, health care policy, education, and future research are described.

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Chapter 2. Organizational characteristics of highly specialized units for people with dementia and severe challenging behavior

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BMC Geriatrics 2024. 24(1), 681

Abstract

Background: People with dementia and severe challenging behavior in the Netherlands can be temporarily admitted to highly specialized units when their behavior is not manageable in regular dementia special care units (DSCUs). With scarce evidence available for the treatment of these patients, treatment in these units is in a pioneering phase. To gain more insight into these units, this study investigated organizational characteristics, i.e. admission and discharge characteristics, staffing, the physical environment, and the management of severe challenging behavior.

Methods: Three data collection methods were used: 1) a digital questionnaire to be completed by the unit manager, 2) an interview with the physician responsible for medical care and often another practitioner, and 3) an observation of the physical environment for which the OAZIS-dementia questionnaire was used. Descriptive analysis was used for quantitative data and thematic analysis for qualitative data, after which data was interpreted together. Thirteen units participated, with their sizes ranging from 10 to 28 places.

Results: Patients were mainly admitted from regular DSCUs, home or mental health care, and discharged to regular DSCUs. A multidisciplinary team comprising at least an elderly care physician or geriatrician, psychologist, and nursing staff member and other therapists as needed provided the treatment. Nursing staff hours per patient considerably differed among units. Nursing staff played a central role in the treatment. Competences such as reflectiveness on one's own behavior, and being able to cope with stressful situations were described as relevant for nursing staff. Investing in a stable nursing staff team was described as important. The units varied in whether their work-up was more intuitive or methodological. In the diagnostic phase, observation together with an extensive analysis of the patient's biography was essential. The units used a broad variety of interventions, and all paid attention to sensory stimuli. In the observation of the physical environment, the safety scored well and domesticity relatively low.

Conclusion: Highly specialized units show strong heterogeneity in organizational characteristics and management, which can be understood in the light of the pioneering phase. Despite this, similarities were found in nursing staff roles, frequent multidisciplinary evaluation, and attention to sensory stimuli.

Keywords: Challenging behavior, long-term care, dementia, treatment, organizational, physical environment, sensory stimuli

Background

Challenging behavior in persons with dementia – also known as behavioral and psychological symptoms of dementia (BPSD) or neuropsychiatric symptoms (Gerritsen et al., 2019) – is common in nursing homes, with a mean prevalence of 82% (Selbaek et al., 2013). The burden of challenging behavior is high, being associated with a lower quality of life (Henskens et al., 2019; Livingston et al., 2017; Majer et al., 2020), and increased distress in caregivers (Black & Almeida, 2004; Brites et al., 2020; Majer et al., 2020; Svendsboe et al., 2016). Severe challenging behavior – especially aggression and agitation – is known to lead to admission to psychiatric services, specialist care units or long-term care (Backhouse et al., 2018). Moreover, the costs of especially agitation at the end of life in dementia increases informal and formal health care costs by 30% (Buylova Gola et al., 2020). A small proportion of people with dementia show very frequent or severe agitation with a prevalence of 7.4% and 6.3%, respectively (Palm et al., 2018; Veldwijk-Rouwenhorst et al., 2017). For very frequent physical aggression and very frequent vocalizations, a two-week prevalence of 2.2% and 11.5%, respectively, has been found in nursing home patients (Veldwijk-Rouwenhorst et al., 2021).

In the Netherlands, most people with dementia who cannot live on their own anymore live in a dementia special care unit (DSCU) (Verbeek et al., 2009). Although DSCUs have varying characteristics, common elements are the psychogeriatric expertise of trained staff and activities that meet the needs of the people with dementia in a tailored environment (Bergmann et al., 2023; Joyce et al., 2018). In the Netherlands, DSCUs commonly have a multidisciplinary team available that comprises of an elderly care physician, a health care psychologist, and nursing staff – the majority regards certified nursing assistants - which can be extended with therapists, i.e. physiotherapist, occupational therapist, speech therapist and dietician, when indicated (Backhaus et al., 2018; Koopmans et al., 2017; Zwijsen et al., 2014). Box 1 describes the roles and education of the usual team members in further detail.

Box 1. Role and education of elderly care physicians, health care psychologists and nursing staff in the Netherlands

Elderly care physicians
Elderly care physicians are medical doctors who have completed a three-year specialist training program in elderly care medicine where they worked 80% of their training time in clinical practice, and one day a week engaging in a training program at the university department. During their training time in practice, they work at least in a nursing home, a rehabilitation unit, a hospital department, and a geriatric psychiatry institution. Further specialized training is possible in primary health care, psychogeriatric medicine, geriatric rehabilitation, and palliative medicine (Koopmans et al., 2017; Verenso, 2015).

Health care psychologists
Health care psychologists are trained in a two-year post-master study program comprising an academic course and training in professional practice. During this training, they study diagnosis, care needs assessment, treatment and other duties. Training is provided by independent institutions throughout the Netherlands that work in close cooperation with Dutch universities. Health care psychologists often work in mental health, nursing homes or a general hospital (FGZPT, 2014).

Nursing staff
The nursing staff comprises baccalaureate-educated registered nurses, registered vocationally trained nurses, certified nurse assistants, nurse assistants, and nurse aides corresponding with qualification levels 6, 4, 3, 2 and 1 of the European Qualification Framework (EQF), respectively (Backhaus et al., 2018; European Union europass, 2005). Baccalaureate-educated registered nurses had graduated from a four-year training course at a university of applied sciences (Backhaus et al., 2018). Registered vocationally trained nurses followed a four-year vocational education training course in a vocational education and training college. Both baccalaureate-educated registered nurses and registered vocationally trained nurses have a nationally qualified title, title protection and nurses are recorded in a national qualification register (Backhaus et al., 2018; Maessen et al., 2019). Certified nurse assistants in the Netherlands are vocationally trained in an vocational education and training college in a two- to three-year training program, nurse assistants are trained in a two-year training program, and nurse aides in a half- to one year training program (Backhaus et al., 2018).

In the Netherlands, since approximately a decade, a small selection of people with severe challenging behavior can be temporarily admitted to highly specialized units when their behavior is not (regarded) manageable in a regular DSCU, such as behavior that causes serious safety problems, is very unpredictable or is very vocally disruptive. Several developments in health care have possibly contributed to the need for such units. First, the number of people with dementia is increasing whereas the number of nursing home places is not growing accordingly (Nichols et al., 2022; van Bussel et al., 2017). Second, nursing homes tend to have more people admitted with challenging behavior which also is more severe (L. Adlbrecht et al., 2021; Kok et al., 2013). Third, admission possibilities in mental health care have been phased out in the Netherlands, leading to a decrease of 25.4% of admission days at wards in mental health care for people with delirium, dementia or other amnestic and cognitive disorders from 2012 to 2018 (Kroon, 2021). Fourth, it is believed that people with dementia and severe challenging behavior need expertise from both long-term care

and mental health care (de Bruin et al., 2021). Finally, the health care inspectorate has reported concerns about the quality of care for people with dementia and severe challenging behavior in the Netherlands (Health and Youth Care Inspectorate, 2020). These highly specialized units have been developed by long-term care organizations often in close cooperation with mental health care institutions.

However, at present little is known about these highly specialized units. For the aim of understanding whether these units contribute to a better quality of life and care for people with dementia and severe challenging behavior, it is needed to know what the organizational characteristics of these highly specialized units are. These insights can be used for further research into whether and why these units provide effective management of the challenging behavior. Elements of this knowledge about the management may eventually be proven useful in other settings. In Australia, a specialist residential dementia care program exists (Department of Health, 2018). In one of these units, people with dementia and severe challenging behavior reside in an eight-place domestic-style residential cottage on average for twelve months, after which they are transferred to regular dementia care services (Gresham et al., 2021). Despite this example, little is known about this specific patient group, other similar care settings and the treatment applied there. Therefore, we studied these highly specialized units in the Netherlands to gain insights for clinical practice and further research.

Our aim was to describe the general characteristics of these units based on the following questions:

1) What are the organizational characteristics of these units regarding admission and discharge, staffing, and the physical environment?
2) What characterizes the management of severe challenging behavior on these units?

Methods

Sample and setting

Only units with temporarily admitted patients with dementia and severe challenging behavior in dementia were included. Units were identified and recruited by the six academic networks of long-term care (Koopmans et al., 2013). At the start of this study, sixteen units were identified and invited to participate, fourteen of which gave consent. One of these units was closed at the start of the study, leaving thirteen units located throughout the Netherlands. Five units were

part of a mental health care organization, and seven part of a long-term care organization, with two units in one organization (units 08 and 09), and one unit was a collaboration of both.

Procedure

To answer the research questions, we used three data collection methods: 1) a digital questionnaire with mainly factual questions to be completed by the unit manager, 2) an interview about the treatment with the physician responsible for medical care, who was encouraged to invite another practitioner, and 3) an observation of the physical environment by the researcher. We chose these different methods to be able to answer our research questions, to provide for time for the unit manager to look up data, and to establish richer results for the topics competences of nursing staff, and physical environment. Data about these topics were integrated where applicable in the analysis (Guest et al., 2012). Interviews and observations were scheduled on the same day and conducted at the workplace of the interviewees from May until August 2018.

Table 1. Items digital questionnaire for the unit managers

Research questions:	**Items:**
1: Admission and discharge characteristics per unit	- mean number of admissions per year - number of compulsory admissions as percentage at present - reasons for admission (open-ended) - mean age of admitted patients - residence before admission as percentage per year for given categories (home, DSCU, somatic care unit in a nursing home, hospital, mental health care institution, other) - mean length of stay in months - discharge location as percentage per year for given categories (home, back to referring unit, long-term care unit within the organization, long-term unit in another long term care organization, mental health unit for long term care, no discharge possible, other)
1: Staffing	- staff available in full time equivalents per education level (categories) - nursing staff hours from the working schedule per 24 hours - sick leave nursing staff as percentage in 2017 (without maternity leave) - competences nursing staff (open-ended) - training nursing staff (open-ended)
1: Physical environment	- unit size as number of beds available
2: Management of the behavior	- use of guidelines (yes/no; if yes which) - use of clinical evaluation instruments (yes/no; if yes which)
Details unit manager:	- tenure in this unit since (year) - work experience (open-ended) - educational background (open-ended) - age

Measurements

Digital questionnaire

The digital questionnaire was self-developed with Lime Survey and sent to the unit managers (LimeSurvey GmbH, 2015). The questionnaire comprised 43-48 mandatory, mainly fact-based questions at the unit level (see Table 1). Questions concerning the reasons for admission, competences and training of nursing staff, and work and education of the unit manager were open-ended. Twelve digital questionnaires were completed by the unit managers, and one by a baccalaureate-educated registered nurse in the unit due to time constraints of the unit manager. The patient administration had no exact data regarding residences before admission, number of compulsory admissions, discharge locations, and full-time equivalents of nursing staff (see Supplementary materials Tables S1-S3), which were estimated by unit managers. Unit managers often had an educational background as baccalaureate-educated registered nurse after which they were trained in care management. They were on average 53.1 years old, and for 2.8 years involved.

Interview

We developed an interview guide that followed the patient journey which was inspired by the (clinical) experience from the authors and piloted. It comprised of topics such as first day of admission, characterization of treatment, training in the management of behavior, and experienced difficulties (for all topics and questions see the interview guide in Supplementary materials Table S4). The interviews were conducted by the first author (GV), who was not known to the interviewees. The principal interviewee – the physician(s) responsible for medical care – was requested to invite another professional, preferably a psychologist as they are usually involved in case of challenging behavior on regular DSCUs (Zwijsen et al., 2014). All interviews were audiotaped and transcribed verbatim, and a summary of the transcript was sent to the interviewees as a member check. Twelve interviews were held, lasting between 56 and 85 minutes. The interviewees comprise nine elderly care physicians, two geriatricians, and one geriatric psychiatrist. In seven units, the (health care) psychologist joined, in one unit the other physician responsible for medical care, and in one unit the nurse practitioner. Interviewees where on average 46.4 years old, and 19% of the interviewees were male. Saturation was reached after nine interviews, in the sense that no new themes were identified.

Observation of physical environment

The OAZIS-dementia (de Boer et al., 2015) was used, which has been developed to assess long-term care environments in a Dutch setting (de Boer et al., 2018; Rosteius et al., 2022). The OAZIS-dementia has a good inter-rater reliability, with higher

scores indicating a higher probability that the environment has positive effects on its residents (de Boer et al., 2018). It comprises 72 items to be rated on a five-point Likert scale, ranging from 1 'not at all' to 5 'completely' applicable. The instrument is divided into seven themes: 1) privacy and autonomy, 2) sensory stimulation, 3) view and nature, 4) facilities, 5) orientation and routing, 6) domesticity/small scale, and 7) safety. An example item from the theme facilities is: 'there is enough space for the resident to receive visitors in his/her own room.' In addition, we added items about the number of other rooms available and their function, e.g. the availability of a seclusion room. The OAZIS-dementia and general observation form was completed by GV. In two units, GV observed together with ML.

Analysis

Quantitative data

The quantitative digital questionnaire responses and OAZIS-dementia scores were analyzed by the use of descriptive statistics. For each category in the OAZIS-dementia, the points reached were summed up and divided by the total number of items in this category. For the weighed final score, all items were summed up and divided by the total item number.

Qualitative data and data integration

Qualitative data from the digital questionnaire, interviews, and the observation of the physical environment was analyzed together. Investigator triangulation was realized by GV and ML jointly analyzing the interview transcripts supervised by DG, following the principles of thematic analysis (Guest et al., 2012). GV and ML manually coded the first transcript separately by labeling meaningful fragments using open coding in a pragmatic way (Evers & de Boer, 2012; Mills et al., 2010), discussing differences until they reached agreement. Atlas.ti version 8.3.16 was used for coding (ATLAS.ti Scientific Software Development GmbH, 2018). The other interviews were coded by ML or GV and discussed. Codes referred to facts as well as experiences and views, in line with the interview questions asked. First, GV and ML analyzed coded text fragments that related to management of severe challenging behavior, which led to the merging and splitting of codes, finalized by a visualization of relevant themes in management according to the interviewees. Furthermore, remaining codes were analyzed together with the open-ended questions from the digital questionnaire about the competences of nursing staff and the description of the general impression of the physical environment by GV, supervised by DG.

Quantitative and qualitative data were, after the above mentioned analyses, interpreted together in relation to the research questions.

Quality of interviews

GV reflected on the course of the interview, the agreement between the interviewees, the impression of the interviewees, the first impression of the added value of the interview, and whether there were moments of being suggestive after every interview (Evers & de Boer, 2012). GV wrote memos during data collection and analysis. GV and ML wrote memos during the interview analysis in a shared document. After six interviews, they decided to elaborate on the topics of non-pharmacological interventions, physical restraints and psychotropic drugs as they often lacked in-depth information concerning why these were applied in treatment. We followed the consolidated criteria for reporting qualitative research (COREQ) for the qualitative parts (see Supplementary materials Table S5 (Tong et al., 2007)).

Ethics statement

The study was conducted in accordance with the Declaration of Helsinki as well as the rules applicable in the Netherlands. The local Medical Ethics Review Committee, CMO region Arnhem-Nijmegen at the Radboud University Medical Center, stated that the Medical Research Involving Human Subjects Act (WMO) does not apply to this study and that an official approval of this study was not required (reference number 2018-4354). Informed consent was obtained from all participants, i.e. unit managers and interviewees, prior to data collection.

Results

Organizational characteristics (research question 1)

Admission and discharge characteristics

The majority of patients were admitted from regular DSCUs, home or a mental health care institution. Details of the admission and discharge characteristics per unit can be found in Supplementary materials Table S1. Before admission, the admission criteria were checked in terms of severe challenging behavior and (suspected) dementia. In three units, a maximum of two to three patients with physical aggression was allowed. Nine units exclusively treated patients with dementia, whereas three units also treated other older patients within the same or another sub-unit. Psychiatric comorbidity was not an exclusion criterion, except alcohol dependency in three units, and reflected the rule rather than the exception according to unit managers and interviewees. The proportion of compulsory

admissions on a unit varied between 4% and 90% (median 20%) at the moment the digital questionnaire was completed. The mean age of patients ranged from 65 to 82 years. At admission, the vast majority of patients used many different types of psychotropic drugs, often without a good rationale, according to the interviewees. Some interviewees mentioned that the severe challenging behavior for which patients were admitted was not present after admission in a few cases, and suggested that another social and/or physical environment may explain this. The length of stay ranged from one to twelve months. The majority of patients were discharged to regular DSCUs, and the proportion of deaths ranged between 6% and 63% (median 19%) on average per unit per year.

Staffing

A multidisciplinary team comprising at least a physician responsible for medical care, a psychologist and a nursing staff member but often more professionals such as therapists treated the patients.

One, two or three physicians were responsible for medical care (see Supplementary materials Table S2): eleven elderly care physicians, two geriatricians, and three (geriatric) psychiatrists. In six units, (geriatric) psychiatrists were permanently involved in the treatment. In four units, a psychiatrist was sometimes consulted. Psychiatrists were valued by the interviewees for their expertise regarding the prescription of psychotropic drugs and psychiatric diagnostics. In three units, neurologists were permanently involved for their expertise in diagnostic problems in neurodegenerative diseases. In all units, therapists such as physiotherapists, occupational therapists, speech therapists and dieticians were involved by the physician when necessary. A few units had a music therapist or psychomotor therapist involved. One unit had therapists who had received extra training in sensory integration (Champagne, 2018). This unit also employed personnel who were so-called miMakkus clowns, which is a practice-based psychosocial intervention using clowning for people with advanced stage dementia with the goal to make contact where communication in the usual cognitive way is no longer possible (Hendriks, 2017).

In ten units, baccalaureate-educated registered nurses worked in relatively low numbers, but the vast majority comprised registered vocationally trained nurses, and certified nurse assistants with a median average age of 38 years. Most units had a vast majority of registered vocationally trained nurses (n=5) or a vast majority of certified nurse assistants (n=5). The availability of nursing staff hours per patient substantially differed among units, ranging from 2.9 to 6.2 nursing staff hours per 24 hours per patient (median 3.9). The median average sick leave was 5% in the

former year (without maternity leave). All but one unit had vacancies for nursing staff (details per unit can be found in Supplementary materials Table S3). A stable team was seen as important, and thus in some units nursing staff were employed for a minimum of 24-32 contract hours per week.

Nursing staff were seen as central in the treatment by the interviewees: *"They [nursing staff members] also try things before agreements [about management] are made. They are often the ones who come up with new approaches. We also come up with them, but I think that the performing and also coming up with is a very big task of the [nursing staff] team" (unit 11).* Competences that were seen as important in nursing staff by both unit managers and interviewees included being open to new approaches, flexibility, reflectiveness on one's own behavior, being good at observing and describing behavior, and being able to cope with stressful situations such as aggression. The ability to provide personal care with a caring attitude together with being able to set boundaries and act upon the challenging behavior was seen as key: *"On the one hand, you should be able to provide warm personal care and be creative, but you should also be able to be directive when necessary and sense when you should approach someone from below and when from above" (unit 03).* At one unit, the staff were also trained in the principles of miMakkus for communication in alternative ways (Hendriks, 2017). Most units provided training for nursing staff to manage with physical aggression. Some units started with peer consultation focusing on the experience of caring for patients with severe challenging behavior, led by the psychologist. It helped staff in being able to set boundaries and gaining confidence in their ability to search for and apply suitable interventions. The support of the nursing staff manager was seen as important. Attention to work balance, mental support and extra staff during times of crisis helped in preventing sick leave and being more open to new behavioral approaches, according to the interviewees.

Six units involved volunteers, whereas in the other units interviewees considered this impossible due to the severity of the patients' behavior. Units with volunteers focused on recruiting volunteers who could manage severe challenging behavior, and strongly invested in their supervision.

Physical environment

General impression

Unit sizes ranged from 10 to 28 one person rooms available. Three units had the possibility to walk all around the unit. Interviewees mentioned their experience that this could reduce agitation in some patients and was missed when not available. Three units had sub-units with very low visual stimuli and very few objects. One

sub-unit had only very soft objects. Eight units had seclusion rooms and in eight units enclosure beds were available, namely a bed with a canopy with zippered panels attached to a height-adjustable bed (Haynes & Pratt, 2009; Molleman et al., 2015). Details of the general impression per unit can be found in Supplementary materials Table S6.

OAZIS-dementia

The theme of safety scored highest on average in terms of the probability that the environment has a positive effect on the safety of a patient, while the theme of domesticity scored lowest (Table 2). Other individual items that scored relatively low were reducing noise by spatial planning (n=11), bath rooms not being visible from the general living room (n=6), and bath rooms not being directly accessible from the patients' room (n=7). The unit with the lowest score (unit 10) had a low score on the view and nature, and invested little in domesticity. The unit with the highest score (unit 01) had invested in the physical environment of the unit with special attention to sensory stimulation.

Management (research question 2)

Units varied in the degree in which they used a more intuitive or methodological work-up. Two interviewed elderly care physicians described their work-up explicitly as intuitive, although this was nuanced in one interview by the psychologist. In three units, specific evidence-based methods and/or multi-disciplinary programs developed for regular DSCUs were used, such as the ABC method, and the multidisciplinary programs STA-OP! protocol and Grip on Challenging Behavior (Pieper et al., 2016; Stokes, 2000; Zwijsen et al., 2011). Three units had explicit wishes or plans for training in a multidisciplinary program.

Before admission

Prior to admission, it was considered critically whether treatment was needed. Units considered which interventions had been used to date, and often gave advice to prevent admission. In one unit, the interviewee mentioned they insisted on consultation in the current residence beforehand, thereby preventing about one-third of proposed admissions. This prior consultation was conducted by the physician responsible for medical care or the psychologist, sometimes together with a nursing staff member. In three units, there was close collaboration with an ambulant team within the organization that advised in home situations.

Table 2. OAZIS-dementiaa

	Privacy and autonomy	Sensory stimulation	View and nature	Facilities	Orientation and routing	Domesticity	Safety	Total
Unit no.	**Item no. 1-7**	**Item no. 8-25**	**Item no. 26-36**	**Item no. 37-45**	**Item no. 46-52**	**Item no. 53-69**	**Item no.70-72**	**Item no. 1-72**
01	4.6	4.5	4.1	4.3	4.5	3.6	5	4.2
02	4.3	3.7	3.5	3.8	3.6	3.2	4.7	3.6
03	4.3	4.4	3.7	4.4	4	3.5	3	4
04	4.3	3.8	3.5	3.4	3.4	3.9	5	3.8
05	3.7	3.8	3.8	4.2	3.3	3.5	5	3.8
06	3.4	3.8	3.4	3	3.6	3.1	4.3	3.4
07	4.9	3.5	3	3.1	3.7	3.5	5	3.6
08	4.4	4.3	3	4.2	4.4	3.9	4.7	4
09	3.9	3.9	3.4	3.1	3.4	3.5	5	3.6
10	4.1	3.4	2.5	3.1	3.9	2.9	5	3.3
11	4.1	3.8	4.2	4.2	3.9	3.6	4.7	3.9
12	4.1	4.1	3.4	Missing	3.9	2.8	4	3.7
13	4.7	Missing	3.8	3.8	3.7	3.4	4.3	4
Average per theme	4.2	3.9	3.5	3.7	3.8	3.4	4.6	3.8

[a] Averages of the themes of the OAZIS-dementia: averages per theme per unit, theme (last row), and unit (last column). Averages are calculated back to the range on a scale from 1 'not at all' to 5 'completely applicable'. Higher scores indicate a higher probability of the environment having a positive effect on its residents (de Boer et al., 2018).

Diagnostics

Interviewees explained that they had a program of clinical investigation in the first week after admission, comprising an analysis of the medical history in conjunction with the (psychotropic) drug use, physical and psychiatric examination, laboratory examination, making a first plan for the behavioral approach with interventions for the nursing staff, and a hetero-anamnesis of the biography, often with attention to personality and coping style. Two interviewees mentioned that without a biography it was often difficult to treat these patients well: *"Yes, that's when you miss quite a part of the puzzle. This can make it very difficult to draw conclusions,. in which case you find yourself struggling to find the correct approach for quite some time" (unit 04)*. All units paid attention to sensitivity for sensory stimuli, although the intensity and expertise available differed among units. Tolerance of a certain level of challenging behavior was essential in this phase to enable effective observation: *"If someone wants it [the challenging behavior] gone immediately, it changes your perspective. There's a certain peace like: 'okay, this is it, let's see where we still can be of any help to someone'" (unit 05)*. *"A very enthusiastic team that is really able to let people be. I find that really important too. [A team] that does not react immediately but is able to let it run its course for a while and see what happens together" (unit 11)*. The multidisciplinary team interpreted the behavior and discussed treatment every week (every other week in one unit). To ensure a consistent approach by the nursing staff, attention to differences in the experience and interpretation of the behavior was seen as essential.

Treatment

For most patients, the treatment comprised a combination of non-pharmacological interventions and psychotropic drugs. Although interviewees strived to taper off the psychotropic drugs, they did not always consider this to be possible. They were satisfied when they could reduce the number of different types of psychotropic drugs and prescribe psychotropic drugs with a better rationale. Overall, interviewees mentioned that guidelines held limited usefulness for the treatment in these units: *"Almost everything we do is no longer evidence-based and that's a huge problem." "We all have mainly expert opinions, meaning the knowledge of people who know more about it" (unit 06)*. Interviewed psychiatrists described that they used the psychiatric guidelines more freely than usual: *"For example, in severe disinhibited behavior - not sleeping any more, being very restless. You can also interpret this as manic and we treat it as manic, and we find we achieve good results. We try especially try to find which box to tick, because the guideline is not able [to provide for a proper label], which label fits best and try to treat for that" (unit 02)*. As a clinical evaluation instrument of the challenging behavior, four units completed the Neuropsychiatric

Inventory (NPI-Q) and the Cohen-Mansfield Agitation Inventory (CMAI) at regular intervals (Cohen-Mansfield et al., 1989; de Jonghe et al., 2003). In two units, these were used in the actual evaluation of the treatment. In one of these units, goals were identified and evaluated with a goal attainment score.

Overall, visual stimuli were minimized and few objects were available to prevent over-stimulation and harm. In three units, patients were first admitted to a sub-unit with very few stimuli, before being moved to a sub-unit with more stimuli when they showed less aggression. Enclosure beds were also used to reduce stimuli, but also for improving sleep during the night, reducing ongoing restlessness and preventing falls. Other examples of specific interventions in sensory stimuli were deep pressure through a weighted vest or a headphone.

Non-pharmacological interventions used varied among the units, and included video-interaction training, sensory integration therapy, music therapy, Snoezelen, psychomotor therapy, and principles of "powerless in daily living" (PDL) care, a type of emotion-oriented care for patients with an irreversible self-care deficit (van Dijk, 2008). As previously mentioned, one unit also used the principles of miMakkus, one unit paid special attention to the role of sleeping disorders, and one stimulated a break with patterns in the family system by discouraging visits during the first two weeks after admission. In one unit, patients with therapy-resistant severe challenging behavior were sometimes treated with electroconvulsive therapy with relevant results, although the therapy had to be continued to sustain the results.

Discharge

Discharge was regarded possible when the patient's behavior was expected to be manageable in a regular DSCU. Discharge was often difficult due to the specific needs of the patients, while being stigmatized by the assumed psychiatric comorbidity of potential units was also a problem according to interviewees from units with a background in mental health care. Some interviewees mentioned that discharge seemed to be impossible for some patients, sometimes after a probation discharge: *"I might say that we go on trying, but that's actually not always the case. Because at a certain moment we simply don't know any more, than it's manageable for the unit." "Exactly, sometimes it's manageable for us, and then we say that this is the best possible. But we mean that it's not manageable in a regular unit" (unit 05)*

Some units strongly invested in discharge by inviting the nursing staff of the proposed unit for discharge to care for the patient together to explain behavioral guidance in practice. These units' teams were also available for the new units after discharge.

Discussion

The main finding of this study is that units are pioneering and have strong heterogeneity in the management of severe challenging behavior in dementia. This heterogeneity was demonstrated by the varying degree to which a more intuitive or methodological work-up was used, the broad variety of non-pharmacological interventions used, and the differences in nursing staff hours, nursing staff education levels, length of stay, and the physical environment. Despite these differences, there were similarities in emphasis on observation with an open attitude, the key role of nursing staff, frequent multidisciplinary meetings, and attention to sensory stimuli.

Management

Although units varied in the degree to which they adopted a more intuitive or methodological work-up and the fact that a broad variety of non-pharmacological interventions was used, the ability – especially of the nursing staff members – to observe behavior was seen as key. These observations together with an analysis of the (non-)medical biography and personality were interpreted and discussed by management in the multidisciplinary team meetings. From literature, we know that pre-morbid personality may play a role in challenging behavior (Osborne et al., 2010). In a qualitative study in patients with extreme challenging behavior in regular DSCUs, sub-optimal interdisciplinary collaboration and communication was one of the factors that contributed to the experience of an impasse (Veldwijk-Rouwenhorst et al., 2022). The frequent multidisciplinary meetings may have facilitated collaboration and communication, although from our own research about severe challenging behavior we also know that this needs to be facilitated by process conditions such as the organization's support of the professionals, and clear agreements and defined roles (van Voorden et al., 2023).

All units paid attention to sensory stimuli that were thought to affect the behavior, although the methods to analyze this and their intensity varied among units. In some units, special adaptions to the physical environment were made. Challenging behavior may be due to sensory impairment and/or sensory processing abnormalities (Ravn et al., 2018; Sánchez et al., 2016), which therefore require assessment and individualized sensory stimuli. Compulsory admissions were common, which means that the challenging behavior caused danger to oneself or others (Salize, 2002). These and other possible coercive measurements in the form of physical restraining interventions such as enclosure beds and seclusion rooms were used to prevent harm or diminish sensory stimuli. However, further research into the effectiveness of interventions that are or may be physically restraining is necessary.

Role of nursing staff

The nursing hours per patient per 24 hours substantially differed among units. The median average of 3.9 hours per patient per day is similar to the current hours per resident per day in regular nursing home units in the United States (Chen et al., 2023). Despite this, in five units the education level of nursing staff was higher than in regular DSCUs in the Netherlands, and all units hired nursing staff with specific competences. Nursing staff competences that were seen as relevant were an openness to new approaches, flexibility, reflectiveness, being able to observe behavior well with a certain tolerance towards challenging behavior, and being able to cope with stressful situations. Indeed, these are competences that are known to be important in regular dementia care (Milte et al., 2016; Piirainen et al., 2021) (Geoffrion et al., 2020). Moreover, a consistent approach by the nursing team seems essential, which was facilitated discussing the interpretations of the behavior. A consistent approach by the nursing staff and an open attitude of those involved in the direct environment have also been found to be part of the successful treatment of severe challenging behavior (van Voorden et al., 2023).

Being open to new approaches, showing a certain tolerance towards the behavior, and coping with stressful situations possibly corresponds with the competence of the therapeutic use of self, which includes perseverance, situational awareness, and the ability to be present (Piirainen et al., 2021). This therapeutic use of self probably requires a reflectiveness on one's own behavior as a nursing staff member. Learning this is part of training as a registered nurse, but not as a nursing assistant (Kroezen et al., 2018; Rasheed et al., 2019). The participating units fostered this reflectiveness on one's own behavior by recruiting nursing staff, and some units offered training through peer consultation. This reflectiveness may also be valuable in and improved by the frequent multidisciplinary meetings.

Strengths and limitations

There are two main strengths of this study. First, the integration of different types of data collection offers rich insights into the organization of these units. Second, this study represents the organization and management of challenging behavior of highly specialized units in the Netherlands, with thirteen out of sixteen known units having participated.

There are some possible limitations to this study. First, the data were collected in 2018 when several of these pioneering units had recently started. Therefore, characteristics and management of behavior on these units may have developed, and insights may have changed from the experience of these pioneering units.

Second, we found that most unit managers did not have complete data, which is a concern for better monitoring in the future. Moreover, this led to estimations by the unit managers and therefore led to less precise data. Third, we asked the physician responsible for medical care to invite another practitioner – such as the psychologist – whom he/she considered important in the treatment. Nurses and nursing assistants were not interviewed about the experiences and competences that they consider useful in their work, which may have led to selection bias towards the perspective of what is relevant for the physician. Moreover, nursing staff was considered as most important in the management of challenging behavior, meaning that their perspective is particularly relevant and that further research should include this. Fourth, interventions used in the management of challenging behavior may have remained unmentioned, whereby data saturation was not reached concerning this. Despite this, the main finding of heterogeneity in interventions persists together with the representativeness for the Netherlands. Fifth, the units differed in their experience and expertise, i.e. six units had opened less than two years prior to the study, which may have resulted in less in-depth interviews.

Conclusions and implications

We found that these pioneering units have strong heterogeneity in their organization and management of severe challenging behavior in people with dementia. This finding emphasizes the need for further research into what is effective in interventions, the (social) context such as the attitude of persons surrounding the patients, as well as the physical environment. The framework for complex interventions may prove useful to investigate this (Skivington et al., 2021). Furthermore, research into the necessity of these highly specialized units could shed light on what is needed on regular DSCUs to manage challenging behavior better and prevent transfers of patients. Recent research in patients admitted to some of these highly specialized units has shown that increasing severity of the challenging behavior, realization that the needs of the person with dementia cannot be met, and the burden of the nursing staff - often triggered by a life-threatening event - may lead to these admissions (Verhees et al.). Combining this knowledge with information about organizational influences on both highly specialized units and DSCUs, such as already known influences, i.e. staff availability, staff training, the use of specific methods such as dementia care mapping, and influence of the physical environment (Laura Adlbrecht et al., 2021; L. Adlbrecht et al., 2021; Bergmann et al., 2023; Joyce et al., 2018; Kok et al., 2013), but also societal developments such as

the tendency to live at home longer (Verbeek-Oudijk & Koper, 2021), could provide relevant insights for improving the quality of care on both DSCUs and highly specialized units. This also holds for insight into specific patient characteristics of patients admitted to highly specialized units such as dementia type, character and severity of the challenging behavior, and whether and why treatment is effective.

Although this study found a great variety in organization and management of severe challenging behavior, we think that three suggestions for practice can be formulated. First, nursing staff plays a key role in the management of the behavior. A stable, higher educated team with many contract hours per nursing staff member as well as a certain tolerance for severe challenging behavior to observe well was described as necessary. Second, investing in the physical environment seems to be of value. Safety, a low amount of visual and auditive stimuli, space and interventions to dose stimuli individually probably add to the wellbeing of patients on these units. Third, the involvement of expertise from mental health care was valued. These possible implications deserve further study.

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Supplementary materials

Supplementary Table S1. Patient characteristics per unit

Unit	Residence before admission [a]	Compulsory admission [a]	Average age patients (years)	Average length of stay (months)	Discharge location [a]	Death rate
01	- home 72% - long term dementia care 13% - hospital 9% - mental health care 3% - other: care for mentally disabled 3%	10%	79	3	- home 32% - back to referring unit 1% - long term care unit in long term care organization 66% - mental health unit for long term care 1%	12%
02	- home 7% - long term dementia care 41% - hospital 7% - mental health care 45%	67%	73	5	- home 5% - back to referring unit 10% - long term care unit within organization 45% - long term care unit in long term care organization 40%	22%
03	- home 31% - long term dementia care 6% - hospital 2% - mental health care 61%	62%	72	6	- home 26% - long term care unit in long term care organization 50% - other 24%: other in treatment in general mental health care 15%, hospital 9%	6%
04	- home 29% - long term dementia care 58% - long term somatic care 2% - mental health care 9% - other 3%: unit for acquired brain injury, residential care home	20%	74	7	- home 6% - back to referring unit 24% - long term care unit within organization 42% - long term care unit in long term care organization 11% - mental health unit for long term care 1% - no discharge (patient stays) 15%	29%
05	- home 36% - long term dementia care 56% - mental health care 8%	37%	73	6	- back to referring unit 3% - long term care unit within organization 51% - long term care unit in long term care organization 17% - no discharge (patient stays) 30%	23%

Supplementary Table S1. Continued

Unit	Residence before admission [a]	Compulsory admission [a]	Average age patients (years)	Average length of stay (months)	Discharge location [a]	Death rate
06	- home 25% - long term dementia care 55% - hospital 10% - mental health care 10%	80%	70	4	- home 5% - back to referring unit 60% - long term care unit within organization 5% - long term care unit in long term care organization 30%	8%
07	- home 8% - long term dementia care 34% - long term somatic care 17% - hospital 8% - mental health care 17%	4%	76	12	- home 20% - long term care unit within organization 43% - long term care unit in long term care organization 30% - mental health unit for long term care 8%	20%
08	- home 42% - long term dementia care 17% - long term somatic care 17% - hospital 8% - mental health care 17%	10%	65	8	Insufficient data available because unit started since several months, discharges were to: - long term care unit within organization - long term care unit in long term care organization	63%
09	- home 65% - long term dementia care 10% - long term somatic care 10% - hospital 10% - mental health care 5%	20%	76	4	- back to referring unit 10% - long term care unit within organization 46% - long term care unit in long term care organization 4% - no discharge (patient stays) 40%	50%
10	- home 10% - long term dementia care 70% - hospital 20%	20%	75	5	- back to referring unit 60% - long term care unit within organization 20% - long term care unit in long term care organization 20%	18%
11	- home 5% - long term dementia care 20% - hospital 10% - mental health care 65% (35% from a mental health care unit in the hospital)	20%	81	2	- back to referring unit 68%[b] - long term care unit within organization 4% - long term care unit in long term care organization 3% - other 25%: hospital 4%, unknown 23%	8%

Supplementary Table S1. Continued

Unit	Residence before admission [a]	Compulsory admission [a]	Average age patients (years)	Average length of stay (months)	Discharge location [a]	Death rate
12	- home 23% - long term dementia care 10% - hospital 11% mental health care 2% - other 54%: unknown	38%	82	1	- home 24% - back to referring unit 10% - long term care unit within organization 7% - long term care unit in long term care organization 56% - mental health unit for long term care 3%	3%
13	- home 75% - long term dementia care 10% - hospital 5% - mental health care 10%	90%	80	3	- home 13% - long term care unit within organization 17% - long term care unit in long term care organization 68% - no discharge (patient stays) 1%	24%

[a] These results are probably not precise due to estimation.
[b] When admitted from hospital or mental health care to unit 11 this meant the place before (no data available about this).

Supplementary Table S2. Involvement of physicians

ID (background)	Physician responsible for medical care 1	Physician responsible for medical care 2	Physician responsible for medical care 3	Consultant psychiatrist	Other consulting physician(s) [b]
01 (mental health care)	elderly care physician [a]	psychiatrist [c, d]		Not applicable	Sometimes consults neurologist
02 (mental health care)	geriatric psychiatrist [a]	elderly care physician		Not applicable	Sometimes consult neurologist, rehabilitation doctor, geriatrician
03 (mental health care)	elderly care physician [a]	geriatric psychiatrist		Not applicable	Neurologist
04 (long term care)	elderly care physician [a]			Yes, psychiatrist (specialization unknown) sees every patient once in four weeks	
05 (long term care)	elderly care physician [a]			Yes, psychiatrist (specialization unknown) involved in at least every multidisciplinary meeting	
06 (collaboration of mental health care and long term care)	geriatrician [a]	psychiatrist [a, e]	elderly care physician	Not applicable	
07 (long term care)	elderly care physician [a]			Occasionally this physician discusses patients by phone	
08 and 09 (long term care)	elderly care physician [a]			Occasionally this physician discusses patients by phone	Sometimes consults neurologist

Supplementary Table S2. Continued

ID (background)	Physician responsible for medical care 1	Physician responsible for medical care 2	Physician responsible for medical care 3	Consultant psychiatrist	Other consulting physician(s) [b]
10 (long term care)	elderly care physician [a]			Yes, psychiatrist (specialization unknown) sees patients every six weeks, in collaboration with elderly care physician who works in the consulting mental health care organization, this physician sees patient every two weeks	
11 (long term care)	elderly care physician [a]			Occasionally this physician discusses patients by phone	
12 (mental health care)	geriatrician [a]	geriatric psychiatrist [c]		Not applicable	Neurologist
13 (mental health care)	elderly care physician [a]	psychiatrist [c, d]		Not applicable	Neurologist (4 contract hours a week), sees every patient

[a] Was also interviewed.
[b] This is information from interviews and may be incomplete concerning the occasional calls to specialists.
[c] In this unit this was only a formality due to the criteria of the insurance. These psychiatrists were involved in the treatment of all patients, but in practice not in the role of the physician responsible for medical care.
[d] Uncertain whether this was a geriatric or general psychiatrist.
[e] In unit 06 normally a geriatric psychiatrist worked as responsible physician, but he was replaced temporarily by a general psychiatrist.

Supplementary Table S3. Nursing staff characteristics per unit

Unit	Unit size	Nursing staff (in full time equivalents) [a, b]	Nursing hours/24 hours/patient (staff-patient ratio)	Sick leave nursing staff (%)	Average age nursing staff (years)	Vacancies nursing staff
01	17	- **EQF 3: 12.28** - EQF 4: 1 - EQF 6: 2.11	4.4	1.2	35	1
02	28	- EQF 2: 3 **- EQF 3: 9** **- EQF 4: 8** - EQF 6: 2	3.2	8	35	1
03	21	- EQF 2: 1.5 - EQF 3: 1.5 **- EQF 4: 11** - EQF 6: 3	3.5	5	38	0
04	12	- EQF 2: 0.67 **- EQF 3: 5.42** - other: 'care companion' 0.1	2.9	5	35	1
05	24	- EQF 2: 3.14 - **EQF 3: 12.16** - EQF 4: 3.52 - EQF 6: 0.88	3.6	2.7	40	1
06	19	- EQF 2: 1 - EQF 3: 4 - **EQF 4: 15** - EQF 6: 2	4.1	8	35	1
07	25	- EQF 2: 1.5 **- EQF 3: 5.4** **- EQF 4: 4.3** - EQF 6: 0.67	3.9	7	40	6

Supplementary Table S3. Continued

Unit	Unit size	Nursing staff (in full time equivalents) [a, b]	Nursing hours/24 hours/patient (staff-patient ratio)	Sick leave nursing staff (%)	Average age nursing staff (years)	Vacancies nursing staff
08	12	- EQF 2: 1 - EQF 3: 2 **- EQF 4: 5** - EQF 6: 1	3.8	0.6	33	1
09	10	**- EQF 3: 8.89** - EQF 4: 1.76 - EQF 6: 1	3.8	5	35	0
10	11	- EQF 3: 4 - **EQF 4: 6**	4.3	3	45	1
11	10	**- EQF 3: 8.35** - EQF 4: 2.56 - EQF 6: 1.78 - other: miMakkus-clown: 0.3	6.2	9.5	43	1
12	16	- EQF 2: 0.78 - EQF 3: 3.11 **- EQF 4: 13.86**	5.1	6	47	2
13	17	- EQF 3: 1.56 **- EQF 4: 11.04** - EQF 6: 2.56	4.2	12	40	1

Bold values indicate that nursing staff members of this level formed the majority working in the unit.

[a] For most units this numbers did not match the separately asked total of fulltime equivalents (including vacancies) and/or precise numbers could not be obtained.

[b] Fulltime is calculated as 36 contract hours a week.

Supplementary Table S4. Interview guide of interview with physician responsible for medical care and another practitioner

Topics:	Questions:
Before admission	For the period from registration for admission to admission: Who are involved? How is the collaboration with other care providers?
First day on the unit	What is the process of a new admission on the first day on the unit?
Admission after first day	- What is an admission like after this? - What does a day on the unit look like? - Who are involved during the course of an admission? How? Who do you consult? When? Do they see the person with dementia in person? What is your experience in the collaboration with mental health care/nursing home institution (choose what is applicable)? - What guidelines and/or methods are used? What is your experience with these? - What is the role of non-pharmacological interventions in the treatment of severe challenging behavior? [a] - How do you see the role of the nursing team? What does the collaboration look like? What characterizes a nurse or nursing assistant who fits in this unit? - How are family or other informal caregivers involved? - Ask through about methodological or intuitive characterized work-up. [a] - Ask through about physical restraints. [a] - Ask through about psychotropic drugs used. How often? What? Experience with this? [a]
Explanation length of stay longer	If the expected and actual lengths of stay differ: What explains the difference between the expected and actual durations?
Characterization treatment	What characterizes your approach in treating patients with severe challenging behavior? What makes this unit different from the work-up at home or in a nursing home? [a]
Evaluation treatment	How does evaluation of treatment take place? Who are involved? Is there a set format? To what extent do/does the treatment vision/protocol/method support this?
Training management behavior	How much room is there for training of staff in managing severe challenging behavior? What does this training look like?
Training specific methods	What attention is paid in the training about methods used in this unit for the treatment of challenging behavior? What does this training look like?
Satisfied with treatment	When are you satisfied with the treatment? How did you accomplish such a result?
Experienced difficulties	There will be times when treatment does not work out as hoped for. What are issues that you face? How do you deal with these?
Completion	Summarize and check. Are the other issues you would like to share?

[a] Added after six interviews.

Supplementary Table S5. Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No. Item	Guide questions/description	Reported under heading (and subheading(s))
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Author 1 Methods (Measurements – Interview) Author 1
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	MD, PhD candidate
3. Occupation	What was their occupation at the time of the study?	PhD candidate
4. Gender	Was the researcher male or female?	Female
5. Experience and training	What experience or training did the researcher have?	Interview study in 2011, MD since 2013, Course Qualitative Research Methods and Analysis in 2019
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Methods (Measurements-Interview)
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Methods (Measurements-Interview)
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Methods (Analysis-Qualitative data)
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods (Analysis-Qualitative data)
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Methods (Sample and setting, Procedure)
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Methods (Sample and setting, Procedure, Measurements - Interview)

Supplementary Table S5. Continued

No. Item	Guide questions/description	Reported under heading (and subheading(s))
12. Sample size	How many participants were in the study?	Methods (Sample and setting, Measurements - Digital questionnaire, Measurements – Interview)
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Methods (Sample and setting)
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Methods (Procedure)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Not applicable. Methods (Measurements – Interview)
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Methods (Measurements -Digital questionnaire, Measurements – Interview)
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Methods- Table 1 Methods (Measurements-Interview)
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	Methods (Measurements – Interview)
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Methods (Measurements – Interview)
20. Field notes	Were field notes made during and/or after the interview or focus group?	Methods (Analysis – Interviews)
21. Duration	What was the duration of the inter views or focus group?	Methods (Measurements – Interview)
22. Data saturation	Was data saturation discussed?	Methods (Analysis – Interview) Discussion (Strengths and limitations)
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Methods (Measurements – Interview)
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Methods (Analysis – Interview)
25. Description of the coding tree	Did authors provide a description of the coding tree?	Methods (Analysis – Qualitative data)
26. Derivation of themes	Were themes identified in advance or derived from the data?	Methods (Analysis – Qualitative data)

Supplementary Table S5. Continued

No. Item	Guide questions/description	Reported under heading (and subheading(s))
27. Software	What software, if applicable, was used to manage the data?	Methods (Analysis – Qualitative data)
28. Participant checking	Did participants provide feedback on the findings?	Methods (Measurements – Interview)
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Results
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Results
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Results

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

Supplementary Table S6. Start year and general information physical environment per unit

Unit	Start year	Unit size	Subunits *(Specific subgroups and/or other indication)*	Seclusion room(s)	Enclosure bed
01	2004	17	No subunits. (Other indication: patient group admitted for cognitive diagnostics often with mild challenging behavior.)	Yes	No
02	2017	28	Two subunits, physically closed to each other. (No difference in patient group for the subunits.)	Yes	Yes
03	2014	21	Two subunits, possible to close them to each other, normally open. (Other indication: one subunit for patient group with primarily psychiatric diagnosis and cognitive problems.)	Yes	Yes
04	2013	12	Two subunits, physically closed to each other. (One subunit for very severe behavioral problems. [a])	No	Yes
05	2016	24	Four subunits, one subunit mostly closed to the other three units and possible to close them all to each other. (One subunit for very severe behavioral problems [a] with a maximum of three patients with physical aggression.)	Yes	Yes
06	2016	19	Two subunits, physically close to each other. (One subunit for very severe behavioral problems. [a] Other indication: Incidentally patients with a primarily psychiatric diagnosis.)	Yes	No
07	2009	25	Three subunits, physically closed to each other. (Other indication: one subunit for older adults with primarily psychiatric diagnosis.)	No	Yes
08	2017	12	No subunits. (No subgroups or other indications.)	No	No
09	2014	10	No subunits. (No subgroups or other indications.)	Yes	Yes
10	2010	11	No subunits. (No subgroups or other indications. A maximum of three patients with physical aggression.)	Yes	No
11	2012	10	No subunits. (No subgroups or other indications.)	No	Yes
12	1977	16	No subunits. (No subgroups or other indications.)	No	Yes
13	1994	17	No subunits. (No subgroups or other indications.)	Yes	No

[a] Patients are admitted to the other subunit(s) when the challenging behavior, often physical aggression, declines.

Chapter 3. Well-being, multidisciplinary work and a skillful team: essential elements of successful treatment in severe challenging behavior in dementia

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Abstract

Objective: Conceptualize successful treatment of persons with dementia and severe challenging behavior as perceived by professionals.

Methods: In this concept mapping study 82 experts in dementia care participated. The study followed two phases of data collection: 1) an online brainstorm where participants completed the focus prompt: *'I consider the treatment of people with severe challenging behavior in dementia successful if..';* 2) individual sorting and rating of the collected statements followed by data analysis using multidimensional scaling and hierarchical cluster analysis, resulting in a concept map.

Results: Three clusters were identified, the first addressing treatment outcomes and the latter two addressing treatment processes, each divided into sub-clusters: 1) *well-being,* comprising *well-being of the person with dementia* and *all people directly involved*; 2) *multidisciplinary analysis and treatment*, comprising *multidisciplinary analysis, process conditions, reduction in psychotropic drugs,* and *person-centered treatment;* and 3) *attitudes and skills of those involved*, comprising *consistent approach by the team, understanding behavior, knowing how to respond to behavior,* and *open attitudes*.

Conclusions: Successful treatment in people with dementia and severe challenging behavior focuses on well-being of all people involved wherein attention to treatment processes including process conditions is essential to achieve this.

Keywords: Challenging behavior, long-term care, dementia, treatment, outcome

Introduction

Challenging behavior in persons with dementia – also known as neuropsychiatric symptoms or behavioral and psychological symptoms in dementia (BPSD) (Gerritsen et al., 2019) – is common in nursing homes, with a prevalence rate of more than 80% (Selbaek et al., 2013). Challenging behavior includes a broad range of behaviors such as agitation, physical or verbal aggression, vocalizations, disinhibition, irritability or nighttime disturbances. Challenging behavior is associated with lower quality of life for persons with dementia living in long-term care institutions (Henskens et al., 2019; Klapwijk et al., 2016; Livingston et al., 2017; Winzelberg et al., 2005) and increased caregiver distress (Brites et al., 2020). Although an exact definition of severe challenging behavior is lacking, Brodaty et al. propose a seven-tiered model for managing BPSD, where the prevalence rates of severe, very severe, and extreme BPSD are estimated at 10%, <1%, and rare, respectively, each requiring a different level of management (Brodaty et al., 2003). In a minority of residents challenging behavior can be very frequent, severe and/or persistent, with reported prevalence rates of 6.3% for severe agitation and 7.4% for very frequent agitation (Palm et al., 2018; Veldwijk-Rouwenhorst et al., 2017). Severe challenging behavior – especially agitation and aggression – may even lead to admissions to other settings such as psychiatric inpatient settings and specialist care units (Backhouse et al., 2018) with more diagnostic facilities, more facilities to prevent harm from physical aggression as well as more highly trained staff members. Although a large number of non-pharmacological and pharmacological interventions have been investigated, the majority of studies vary in their methods applied, including different primary outcome measures, and moderate sample sizes hindering univocal insights into the effectiveness of interventions (Abraha et al., 2017; Dyer et al., 2018). The rationale for the different choice in treatment outcomes is often unclear or arbitrary, and a more standardized approach is needed (Koch et al., 2022). Outcomes used to date with different instruments include behavior, mood, and – less often – quality of life and caregiver distress (Abraha et al., 2017; Dyer et al., 2018; Feast et al., 2016). Some of these outcome measurements were used in a ten-year review of a highly specialized unit for the treatment of severe and persistent BPSD in Australia, although the authors only described discharge to regular long-term care services and reduction of psychotropic drugs as treatment success (Gresham et al., 2021), implying that treatment success is based on more than changes in behavior. This plethora of outcome measures reflects the need for a conceptual framework of treatment success in the context of severe challenging behavior, which may help to improve care and treatment as well as the planning and evaluation of this particular group. To the best of our knowledge, no literature is available describing a

conceptual framework for treatment of this specific group of people with dementia and severe challenging behavior. Therefore, we decided to consult experienced professionals in this treatment, formulating the following research question: *"How do experienced professionals conceptualize successful treatment in severe challenging behavior in dementia?"* This conceptualization will address two aims: 1) improving the understanding of what successful treatment contains in persons with severe challenging behavior in dementia; and 2) evaluation of treatment.

Methods

In this study, concept mapping was used as an integrated mixed method combining quantitative and qualitative research methods for organizing all ideas of a group of stakeholders (Kane & Trochim, 2007; Trochim, 1989). It is a well-established, structured methodology to visualize these ideas and how they interrelate. Concept mapping is especially relevant in healthcare for complex and multidimensional concepts, e.g., quality of life in long-term care, involuntary care in dementia, and for planning and evaluating several mental health care programs (de Boer et al., 2018; Iris et al., 2012; Nabitz et al., 2017).

Concept mapping uses two phases of data collection, with each phase being prepared by the researchers: 1) brainstorming, and 2) sorting and rating of statements resulting from phase 1. This is followed by a data analysis resulting in a concept map (Kane & Trochim, 2007).

Participants

We requested the participation of physicians, psychologists, therapists and nursing staff working in expertise units in the Netherlands where people with dementia and severe challenging behavior are treated. In the Netherlands, people with dementia living in a nursing home commonly live in a dementia care ward (Rutten et al., 2021). The specialization of the participating units is different from common dementia care wards since people with severe challenging behavior are admitted temporarily for treatment to highly specialized or so-called expertise units where expertise from long-term care and psychiatry is combined in staffing and treatment (Van Voorden et al., 2021). These participating expertise units are part of long-term or mental health care organizations. The units were identified and recruited through the six academic networks of long-term care (Koopmans et al., 2013) and the network for long-term care for residents with dementia and severe challenging behavior (Koopmans et al., 2022). The participating units approached are located throughout the Netherlands.

We also requested the participation of professionals from the Centre for Consultation and Expertise (CCE), a supplementary service to standard healthcare services with a unique position within the Dutch national healthcare system. The CCE provides consultations for people in need of long-term care when there is severe challenging behavior and caregivers are no longer able to find solutions (CCE, 2021). CCE professionals who provide consultations in nursing homes were recruited by a coordinator of the CCE. These professionals have a broad range of expertise, e.g., specialized therapists, nurses, managers, physicians and behavioral scientists.

Table 1. Study flow: phases, actions and results of data collection and analysis

Phase	Action	Result
Preparation phase 1	- Develop focus prompt (GV, DG) - Choose focus prompt for pilot (GV, DG, RK, SZ, AP, AB, MS, ROV) - Pilot test and final choice focus prompt (GV, DG, RK)	*1 focus prompt*
Phase 1: brainstorm	Create statements following the focus prompt: - Online brainstorm with 82 professionals	*187 statements*
Preparation phase 2	Reduce statements using the following procedure (GV, DG): - Assign keywords to the statements - Split up statements containing >1 idea - Remove identical statements - Combine overlapping statements	*Statements reduced to 93 statements*
Phase 2: sorting and rating	- 54 participants sort statements into piles according to their own idea [a] - 52 participants rate statements on a five-point Likert scale	*93 statements individually sorted and rated*
Data analysis	I) *Two-dimensional nonmetric multidimensional scaling* - Create a point map based on the sorting data where statements are plotted in a two-dimensional map visualizing relationships, calculate a stress value for the fit and bridging values for each statement	*I) Point map*
	II) *Hierarchical cluster analysis:* create a cluster map - Decide upper and lower limits of clusters (GV, DG) - Determine most useful number of clusters by examining how the clusters merge together moving from the upper limit to the lower limit of the cluster sizes and considering the bridging values of individual statements (GV, DG) - Choose final number of clusters, name clusters and make cluster descriptions (GV, DG, RK, SZ, AP, AB, MS, ROV) - Calculate the cluster bridging values for the final cluster map	*II) Cluster map*
	III) *Analyze importance ratings* - Calculate mean rates for statements and clusters	*III) Rating of statements and clusters*

[a] 68 participants started, 12 did not complete sorting: 1 nursing assistant, 4 nurses, 3 elderly care physicians, 1 psychologist, 3 CCE professionals, 2 CCE professionals sorted not according to instruction (one made five categories of importance and one made two categories)

Data collection and analysis

The data for phases 1 and 2 were collected between October 25, 2019 and February 10, 2020. Data were collected using groupwisdom™ software (*The Concept System® groupwisdom™ [Web-based Platform] (2019)*, Build 2019.24.01). Table 1 provides an overview of the study flow and its phases, displaying actions and results of the data collection and analysis.

Preparation for phase 1

A focus prompt was developed and piloted in the preparation for phase 1. Developing a proper focus prompt is crucial to guide the brainstorm, and it generally comprises one or two sentences to be completed with as many ideas as possible by the participants. We tested two focus prompts in a pilot with other professionals working in long-term care. We divided the two prompts among them and asked them to complete it with as many ideas as possible. We also asked whether they would have answered differently if the same prompt had a different word order. Both prompts resulted in similar answers with aspects addressing treatment outcomes – our main goal – as well as statements addressing treatment processes. Five of six pilot participants thought that they would not have answered differently with a different word order. After discussion, we agreed on the following focus prompt: *'I consider the treatment of people with severe challenging behavior in dementia successful if..'*

Phase 1: Brainstorm

The brainstorm was conducted online and participants could participate at their convenience during a given timeframe of three weeks. In the brainstorm, participants were asked to complete the focus prompt with as many ideas as possible. Participants' statements were immediately visible to all participants.

Preparation for phase 2

As required, the statements were reduced by two researchers (GV and DG) to a recommended set of fewer than 100 statements with optimal preservation of content and making them comprehensible for all participants. We achieved this by assigning keywords to all of the statements, splitting the statements containing more than one idea, removing identical statements and combining overlapping statements (Kane & Trochim, 2007). When we considered a participant's statement as difficult to understand for other participants, we used more comprehensible synonyms.

Phase 2: Sorting and rating

In phase 2, participants individually sorted the statements into categories according to their own perception of similarity. Participants were also asked to provide a name

for their categories according to their content. In the rating procedure, participants rated the individual statements according to their importance for the concept of successful treatment on a five-point Likert scale (Kane & Trochim, 2007).

Data analysis

Data approval, i.e. checking whether participants finished sorting according to instruction, and analysis were also conducted using the groupwisdom™ software. Sorting data were excluded when participants did not complete sorting (fewer than 75% of the statements sorted) or when participants did not sort according to the instructions, e.g., by sorting statements according to their importance instead of their contents. From the individual sorting input, a *similarity matrix* was formed, which is a symmetric matrix showing the number of participants that sorted each pair of statements together. Based on the similarity matrix, *two-dimensional nonmetric multidimensional scaling* was performed, which resulted in the statements being plotted in a two-dimensional *point map*. For this point map, a stress value was calculated (range 0 to 1), indicating the fit of the two-dimensional map. Stress values in concept mapping typically lie between .21 and .37 (Kane & Trochim, 2007). A high stress value implies that there is a greater discrepancy between the *similarity matrix* and the presentation of these data in a two-dimensional *point map* (Kane & Trochim, 2007). A bridging value is calculated for each statement (range 0 to 1). A lower value indicates that a statement is more anchored because it reflects well the content in its vicinity on the map, given that it was sorted more often with statements in its direct vicinity. A higher value is considered as bridging because it links more distant areas on the map and therefore may conceptually link to areas that are more distant on the map (Kane & Trochim, 2007). *Multidimensional scaling* was followed by *hierarchical cluster analysis* using the coordinates of the point map and evaluating statements' bridging values. In this analysis, we assessed which number of clusters is most suited for describing the contents by examining which statements merged per step in an agglomerative way, i.e., from the highest number of clusters to the lowest number (Kane & Trochim, 2007). We decided to assess the range of three to twenty clusters as it is very probable to find the best fit in this frame, whereby an average number of 7.86 clusters (SD = 3.0) was found in 104 concept mapping studies (Donnelly, 2017). The preferred number of clusters was chosen independently by each research team member and discussed until consensus was reached (Kane & Trochim, 2007). Cluster membership is ambiguous for statements with high bridging values and located on the edge of a cluster. Therefore, discussion was focused on statements with high bridging values. Their placement was evaluated regarding its connection with other statements in that cluster as well as its coherence with other clusters on the map. Cluster names and descriptions were prepared by GV and DG and discussed by the

research team. Sub-cluster average bridging values were calculated for the final cluster map, indicating whether sub-clusters are more anchors or bridges to other areas of the map. Finally, average cluster ratings and a *cluster rating map* were calculated.

Ethics statement

The study was conducted in accordance with the Declaration of Helsinki as well as the rules applicable in the Netherlands. The local Medical Ethics Review Committee stated that the Medical Research Involving Human Subjects Act (WMO) does not apply to this study and that an official approval of this study is not required (CMO region Arnhem-Nijmegen, reference number 2018-4354). Informed consent was obtained from all participants prior to data collection.

Results

Participants

Fifty-two professionals of participating units and 41 CCE professionals registered to participate. The response rate was 88% (n = 82) for the brainstorm, including CCE professionals, nursing staff members, physicians, psychologists and therapists with a median of 10.0 years of experience in the treatment of severe challenging behavior in dementia (Table 2). The response rate was 73% (n = 68) for sorting. Not everyone completed sorting and two participants did not follow the sorting instructions (see details in Table 1). After this, 56% of the participants (n = 52) rated the statements.

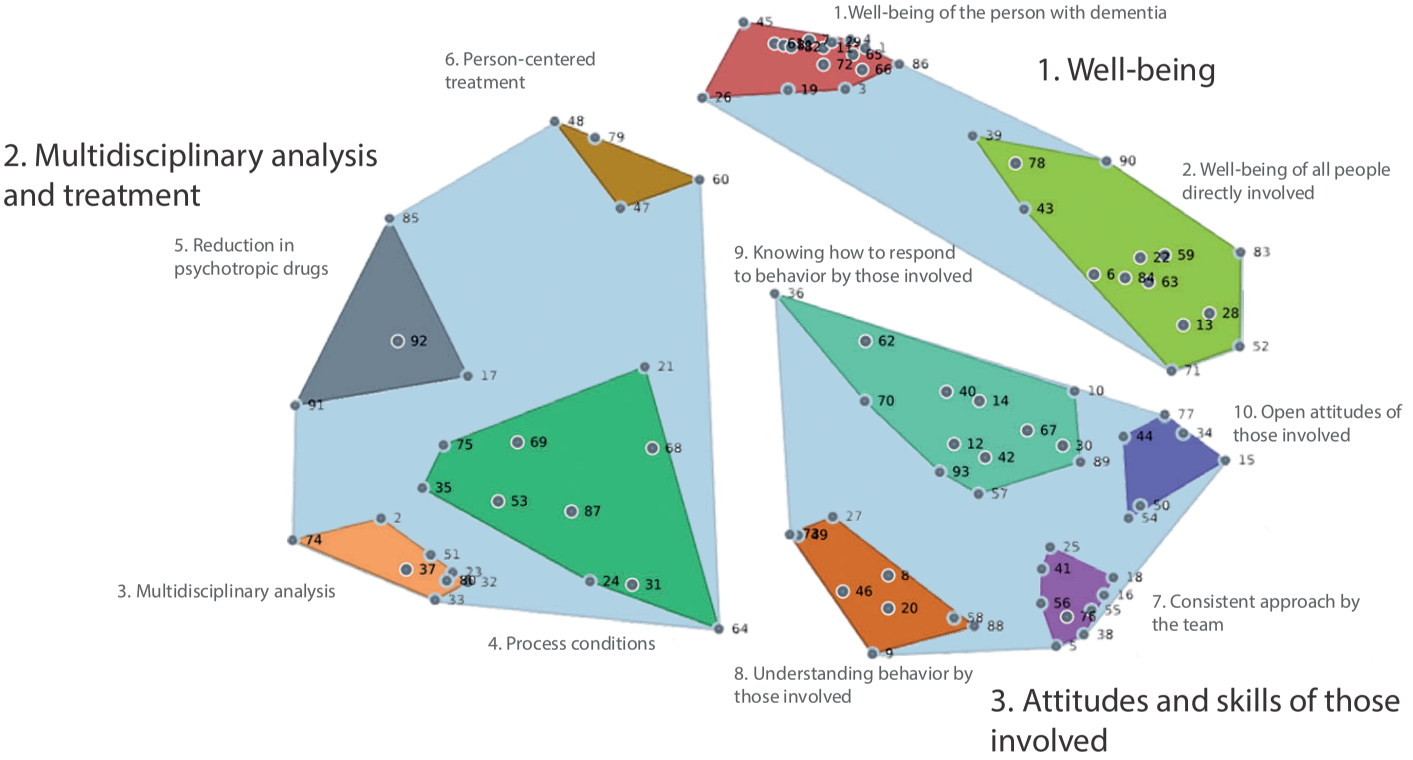
Table 2. Participant demographics (n = 82)

Age (years)	48.5 (SD 11.3) [a]
Sex (% female)	69.5% (n = 57)
Experience with treatment of dementia and severe challenging behavior (years)	Median 10.0 years (range 1.5 to 45 years)
Function	21 nursing staff
	9 psychologists
	10 physicians (7 elderly care physicians, 2 psychiatrists, 1 geriatrician)
	5 therapists (2 physiotherapists, occupational therapist, music therapist, psychomotor therapist)
	35 CCE professionals [b]
	2 started brainstorm but did not answer participant questions

[a] without n = 3 that did not complete age

[b] often have more than one vocational training, ranging from nurse, physiotherapist, occupational therapist, physician assistant, psychologist, elderly care physician, psychiatrist and (team) manager

Figure 1. Final concept map: representations of how 93 *statements* (dots with numbers in grey) relate to the clusters



Data collection and analysis

The brainstorm resulted in 187 statements, which we reduced to 93 statements. The *two-dimensional nonmetric multidimensional scaling* of the sorting data resulted in a *point map* (see Supplementary materials Figure S1), with a stress value was 0.21. In the *hierarchal cluster analysis*, we agreed upon a set of three main clusters and ten sub-clusters optimal representing successful treatment.

Cluster map clarification

Three clusters described successful treatment in people with dementia and severe challenging behavior, with each cluster divided into 2-4 sub-clusters (Figure 1). The first cluster considered treatment outcomes, namely 1) *well-being*. The other two clusters considered the treatment process: 2) *multidisciplinary analysis and treatment*; and *3) attitudes and skills of those involved.* In Table 3, all clusters and sub-clusters, cluster descriptions, average bridging values and average rating values per cluster are shown. In Table S1, all bridging values and average rating values per statement are shown (see Supplementary materials Table S1).

Table 3. Clusters, descriptions, mean bridging values (B) and importance ratings (I)

Clusters and sub-clusters (number of statements)	Descriptions	B [a]	I [b]
1) Well-being (30 statements)	**Improvement of the well-being of the person with dementia and the people directly around the person with dementia.**		
1) Well-being of the person with dementia (16 statements)	Improvement of the well-being of the person with dementia. Aspects also mentioned here are stable behavior, recognizing the person behind the disease, being allowed to be oneself, experiencing positive contact with other people on a daily basis, feeling understood, being able to enjoy life, having meaningful daytime activities, appearing to be more relaxed, more peace and comfort for the person with dementia, dignity of existence, no longer being distressed by the behavior or the reason for the behavior, less suffering, and being able to be transferred to a regular long-stay ward.	0.08	3.98
2) Well-being of all people directly involved (14 statements)	Improvement of the well-being of the people around the person with dementia, including other patients. Aspects also mentioned here are manageability of the behavior, improvement of the tolerability of the behavior, less despair, being able to accept the behavior, feeling understood, experiencing better contact with the person with dementia, having a sense of control over the behavior, no longer being affected by the behavior, and no more unsafe situations arising.	0.38	3.89
2) Multidisciplinary analysis and treatment (26 statements)	**The behavior of the person with dementia is analyzed and treated from different perspectives. The roles of the persons involved in this are clear, and the treatment does justice to the person behind the disease.**		
3) Multidisciplinary analysis (8 statements)	The behavior is analyzed from different perspectives and disciplines and evaluated by a multidisciplinary team and relatives.	0.48	4.17
4) Process conditions (10 statements)	Conditions for a proper treatment process. These include aspects such as the organization's support and facilitation of professionals, clear problem definitions, agreements and roles, having a picture of the background of the behavior of the person with dementia, adhering to the guideline, involving relatives, and seeing the behavior as dynamic.	0.6	4.17
5) Reduction in psychotropic drugs (4 statements)	Reduction of psychotropic drugs, if possible.	0.86	3.67
6) Person-centered treatment (4 statements)	The treatment takes into account the individuality of the person with dementia. Aspects mentioned here are meeting the needs of the person with dementia, and doing justice to the dignity of the person with dementia and their need for control.	0.52	4.49

Table 3. Continued

3) Attitudes and skills of those involved (37 statements)	**The people around the person with dementia understand their behavior and approach them consistently, and have adequate knowledge and skills to do so.**		
7) Consistent approach by the team (9 statements)	The team can consistently apply their knowledge of the behavior while adequately adapting their approach if necessary.	0.27	4.3
8) Understanding behavior by those involved [c] (9 statements)	The team and relatives understand the background of the behavior. Aspects mentioned here are joint efforts by the team and relatives, better gauging and preventing the behavior's escalation, the allocation of meaning to the behavior and own actions by the person involved, and exploration of their personal values in relation to the behavior of the person with dementia.	0.32	4.17
9) Knowing how to respond to behavior by those involved [c] (13 statements)	Those involved know which approach the person with dementia requires and can apply it. Aspects also mentioned here are reacting towards the person with dementia with more sensitivity, tailoring sensory stimuli, focusing on whatever goes well, and professionals developing self-confidence.	0.29	4.06
10) Open attitudes of those involved [c] (6 statements)	Those involved have the skills to tailor their (re)actions to the person with dementia. Aspects also mentioned here are being able to look at the behavior with an open mind, not judging strong emotions, and seeing the behavior as a way of communicating about well-being.	0.36	4.22

[a] mean bridging value for clusters from 0 to 1
[b] mean importance rating for cluster, rated on a five-point Likert scale
[c] not including other persons with dementia at the ward

Cluster 1: Well-being

The first cluster comprised two sub-clusters: *1) well-being of the person with dementia;* and *2) well-being of all people directly involved.* The sub-cluster of *well-being of the person with dementia* was conceptually most anchored to its place on the map (cluster bridging value 0.08).

Cluster 2: Multidisciplinary analysis and treatment

The second cluster comprised four sub-clusters. The sub-cluster of *process conditions* provided a set of criteria that can be used to plan and evaluate the conditions needed for multidisciplinary analysis and treatment. Statement 35 *'..the organization supports, guides and facilitates the professionals involved in the appropriate manner to carry out the desired interventions'* had the second highest bridging value (0.96) and scored second highest of all statements (4.55) (see Supplementary materials Table S1). This indicates that organizational facilitation was conceptually related to many statements and considered a very important factor of successful treatment.

We consider this statement a precondition for a successful treatment process and outcome. The other statements in this sub-cluster were also related to more distant statements (cluster bridging value 0.6), probably because these statements were formulated as a relatively concrete criterium despite being related to the other topics.

The sub-cluster of *reduction in psychotropic drugs* had the highest bridging value (0.86) and the lowest average sub-cluster rating (3.67). This indicates that the possibility to reduce psychotropic drugs is related to many other aspects and was seen as a less important domain of successful treatment.

The sub-cluster of *person-centered treatment* was rated highest (4.49) of all sub-clusters for its importance to the concept of successful treatment with a cluster bridging value of 0.52. In this cluster, statement 60 *'.. the needs of the person with dementia are met'* scored highest of all statements (4.56). On the map, the sub-cluster of *person-centered treatment* was close to the well-being cluster, which implies that it is closely related to well-being of the person with dementia.

Cluster 3: Attitudes and skills of those involved

The third cluster comprised four sub-clusters: *7) consistent approach by the team, 8) understanding behavior by those involved not including other patients, 9) knowing how to respond to behavior by the those involved not including other patients,* and *10) open attitudes of those involved not including other patients.* The sub-cluster of *consistent approach by the team* was about the treatment by the nursing staff, while sub-clusters 8-10 were also important to others involved.

Discussion

To our knowledge, this is the first study to conceptualize domains of successful treatment of people with dementia and severe challenging behavior as perceived by experienced professionals. Three domains were identified: 1) *well-being* of the person with dementia and all people directly involved, including other patients; 2) *multidisciplinary analysis and treatment*; and 3) *attitudes and skills of those involved*. The first domain considers the treatment outcome, whereas the other two also consider the treatment process. The clusters concerning treatment process can be considered prerequisites to ensure the well-being of people with dementia and people directly involved such as relatives and nursing staff. Below we will discuss the domains and their interrelatedness in the light of what is already known from previous research.

Well-being of all involved

In line with earlier research among people with dementia and less severe challenging behavior we found that treatment is regarded successful when *well-being of the person with dementia* improves (Abraha et al., 2017; Dyer et al., 2018). Improvement of the behavior is part of this, but other aspects of well-being of the person with dementia are mentioned as part of successful treatment as well, such as feeling understood and having meaningful activities. Furthermore, we found that the improvement of the *well-being* of the people around the person with dementia, such as formal caregivers, family and other persons at the ward, is also part of successful treatment. This corresponds with the perspective of relationship-centered care where the caregiving is not only about the resident, formal and informal caregiver, but also about the well-being and needs of all professionals and residents involved (Nolan et al., 2004).

Treatment process

Also the identified domain *multidisciplinary analysis and treatment* with a *person-centered approach*, whereby the *reduction of psychotropic drugs* appears not to be a main priority, is in line with the clinical practice guidelines for the treatment of commonly occurring challenging behavior in dementia describing that the first focus should be placed on non-pharmacological approaches, such as the functional analysis-based approach (Azermai et al., 2012; Dyer et al., 2018; Moniz Cook et al., 2012).

Furthermore, again in line with earlier research in less severe challenging behavior, effective treatment is only deemed possible when *process conditions* such as having defined clear problem definitions, agreements and roles as a team, and an organization supporting and facilitating its professionals in providing the interventions needed are met. In an in-depth exploration of seven cases of extreme challenging behavior in nursing homes, suboptimal interdisciplinary cooperation and communication among nursing staff were found, which may worsen the severe challenging behavior (Veldwijk-Rouwenhorst et al., 2022). Although problems in the organizational support of professionals are known to indirectly lead to persistence of commonly occurring challenging behavior, this is often disregarded in clinical practice and research (Keenan et al., 2020; Rapaport et al., 2018; Visser et al., 2008). Therefore, this organizational support requires more attention in the treatment of challenging behavior in general and probably even more in the treatment of severe challenging behavior. Organizational support in providing treatment has also been shown to improve staff well-being and, with this, improve care; when nursing staff of general nursing homes felt appreciated and supported, they supported person-centered care that was consistently provided (Krein et al., 2022).

In the domain of *attitudes and skills*, the sub-cluster *knowing how to respond by those involved* is likely to result from the skills and knowledge in the other three sub-clusters. Indeed, increased perceived skills in managing behavioral and psychological symptoms of dementia have been found in nursing staff after education and peer support (Visser et al., 2008). Aspects of peer support such as communicative skills and self-awareness are especially found in the sub-cluster *consistent approach by the team.* These aspects are known to be essential within a nursing team (Berg et al., 1998; Younas et al., 2020). Developing self-awareness with insight into one's actions is part of the education of a nurse (Rasheed et al., 2019), but is not always addressed in the education of a nursing assistant. That the other sub-clusters include all involved is also in line with the principles of person-centered care (Nolan et al., 2004). Lastly, acquired knowledge and skills may reduce stress in caregivers (Bressan et al., 2020) and improve their well-being.

Strengths and limitations

This study has three main strengths. First, the participants were very experienced in the treatment and care of people with dementia and severe challenging behavior. Second, participants represented the different disciplines commonly involved in the treatment of people with dementia and severe challenging behavior. Third, the diversity and number of participants was sufficient for the concept mapping in all phases of data collection, adding more rigor to the concept map (Kane & Trochim, 2007).

This study has three main limitations. First, the online brainstorm has the disadvantage of less interactivity among participants than in a live group setting, which might have led to a lack of detail or specificity of some statements, especially clarifying the statements about psychotropic drugs and precising 'those involved', i.e., sometimes it was unclear whether the statement included the professional only or also the informal caregiver. Another disadvantage described for online brainstorming is a lower response rate (Kane & Trochim, 2007). However, our response rates for the data collection phases were comparable to other concept mapping studies, including live, online or hybrid data collections (Donnelly, 2017). We chose an online brainstorm based on its advantages such as involving no travel time, the ability to brainstorm with a larger group, the possibility to complete the brainstorm at participants' convenience during a given timeframe, and formulating this ideas in an environment surrounded by participants' own resources, thus increasing the depth of these contributions (Kane & Trochim, 2007). Given the advantages and disadvantages of an online brainstorm, a hybrid approach would probably be most optimal. Nevertheless, we think that our online

method did not influence the results in its essence, due to the large and diverse group of participants, and because the results were highly interpretable despite incongruences in a few statements. Second, we asked participation of experienced professionals according to our research question. Using this approach, we did not include the perspective of less experienced staff, people with dementia themselves, their relatives or other informal caregivers. We did not choose this for we wanted to focus on the perspective of experts as a first step in exploring the concept of successful treatment of severe challenging behavior, but we think including the perspective of other stakeholders might nuance our findings and even show what experts may overlook. Third, a relatively large group of participants did not start sorting or did not complete sorting according to instruction. One reason for this might be that sorting is a time-consuming and complex task, asking the participants to sort many statements according to their own ideas. Indeed, in concept mapping studies, the sorting task is often not completed (Hanzen et al., 2017; Iris et al., 2012).

Conclusion and implications

This concept mapping study provides a conceptual framework of the domains in the successful treatment of persons with dementia and severe challenging behavior. The themes underline that general knowledge about treatment of challenging behavior in persons with dementia is mainly applicable to our target group. Successful treatment of persons with dementia and severe challenging behavior focuses on improving the well-being of the person with dementia and those directly involved. Moreover, process conditions that are relevant in the treatment of commonly occurring behavior are shown to be very important in the treatment of severe challenging behavior. For the purpose of improving well-being of all, process conditions should be met, and the team should analyze and approach the severe challenging behavior in a skillful way. The latter is a huge effort due to the stress that severe challenging behavior evokes. Therefore, continuing attention to reflection and training as a team is needed. While constantly paying attention to process conditions, the development of attitudes, and a consistent approach are difficult to achieve in daily practice, unless they are prioritized, the stress for nursing staff and other persons involved will increase and the well-being of all will not be achieved.

Our framework can be used as a guide for further research and evaluation in clinical practice. The domains can be used as a guide in understanding and evaluating treatment. E.g., in the treatment of severe challenging behavior in dementia

one can use this framework to describe current treatment and gain insight in what aspects can be improved. Operationalizations should be developed or chosen for measuring some sub-domains such as well-being or knowing how to respond to behavior, because these domains and underlying statements are not directly measurable. In the future, the domains of successful treatment should be investigated in persons with dementia and severe challenging behavior and their proxies to enrich our findings, e.g., in involving relatives of persons with dementia and severe challenging behavior in a concept mapping study or asking them to enrich statements in the domains that mainly apply to them (well-being, and attitudes and skills of those involved).

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Supplementary materials

Supplementary Figure S1. Figure S1 represents the point map that results from two-dimensional nonmetric multidimensional scaling in the data analysis. Each point represents a statement as indicated with the statement number. It visualizes vicinity among the statements in a two-dimensional map.

Supplementary Table S1. Statements per subcluster - with average bridging values and average rating values for sub-clusters in cursive bold and with bridging values and average rating values per statement, cluster descriptions are based on the contents of the statements

		Bridging	Rating
1	**Well-being of the person with dementia**	**0.08**	**3.98**
1	the well-being of the person with dementia has increased.	0.03	4.54
3	the behavior of the person with dementia is stable.	0.14	3.15
4	the person behind the disease can be recognized as themselves again.	0.06	3.27
7	the person with dementia appears to be relaxed.	0	3.77
11	the person with dementia is no longer distressed by the behavior.	0	4.1
19	the person with dementia is no longer distressed by the reason for the behavior.	0.12	3.76
26	a person with dementia can be transferred to a regular long-stay ward.	0.4	2.76
29	there is dignified existence.	0.01	4.5
45	the person with dementia has meaningful daytime activities.	0.09	3.85
61	the person with dementia is allowed to be themself.	0.09	4.37
65	it results in more peace and comfort for the person with dementia.	0.02	4.14
66	optimal functioning has been achieved for the person with dementia and the people around them.	0.08	4.24
72	the person with dementia suffers less.	0.04	4.47
81	the person with dementia experiences positive contact with other people on a daily basis.	0.04	4.08
82	the person with dementia feels understood.	0.03	4.47
86	the person with dementia and their relatives can enjoy life again at certain moments.	0.13	4.19
2	**Well-being of all people directly involved**	**0.38**	**3.89**
6	behavior is manageable for everyone involved.	0.32	4.06
13	the situation is tolerable and bearable for caregivers and relatives.	0.36	4.24
22	people around the patient are no longer affected by the problem behavior.	0.37	3.45
28	all people involved feel understood.	0.46	3.79
39	problem behavior has decreased.	0.33	3.98
43	the effect of challenging behavior on everyone has decreased.	0.35	3.84
52	there is less despair among relatives and professionals.	0.45	4.08
59	those involved experience better contact with the person with dementia.	0.4	3.98
63	behavior is acceptable to all involved.	0.35	3.65
71	the team and relatives experience a sense of control and influence over the behavior.	0.34	3.74
78	the behavior no longer causes unsafe situations.	0.35	4
83	people around the person with dementia suffer less.	0.49	3.9
84	the behavior can be accepted.	0.36	3.73

Supplementary Table S1. Continued

		Bridging	Rating
90	the well-being of all those directly involved has increased.	0.43	3.98
3 Multidisciplinary analysis		**0.48**	**4.17**
2	the following aspects have been identified: personal factors (psychological, life history, physical), social factors (people around the person with dementia, relatives) and environmental factors (physical environment, daily structure).	0.54	4.37
23	all relevant aspects associated with the problem behavior have been thoroughly examined from different angles.	0.4	4.33
32	the reason has been well investigated: at what times does someone show the behavior and when not? It does not come out of the blue as often as the team or family perceive.	0.41	4.33
33	a multidisciplinary approach is used to analyze the problem, determine the treatment goal, choose the interventions and adjust them as necessary.	0.42	4.52
37	a proper analysis is performed in a multidisciplinary manner, in which the relatives have an emphatic role.	0.51	4.13
51	the analysis examines the yields of the problem behavior: for instance, people with vocalizations are usually rewarded more than those who are quietly present.	0.45	3.79
74	we find a physical cause and can treat it.	0.7	3.69
80	the analysis examines when someone does not show the behavior and what this means.	0.42	4.23
4 Process conditions		**0.6**	**4.17**
21	one has an understanding of the underlying needs of the person with dementia.	0.54	4.52
24	professionals can draw up concrete goals and actions.	0.5	3.88
31	it is clear how challenging behavior is defined and for whom this behavior is a problem.	0.44	4.14
35[a]	the organization supports, guides and facilitates the professionals involved in the appropriate manner to carry out the desired interventions.	0.96	4.55
53	the correct interventions have been initiated according to the guideline.	0.58	3.44
64	there is knowledge and expertise as regards the origin of the behavior.	0.44	4.35
68	challenging behavior is not ignored but "heard" and "answered" by considering the cause.	0.45	4.19
69	those directly involved have a clear role in the overall situation.	0.79	3.96
75	relatives are included and involved throughout the treatment process.	0.89	4.25
87	challenging behavior is seen as dynamic, with useful interventions being repeatedly sought whenever possible or necessary.	0.46	4.39
5 Reduction in psychotropic drugs		**0.86**	**3.67**
17	the focus is on behavioral interventions supported by psychotropic drugs if necessary, but as little as possible.	0.72	3.88

Supplementary Table S1. Continued

		Bridging	Rating
85	the psychotropic drugs have been permanently discontinued.	1	2.45
91	it is regularly evaluated whether psychotropic drugs can be phased out.	0.93	3.94
92	the life history of a person with dementia is considered. Who were they? What experiences have they had?	0.78	4.38
6 Person-centered treatment		**0.52**	**4.49**
47	commitment and treatment do justice to the person with dementia and those around them.	0.57	4.33
48	the individuality of the person with dementia is taken into account.	0.55	4.52
60	the needs of the person with dementia are met.	0.44	4.56
79	when the dignity of the person with dementia is seen: it is an adult with a life behind them with a need for control, however small.	0.51	4.54
7 Consistent approach by the team		**0.27**	**4.3**
5	the team members are adequately trained.	0.32	4.42
16	the team can apply acquired knowledge in comparable situations.	0.29	4.27
18	the directly involved team members in a group situation know how to direct others around the person with dementia.	0.29	3.83
25	the team and relatives understand what the person with dementia can still do (e.g. respond to emotions or react impulsively).	0.24	4.17
38	the team is on the same wavelength so that the support can be applied unambiguously and consistently.	0.29	4.42
41	the team and relatives understand that challenging behavior emerges from inability rather than unwillingness.	0.22	4.29
55	the team communicates well about the behavioral approach.	0.28	4.4
56	the team can adapt the behavioral approach to the behavior of the person with dementia.	0.24	4.48
76	the team realizes that there is no fixed format for changing behavior but that it often requires a change of behavior on the part of the team.	0.25	4.42
8 Understanding behavior by those involved not including other patients		**0.32**	**4.17**
8	the team and relatives understand what causes the behavior.	0.28	4.29
9	the care team and relatives make joint efforts.	0.5	3.96
20	staff understand that problem behavior is often caused by anxiety in the person with dementia.	0.28	4.02
27	professionals and relatives see the behavior coming and can intervene earlier to prevent escalation.	0.31	4.4
46	the following question is considered: 'What meaning do I allocate to the behavior and thereby to my own actions?'	0.33	4.15
49	it is mainly about understanding behavior rather than controlling it.	0.31	4.24
58	the team is familiar with the forms of dementia commonly associated with challenging behavior (such as FTD and Lewy Body Dementia).	0.25	4.02
73	the team and relatives have an idea of the cause of the behavior.	0.32	4.19

Supplementary Table S1. Continued

		Bridging	Rating
88	the team realizes the role of personal values and is prepared to explore these in relation to the behavior of the person with dementia.	0.28	4.24
9	**Knowing how to respond to behavior by those involved not including other patients**	**0.29**	**4.06**
10	this behavior has been dealt with differently so that the challenging behavior has become common behavior.	0.28	3.83
12	all those involved feel that we have tried everything.	0.23	3.47
14	people feel that they know how best to support the person.	0.28	4.23
30	those involved have tools for ways to deal with the behavior.	0.26	4.4
36	the reaction toward the person with dementia is more sensitive.	0.47	3.92
40	the team's approach brings a visible change in behavior, even if it is for brief moments.	0.29	4.17
42	all those involved can tailor sensory stimuli to the person with dementia.	0.26	4.18
57	all those involved know how to influence the factors that may affect challenging behavior.	0.23	4.24
62	the challenging behavior can be prevented.	0.38	3.92
67	the emphasis is placed on whatever goes well rather than what has failed: celebrate your successes.	0.26	3.98
70	it can be acknowledged that sometimes the behavior does not improve, despite all efforts.	0.32	3.92
89	the powerlessness of professionals in dealing with the challenging behavior gives way to self-confidence and appropriate action.	0.25	4.33
93	all those involved have gained an understanding of what is needed.	0.23	4.21
10	**Open attitudes of those involved not including other patients**	**0.36**	**4.22**
15	people directly around the person with dementia are sufficiently skilled in tailoring their (re)actions to the person with dementia.	0.44	4.33
34	people directly around the person with dementia know what he or she needs to feel safe and secure.	0.39	4.37
44	those involved can look at behavior with an open mind without immediately seeing this as challenging behavior.	0.29	4.17
50	people around the person with dementia are aware that human beings' strong emotions are not wrong or have to go away as quickly as possible, but rather are part of being human.	0.35	4.04
54	the team and relatives can see all behavior as a way of communicating about unease or well-being.	0.34	4.12
77	all those involved know how to provide the person with dementia support.	0.37	4.27

[a] This statement was originally placed in sub-cluster 4 'Multidisciplinary analysis', but this was arbitrary (indicated by the high bridging value and the location) and was moved to sub-cluster 5 'Process conditions' based on its content.

Chapter 4. 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.

Methods: In this observational study, eleven 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 two 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.

Keywords: 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; Majer et al., 2020; Svendsboe et al., 2016; van Duinen-van den et al., 2018; 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 (Selbaek 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; Veldwijk-Rouwenhorst et al., 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., 2023). 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 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 Netherlands, people with dementia can be admitted to these units when residence in a regular dementia special care unit (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 (Nichols et al., 2022; van Bussel et al., 2017). Second, the number of inpatient psychiatric beds within the Dutch mental health care sector has been systematically reduced over recent years (Kroon, 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 two 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 fifteen identified units, eleven 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 two 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.

CMAI

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 non-aggressive behavior, and verbally agitated behavior (Zuidema et al., 2007).

NPI-Q

The Dutch version of the Neuropsychiatric Inventory Questionnaire (NPI-Q) was also used (de Jonghe et al., 2003). De NPI-Q includes twelve 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 eleven participating units (range: 7-28 beds), one unit withdrew participation after two inclusions due to organizational problems, and one unit started one year later. The median participation rate of all admitted patients was 30% (range: 4% to 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).

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 unit [b]	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 admission [d]	4.0 (2.0-6.3)

Table 1. Continued

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] 2 missing in psychiatric history and chronic somatic disorders
[d] 13 missing in non-psychotropic drug use

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.

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

Psychotropic drug use [a]	**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 CMAI [b]	**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 non-aggressive, 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 non-aggressive, range: 0-6 items	4.0 (2.0-5.0)
Verbally agitated, range: 0-5 items	3.0 (1.0-4.0)

Table 2. Continued

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 non-aggressive, 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] 13 missing in psychotropic drug use
[b] 15 missing in CMAI

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).

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

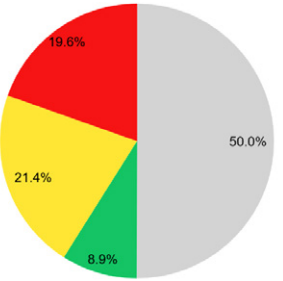
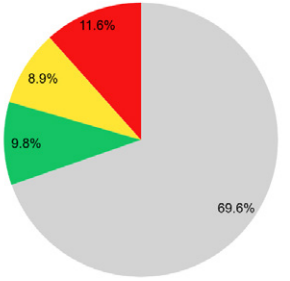
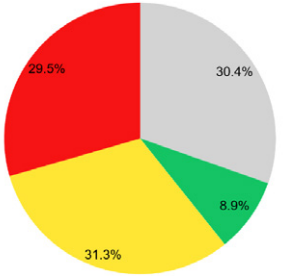
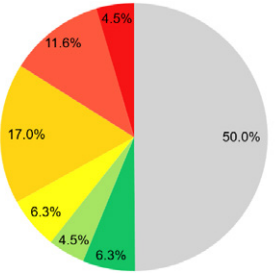
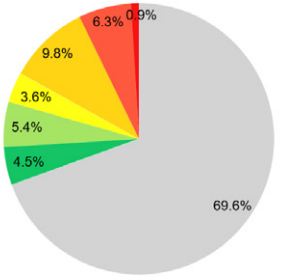
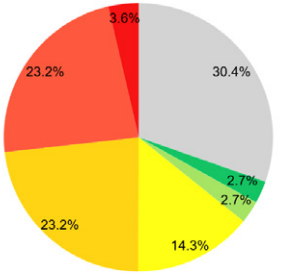
Symptoms		Delusions	Hallucinations	Agitation
Severity	Not present Mild Moderate Severe			
Emotional distress	Not present Not distressing at all Minimal Mild Moderate Severe Extreme or very severe			

Table 3. Continued

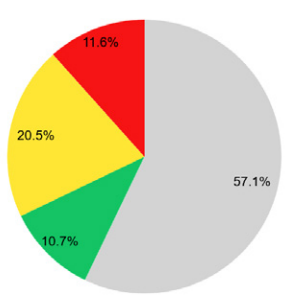
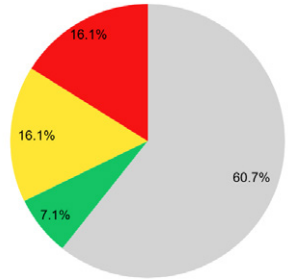
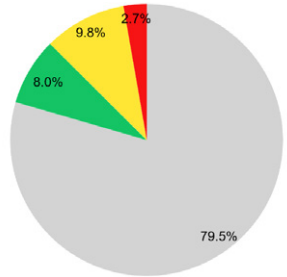
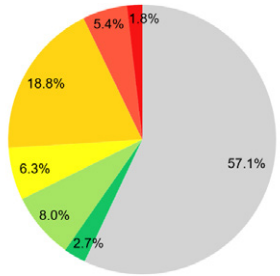
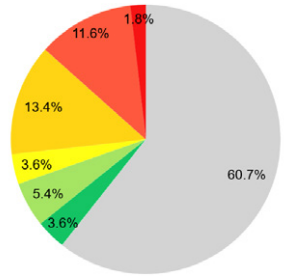
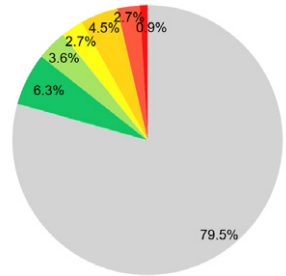
Symptoms		Depression/dysphoria	Anxiety	Euphoria/elation
Severity	Not present Mild Moderate Severe			
Emotional distress	Not present Not distressing at all Minimal Mild Moderate Severe Extreme or very severe			

Table 3. Continued

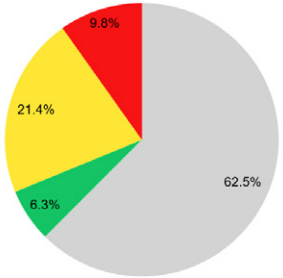
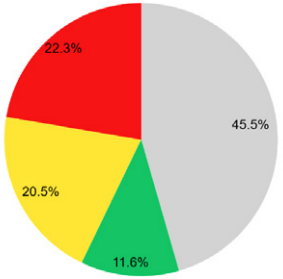
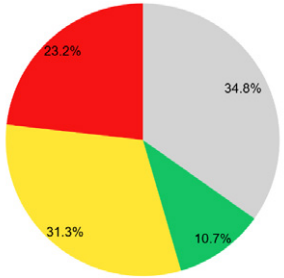
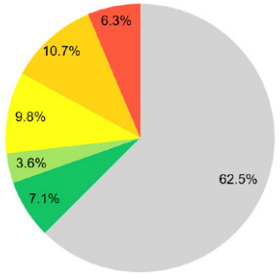
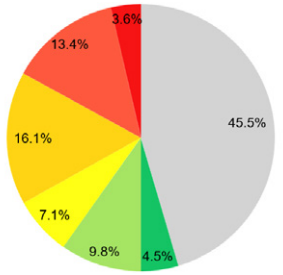
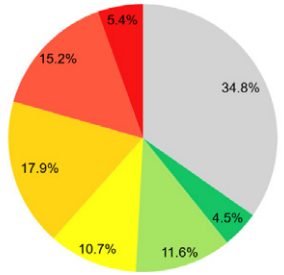
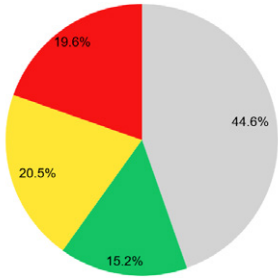
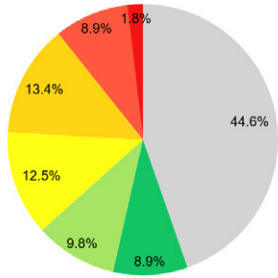
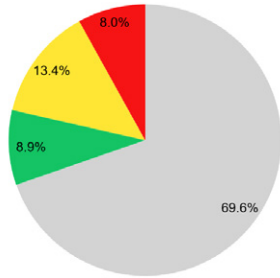
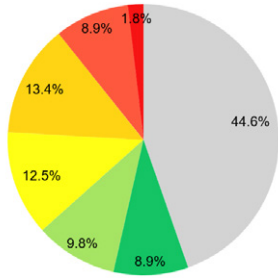
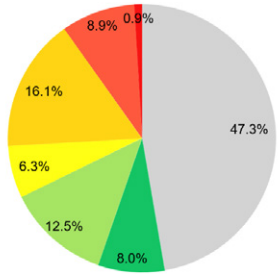
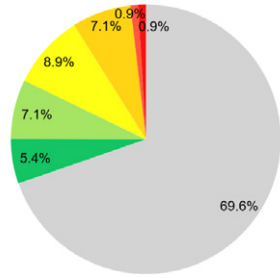
Symptoms		Apathy/indifference	Disinhibition	Irritability
Severity	Not present Mild Moderate Severe			
Emotional distress	Not present Not distressing at all Minimal Mild Moderate Severe Extreme or very severe			

Table 3. Continued

Symptoms		Aberrant motor behavior	Nighttime behaviors	Appetite/eating change
Severity	Not present Mild Moderate Severe			
Emotional distress	Not present Not distressing at all Minimal Mild Moderate Severe Extreme or very severe			

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

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.

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 discharge [b]	**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 <0,05) was found: patients who died were significantly older.

[d] Two missing discharge dates

Discussion

This is the first study to describe the characteristics and discharge locations of patients admitted to highly specialized units 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 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., 2023). 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 towards the behavior (van Voorden et al., 2023) and more suitable attitudes towards 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 (Selbaek 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).

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, i.e. 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, i.e. 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).

Acknowledgments

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Supplementary materials

Table S1. Unit size, number of participants per unit and percentage of participation of all admissions

Unit ID	Unit size	Number of participants	Percentage of participation
01 [a, b]	8	3	60%
02 [a, c]	17	9	4%
04	19	18	44%
05 [a, d]	28	2	5%
06	12	11	69%
07 [a, e]	12	6	14%
08 [a, e]	11	9	19%
09 [a]	28 [g]	26	55%
10 [a, f]	14	13	13%
11	7	18	78%
12 [a]	7	12	30%

[a] Participation was not registered (reliably) by the treating physician. This data were obtained from the manager instead, therefore discerning between nonparticipants who were non-eligible and those eligible with no consent is not possible here.

[b] Participated from January through December 2022.

Underlined are the units with reasons for a low participation rate:

[c] Also another patient group: cognitive and/or behavioral diagnostics.

[d] Organizational problems arose after the study began and further actual participation was not possible.

[e] No inclusions in the last year, but no formal termination by the unit.

[f] Organizational problems arose especially in staffing of the nursing staff. Unit was merged with unit 06 at that location with remaining staff after the end of the study due to these problems.

[g] Average of unit size before and after relocation (24 before and 32 after, relocation was in December 2021 and January 2022).

Chapter 5. Determinants of mortality and causes of death in patients with dementia and very severe challenging behavior

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Abstract

Objectives: To gain insight into the mortality over time of patients with very severe challenging behavior in dementia when they are temporarily admitted to highly specialized units for treating the behavior.

Design: Observational study.

Setting and Participants: Eleven highly specialized units throughout the Netherlands participated from December 2020 until December 2022, with a follow-up in September 2023, with 127 patients participating.

Methods: General clinical characteristics were collected, such as demographics and cognitive functioning, behavior during the first two weeks assessed by the Cohen-Mansfield Agitation Inventory (CMAI) and the Neuropsychiatric Inventory Questionnaire (NPI-Q), date of death, and cause of death. Two Cox regression models were estimated, namely prediction models to describe the relationship between some (regular) determinants and mortality over time and association models between behavioral factors and mortality.

Results: Of the 127 participants, one-third died during their stay. The most prevalent causes of death were dehydration (often with cachexia) and pneumonia. Mortality over time is best predicted by age – i.e. being 80 years old or over – and the number of non-psychotropic drugs, as a proxy for somatic disease burden. The 10% of patients scoring highest on the CMAI factor of physically aggressive behavior had a ninefold increased mortality risk during their stay.

Conclusions and Implications: A considerable number of patients with very severe challenging behavior in dementia admitted to highly specialized units died during their stay, with a ninefold increased mortality risk over time found in patients with very severe physical aggression. This underlines the need to devote attention to suitable terminal palliative care in clinical practice and research in this patient group.

Keywords: Behavioral and psychological symptoms of dementia (BPSD), neuropsychiatric symptoms, agitation, mortality, dementia

Introduction

Dementia significantly shortens life expectancies (Liang et al., 2021). In persons with dementia living in nursing homes, the most common causes of death are drinking and/or eating problems and pneumonia, with most deaths occurring in severe dementia stages before the final stage(Aworinde et al., 2018; Hendriks et al., 2017; Koopmans et al., 2007). Commonly reported causes of death for persons with dementia are respiratory- or circulatory-related problems (Romero et al., 2014). Determinants of mortality in persons with dementia include higher age, male sex, chronic somatic conditions, increased drug use, dementia type, more severe dementia stages, delirium, and psychiatric history (Connors et al., 2016; Garcia-Ptacek et al., 2014; Golüke et al., 2020; Haaksma et al., 2020; Hapca et al., 2018; Kisely et al., 2005; Ono et al., 2023). Interestingly, challenging behavior has also been associated with higher mortality rates when assessed by the neuropsychiatric inventory (NPI) (Bränsvik et al., 2021; Connors et al., 2016; Peters et al., 2015).

In the Netherlands, highly specialized units for the temporary treatment of patients with dementia and very severe challenging behavior have been established in the last decade. These units were developed for situations where care and treatment in a regular dementia special care unit (DSCU) are no longer possible due to the behavior's severity or danger (van Voorden et al., 2024). There is some variation in the allowance of the number of patients with severe physical aggression and alcohol dependency (van Voorden et al., 2024). These units are organized within a long-term care organization, i.e. an organization with nursing home facilities, a mental health care organization, and sometimes a collaboration of both. The median length of stay in these units was five months (van Voorden et al., 2024). Since these units are relatively new, they are pioneering in their organization and treatment. Similarities among specialized units include observation with an open attitude, the key role of nursing staff, frequent multidisciplinary meetings, and attention to sensory stimuli (van Voorden et al., 2024). Comparable units also exist in Australia and the United Kingdom, albeit with different organization and reimbursement most likely due to differences in health policies (Gresham et al., 2021; Jones et al., 2023; Koopmans et al., 2022).

Very severe challenging behavior is more commonly found in persons in more severe dementia stages (Palm et al., 2018; Veldwijk-Rouwenhorst et al., 2017). and knowledge about mortality in persons with dementia and very severe challenging behavior is scarce. In recent research, a sevenfold higher one-year mortality risk was found among patients with dementia and severe aggression incidents within the

first 48 hours of a stay in a specialized psychogeriatric ward in a psychiatric hospital (Van den Bulcke et al., 2024). The context of these highly specialized units offers a unique opportunity to investigate the characteristics of persons with dementia and very severe challenging behavior. Most studies in persons with dementia and challenging behavior include persons among the general population. For severe challenging behavior, scores on a measurement scale – for instance, severity of neuropsychiatric symptoms (Palm et al., 2018) or frequency of agitation (Veldwijk-Rouwenhorst et al., 2017) – are typically used rather than a clinically relevant event such as admission to these highly specialized units.

This study aims to: 1) gain more insights into causes of death in patients with dementia and very severe challenging behavior; 2) explore the previously identified determinants of mortality in dementia during a stay in a highly specialized unit; and 3) explore the association between specific subtypes of very severe challenging behavior and mortality during a stay. We hypothesized that the severity of challenging behavior adds to the predictive value of previously known determinants of mortality in dementia, i.e. higher age, male sex, chronic somatic conditions, delirium, and psychiatric history (Connors et al., 2016; Garcia-Ptacek et al., 2014; Golüke et al., 2020; Haaksma et al., 2020; Hapca et al., 2018; Kisely et al., 2005).

Methods

Study design

Design

This observational study followed patients from admission to a highly specialized unit until discharge or death. For newly admitted participants, demographics, clinical characteristics, behavior during the first two weeks of stay, and details about discharge or death – including causes of death – were collected. The study took place from December 2020 to December 2022 with a follow-up nine months after the study (September 2023). A more detailed description can be found in our paper describing patient characteristics at admission (van Voorden et al., 2025).

Setting

Fifteen units treating patients with dementia and very severe challenging behavior were asked to participate, recruited within the six academic networks of long-term care (Koopmans et al., 2013) and through the network of these highly specialized units (Koopmans et al., 2022). Eleven of the fifteen identified units consented to participate, located throughout the Netherlands. We included *"units where*

patients with dementia and challenging behavior can stay temporarily for diagnosis and treatment". In one unit both patients with dementia and severe challenging behavior and those with cognitive or geriatric psychiatric problems could be admitted. Unit sizes ranged from 7 to 28 places. Seven units were part of a long-term care organization, two were part of a mental health care organization, and two were a cooperation of a long-term care and a mental health care organization.

Participants

Newly admitted patients were eligible if they had 1) dementia or suspected dementia, and 2) very severe challenging behavior, defined according to the Dutch guideline as severe verbal or physical aggression, agitation, and/or vocally disruptive behavior *"associated with suffering or danger to the person or people in his or her environment"* (Zuidema et al., 2018). Exclusion criteria were 1) having acquired a brain injury without (suspected) dementia, and 2) having a life expectancy of less than two weeks. The treating physician considered the eligibility criteria after having received an instruction. This physician was instructed to register all patients admitted to the unit during the study to gain insights into the participation rate and could consult the research team in case of doubt. We aimed to secure 200 participants to include approximately four variables in the models with an expectation of 40 events, i.e. we expected 20% mortality based on a study describing organizational characteristic of highly specialized units and using the rule of thumb of one variable per ten events (Ogundimu et al., 2016; van Voorden et al., 2024).

Data collection and sources

Data were collected at admission, after two weeks, and at discharge or after death. A follow-up about discharge or death was undertaken nine months after the study (see below). The treating physician provided details about demographics, presence of a delirium, medical history, (psychotropic) drug use, and cognitive functioning at admission. Demographics, medical history including dementia type and psychiatric diagnoses, and drug use at admission were extracted from medical files, while delirium and cognitive functioning at admission were based on physician assessments (see below). Castor EDC (https://www.castoredc.com/) was used for data management.

Two weeks after admission, a nursing staff member who was substantially involved in the patient's care during these weeks completed a digital questionnaire with validated assessment scales for challenging behavior (see below). They completed the questionnaires based on their own observations, and reports from other

nursing staff members in the nursing files. A staff member provided details about the discharge date and location or death during the stay. For participants who died during their stay, the physician completed a questionnaire about the cause of death.

A follow-up was undertaken nine months after the end of the study (September 2023), during which the physician completed questions about the discharge date and location, or the cause of death for participants who had not yet been discharged from the unit at the end of the original study in December 2022.

Assessments

The physician assessed the presence or possible presence of delirium at admission according to the diagnostic criteria for delirium from the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), registered as present, possibly present, or not present.(American Psychiatric Association, 2013) Regular drug use was classified using the Anatomical Therapeutical Chemical classification,(WHO Collaborating Centre for Drug Statistics Methodology, 2022) categorized into non-psychotropic and psychotropic drugs, i.e. anticonvulsants, antipsychotics, anxiolytic drugs, hypnotics and sedatives, antidepressants, and anti-dementia drugs. The physician assessed the severity of cognitive functioning at admission using the Global Deterioration Scale, ranging from no cognitive decline (stage 1) to very severe decline (stage 7) (Reisberg et al., 1982). Immediate causes of death were registered with the same open-ended question as used in the Dutch death certificate, and these conditions were categorized by the authors AV and GV.

CMAI

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 strong reliability among persons with Alzheimer's dementia (Koss et al., 1997) and older persons admitted to a geriatric psychiatry ward (de Jonghe & Kat, 1996). Content validity was demonstrated to be good (de Jonghe & Kat, 1996; Miller et al., 1995). For the CMAI, physically aggressive behavior, physically non-aggressive behavior, and verbally agitated behavior can be calculated (Zuidema et al., 2007). Item scores are summed to calculate a total score for each factor.

NPI-Q

The NPI-Q includes twelve 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 for the patient is rated on a three-point (1–3) Likert scale ranging from 'mild' to 'severe.' The emotional distress for the nursing staff member was rated 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 reliability, internal consistency in hospitalized older adults (Resnick et al., 2023), and its content validity has been found to be reasonable in persons with dementia (de Jonghe et al., 2003). We used four factor scores in our analysis: psychosis, comprising delusions and hallucinations; hyperactivity, comprising agitation, disinhibition and irritability; affect, comprising depression/dysphoria and anxiety; and apathy, comprising apathy, nighttime behaviors, and appetite/eating change. These were based on previous research with other versions of the Neuropsychiatric Inventory (NPI), i.e. the NPI and NPI-NH (Nursing Home) (Kang et al., 2010; van der Linde et al., 2014; Zuidema et al., 2011). We used the total severity scores of each item as factor scores, summed from the item severity scores.

Statistical methods

We used descriptive statistics to describe the patient characteristics, causes of death, and behavioral factors. Statistical package SPSS (version 29) was used for the analyses. Missing data for the behavioral assessment scales (n=15=11.8%) were regarded as missing at random because they were distributed among ten units and mostly due to late registration. Missing data in psychiatric history (n=2=1.6%) and (non-)psychotropic drug use (n=13=10.2%) were regarded as missing at random because they were distributed over two and eight units, respectively. For psychiatric history, the mode – no psychiatry history – was imputed and single imputation by linear interpolation was used for drug use. After imputation for both non-psychotropic and psychotropic drug use, paired t-tests compared the variables with and without imputation, with no significant differences found. We did not impute for the behavioral factors – i.e. the central determinants of the association models – since we found outliers where imputation would lead to unreliable results. Therefore, association models were based on the 112 participants with no missing data on behavioral assessments.

Prediction of mortality

When building a prediction model for mortality during stay, we selected a set of covariates that together might best predict mortality over time. We selected age, sex, (possible) presence of delirium, psychiatric history, psychotropic drug use, and non-psychotropic drug use as independent variables and used non-psychotropic drug use as a proxy for somatic disease burden. Psychiatric history was registered as a dichotomous variable – i.e. present or not present – based on the medical

history. Drug use was registered as the number of regularly used non-psychotropic and psychotropic drugs at admission. The outcome was mortality over time during stay. Variables used were events (death or censored) and time to event in days. Patients who were alive at the end of their stay or follow-up were considered censored. Considering the relatively large number of determinants compared to the number of events (Ogundimu et al., 2016) – i.e. deaths – we first checked all univariable associations with mortality. In the case of a non-linear relationship, determinants were either transformed or categorized, representing clinically meaningful categories. This applied to age (dichotomized in under and over 80 years) and psychotropic drug use (dichotomized in two drugs and more and less than two drugs). The proportional hazard assumption was checked by the Kaplan-Meier curves and log-minus-log plots since interpretating Kaplan-Meier curves is partly subjective and might be misleading when sample sizes are small or censoring is high, while the more formal log-minus-log plots might lead to noise due to sparse events and perform poorly at extreme time points (early and late) (Twisk, 2016). Subsequently, we used a backward elimination procedure to select a set of covariates that best predict death. We performed two sensitivity analyses, with one model restricted to participants with Alzheimer's dementia and one without imputed data. Finally, we internally validated our model with a bootstrap procedure.

Explorative association between behavior and mortality

Subsequently, we examined the association between behavioral characteristics (CMAI, NPI-Q) and mortality adjusted for the determinants of mortality during stay as used in the prediction model in our sample. We planned to categorize characteristics in case of non-linear associations based on the assumption of clinical relevance for extreme scores. Based on explorative models for the non-linear CMAI factors, we dichotomized between the highest quartile and the other three quartiles. Sensitivity analyses were performed by dichotomizing between the top 10% and the lower 90% based on our interest in the most severe behavior. For the NPI factors, we chose clinically interpretable cutoffs based on the distribution of the answers and the distribution of the hazard ratios with the scores. We planned a sensitivity analysis restricted to participants without delirium, considering its impact on behavior. Finally, we tested for multicollinearity in these models using variance inflation factors.

This study is reported following the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines (von Elm et al., 2008) (for details, see Supplementary materials Table S1).

Ethics statement

The study was conducted in accordance with the Declaration of Helsinki, as well as the rules applicable in the Netherlands. The local Medical Ethics Review Committee of CMO region Arnhem-Nijmegen located at Radboud University Medical Center rated the study and stated that the Medical Research Involving Human Subjects Act (WMO) does not apply to this study and their official approval is not required (reference number 2020-6979). Informed consent was obtained by the treating physician, who considered the patients' capacity to consent to participation in the study. Written informed consent was obtained from participants with full capacity to consent or from the legal representative of those participants with reduced capacity to consent.

Results

Of the eleven participating units, one unit started one year later and one withdrew consent after two inclusions due to organizational problems. The median participation rate was 30% (ranging from 4% to 78%; for details, see Supplementary materials Table S1 in the former Chapter 4).

Patient characteristics and length of stay

One hundred and twenty-seven patients participated in this study. Two-thirds of the participants were male, about four in ten had Alzheimer's dementia, and about nine in ten had moderately severe or severe cognitive decline. Over half of the participants were discharged, and about one-third died during their stay. One participant was lost to follow-up due to the legal representative withdrawing their consent. The median length of stay was 122 days for discharged patients and 84 days for deceased patients. The most common causes of death were dehydration and cachexia (42.1%) and pneumonia (15.8%; see Table 1).

Table 1. Patient characteristics, behavior and follow-up (n=127) [a]

Determinants in prediction model	
Age	78.5 years (SD 8.8)
Sex, male	86 (67.7 %)
Delirium at admission, yes or possibly	17 (13.4%)
Psychiatric history [b]	41 (32.3%)
No. of non-psychotropic drugs [c]	Median 4.6 (IQR 2.0-6.3)
No. of psychotropic drugs [c]	Median 2.0 (IQR 1.0-3.0)

Table 1. Continued

Dementia type	**n (%)**
Suspected dementia	5 (3.9%)
Alzheimer's dementia	54 (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 dementia	2 (1.6%)
Not specified	12 (9.4%)
Severity of cognitive decline (GDS) [d]	**n (%)**
Stage 2-4 (very mild through moderate)	10 (7.9%)
Stage 5 (moderately severe)	50 (39.4%)
Stage 6 (severe)	61 (48%)
Stage 7 (very severe)	5 (3.9%)
Factor scores behavior [e]	
Factors CMAI	**n (%)**
Physically aggressive, highest quartile = 20.8 and over (range 9-63) [f]	28 (25.0%)
Physically aggressive, highest 10% = 29.0 and over (range 9-63)	10 (8.9%)
Physically non-aggressive, highest quartile = 26.0 and over (range 6-42)	30 (26.8%)
Physically non-aggressive, highest 10% = 31.0 and over (range 6-42)	9 (8.0%)
Verbally agitated (range 5-35)	Median 13.6 (IQR 9.0;21.0)
NPI-Q factors	**n (%)**
Psychosis, severity score 1-2, severity score 3-6 (range 0-6)	Severity score 1-2: 34 (30.4%) Severity score 3-6: 36 (32.1%)
Hyperactivity, severity score 1-4, severity score 5-9 (range 0-9)	Severity score 1-4: 36 (32.1%) Severity score 5-9: 56 (50.0%)
Affect, one or more symptoms/severity (range 0-6)	67 (59.8%)
Apathy, one or more symptoms/severity (range 0-9)	85 (75.9%)
Discharge and mortality	**n (%)**
Discharge	71 (55.9%)
No discharge yet at follow-up	15 (12.6%)
Mortality	40 (31.5%)

Table 1. Continued

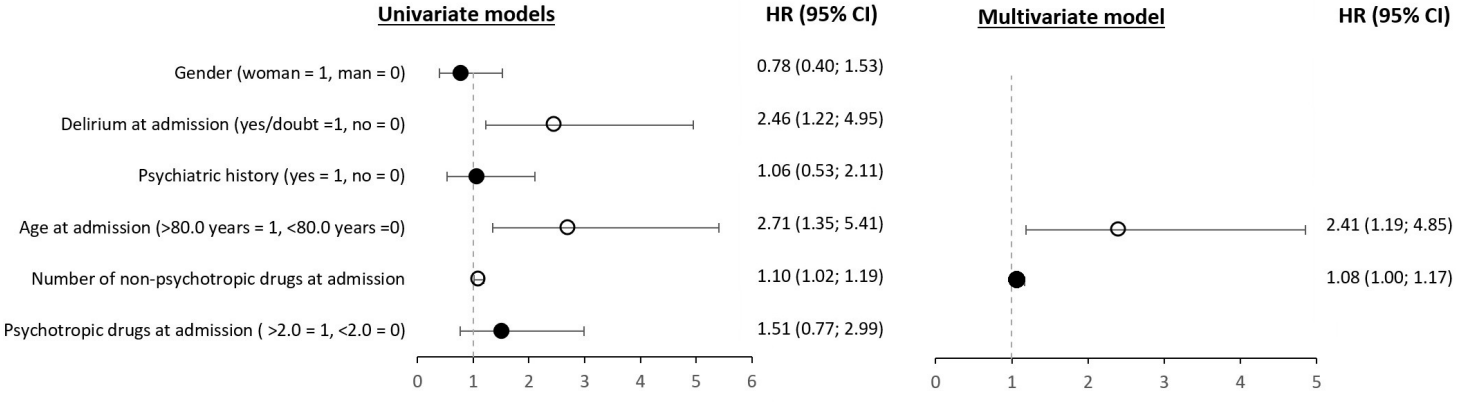
Length of stay [g]	**Median (IQR)**
Discharged patients (n=69) [h]	122 days (59; 224)
Not yet discharged (n=15)	493 days (412; 616)
Deceased patients (n=40)	84 days (57; 195)
Immediate causes of death (n=38) [b]	**n (%)**
Dehydration often (n=16) with cachexia	18 (47.4%)
Pneumonia	6 (15.8%)
Unknown cause of mortality	4 (10.5%)
COVID-19	2 (5.3%)
Gastrointestinal hemorrhage	2 (5.3%)
Other [i]	6 (15.8%)

IQR interquartile range
[a] Overall 6.0% missing of all variables
[b] 2 missing (1.6%)
[c] 13 missing (10.2%)
[d] 1 stage 5 or 6
[e] 15 missing (11.8%)
[f] contains 5 outliers
[g] 1 unknown due to withdrawn consent
[h] 2 missing discharge dates (1.6%)
[i] anemia, cardiac arrest, cardiac asthma, ileus, sepsis, status epilepticus

Prediction mortality over time with regular determinants

Age, the (possible) presence of delirium, and the number of non-psychotropic drugs were statistically significant associated with mortality over time in days during stay in univariable analyses (see Figure 1). The Kaplan-Meier curves did not cross in the latter categorical variables and the log-minus-log plots ran parallel, indicating no violation of the proportional hazards assumption (see Supplementary materials 2). In the multivariable model, age (p-value 0.014) and non-psychotropic drug use (p-value 0.058) best predicted mortality over time (see Figure 1). In sensitivity analysis for Alzheimer's dementia only (n=53), no significant variable was left although the build-up was similar, i.e. the penultimate step showed a similar model with similar effect sizes. For the multivariable model, sensitivity analysis without imputation (n=113) provided similar results. In a bootstrap procedure, a similar model was found with a comparable level of significance (p-value 0.013 for age, and 0.038 for non-psychotropic drugs).

Figure 1. Univariable and multivariable prediction models



HR Hazard ratio
CI = Confidence interval
● = non-significant
○ = significant

Association of behavior with mortality over time

For the participants with the 10% highest scores in the physically aggressive factor of the CMAI, we found approximately a fourfold increased hazard ratio of mortality (4.24, CI 1.91; 9.40). When adjusted for age, delirium, number of somatic drugs, gender, psychiatric history, and psychotropic drug, this increased to a ninefold higher risk (9.18, CI 3.58; 23.52). For the NPI factor of apathy, we found an unadjusted threefold higher hazard ratio of mortality (3.07, CI 1.08; 8,67), which became non-significant when adjusted (2.52, CI 0.85; 7.44). For the other factors, no significant relationship was found (see Table 2). We found no signs of multicollinearity in any of the models (all variance inflation factors <1.18).

Table 2. Association of behavioral factors with mortality over time (n=112) [a]

	Unadjusted		Adjusted [b]	
CMAI factors	**HR (95% CI)**	**p-value**	**HR (95% CI)**	**p-value**
Physically aggressive (highest quartile = 1, lowest three quartiles = 0)	1.54 (0.79; 3.00)	0.205	1.42 (0.69; 2.93)	0.347
Physically aggressive (highest 10% percent =1, other 90% = 0)	**4.24 (1.91; 9.40)**	**<0.001**	**9.18 (3.58; 23.52)**	**<0.001**
Physically non-aggressive (highest quartile = 1, lowest three quartiles = 0)	0.74 (0.34; 1.57)	0.425	0.90 (0.41;1.99)	0.794
Physically non-aggressive (highest 10% =1, other 90% = 0)	1.35 (0.41; 4.44)	0.617	2.25 (0.63; 7.99)	0.211
Verbally agitated (range 5-35)	1.01 (0.97; 1.05)	0.556	1.01 (0.97; 1.06)	0.585
NPI-Q factors				
Psychosis (no symptoms = 0, severity score 1-2 = 1, severity score = 3-6 = 2)	1.03 (0.44; 2.38) 1.48 (0.69; 3.18)	0.951 0.309	1.05 (0.44; 2.49) 1.9 (0.56; 2.95)	0.919 0.545
Hyperactivity (no symptoms = 0, severity score 1-4 = 1, severity score 5-9 = 2)	0.74 (0.25; 2.20) 1.33 (0.54; 3.26)	0.582 0.540	0.88 (0.28; 2.73) 1.67 (0.67; 4.16)	0.824 0.276
Affect (no symptoms = 0, severity score 1-6 = 1)	0.88 (046; 1.70)	0.717	0.88 (0.43; 1.79)	0.725
Apathy (no symptoms = 0, severity score 1-9 = 1)	**3.07 (1.08; 8.67)**	**0.035**	2.52 (0.85; 7.44)	0.094

HR hazard ratio

CI confidence interval.

Bold values indicate statistically significant (P<0.05).

[a] Without the fifteen missing items (11.8%) in behavioral assessment scales

[b] Adjusted for age, delirium, number of somatic drugs, gender, psychiatric history, and psychotropic drug use.

In sensitivity analysis restricted to participants without delirium (n=97), there were no factors for which the effect size changed relevantly and reliably in both adjusted and unadjusted models. For the factor apathy, the hazard ratio increased relevantly to 4.53 (CI 1.07; 19.28), but completely adjusted this was 3.78 (CI 0.88; 16.35). For the CMAI factor of physically aggressive – when divided into the highest 10% versus others – the hazard ratios increased to 5.30 (CI 2.28; 12.32) but was not relevantly different when adjusted, with 8.11 (CI 3.07; 21.48).

Discussion

This observational study is the first to investigate causes of death and determinants of mortality during stay in patients with dementia and very severe challenging behavior admitted for treatment to highly specialized units in the Netherlands. We found similar causes of death as in regular DSCUs (Hendriks et al., 2017), with a higher age and larger number of non-psychotropic drugs best predicting mortality over time. Participants with very severe physically aggressive behavior – i.e. those with the highest 10% scores on the factor of physically aggressive behavior of the CMAI – had a ninefold higher risk of mortality during their stay in a highly specialized unit. We will discuss these findings below in further detail.

Challenging behavior and mortality

One in three patients with very severe challenging behavior in highly specialized units died during their stay, with a median stay of 84 days. We found that some traditional risk factors for mortality – i.e. age, somatic disease burden, and delirium – also apply to this specific population. For the 10% of participants with very severe physically aggressive behavior, this was significantly related with a ninefold increased risk of mortality during the stay in a highly specialized unit. This is somewhat similar to the results of the study among patients with dementia and severe aggression incidents within the first 48 hours of a stay in a specialized psychogeriatric ward in a psychiatric hospital mentioned in the introduction (Van den Bulcke et al., 2024). Finally, we found a trend towards a higher mortality risk over time for the behavioral NPI-Q factor apathy, i.e. patients with apathy, nighttime behaviors and/or appetite/eating change had a higher mortality risk than patients without such factors. This risk over time was higher in participants without delirium. Apathy might be a sign of different problems, such as a symptom of depression, a symptom of declining cognition or a (not recognized) hypoactive delirium (Olin et al., 2002; Schieveld & Strik, 2021). Especially declining cognition and delirium have a known link with higher mortality (Haaksma et al., 2020; Hapca

et al., 2018). These findings emphasize that very severe challenging behaviors might be a sign of impending death. Although not investigated here due to the relatively small sample size, future studies should explore the role of antipsychotic use and psychotropic drug use in general, which are known to be related to several adverse events and outcomes such as sleepiness, stroke, and death (McInerney et al., 2024; Mok et al., 2024; Mühlbauer et al., 2021). These highly specialized settings are established for a temporary stay and treatment and aim to discharge patients to a DSCU (van Voorden et al., 2024), whereas for some patients these units appear to be their place of residence during their last days. This raises the question of whether these patients can be better recognized and how appropriate terminal palliative care can be provided for them.

Clinical implications

It is necessary to acknowledge that this is one of the first investigations into this specific group, which might also differ globally due to contextual differences, especially in countries lacking the resources of highly specialized units. Nevertheless, some lessons can be learned. First, this study has found that the mortality over time of patients with very severe challenging behavior in dementia is high. Especially patients with very severe physical aggression – i.e. the one in ten patients with the most severe physical aggression – were about four times more likely to die during their stay. Moreover, patients scoring any symptom on the NPI factor of apathy – i.e. those with apathy, nighttime behaviors, and/or appetite/eating change – had a threefold increased risk over time of dying during the stay. Second, about half of the patients could be discharged from a highly specialized unit, half of them within 122 days. Finally, one in ten participants stayed in these units for longer than sixteen months. This might imply that highly specialized units are needed for a longer time for a small group.

Implications for research

In this study, we have investigated the relationship between regular determinants of mortality over time and behavioral factors during the first two weeks of stay in highly specialized units. These initial results show the importance of addressing this knowledge gap concerning patients with dementia and the most extreme behavior. Future research might profit from international research to replicate this study with more statistical power, aiming to identify clinical subgroups within patients with very severe challenging behavior in dementia. Latent cluster analysis could be valuable for this purpose (Aflaki et al., 2022). As mentioned earlier, the high mortality over time raises questions about whether admission is appropriate for some patients, whether they can be recognized, and what is needed to provide

terminal palliative care for these patients. Despite not being measured in this study, it is very likely that the well-being of patients with severe challenging behavior is compromised, likewise for the persons in their direct environment, i.e. other patients, nursing staff, and family caregivers (Black & Almeida, 2004; Livingston et al., 2017). Further insights into whether and how their well-being can be improved during a stay in a highly specialized unit are necessary.

Strengths

One strength of this study is that we were able to include eleven of the fifteen identified units in the Netherlands, thereby studying a relatively rare but impacting problem.

Limitations

Our explorative study has some limitations. First, although we were able to provide the overall participation rate of all admissions, we were unable to quantify whether the non-participants did not meet the inclusion criteria, did not consent, or were not asked to participate. Considering the reasons for the lack of these data – namely workload, vacation, and sick leave of treating physicians – selection bias is considered low. Second, we had missing data on behavioral assessment scales for thirteen patients, and it is unknown whether this was related to the severity of challenging behavior. Third, determinants were only derived at admission or – for the behavioral assessment scales – after two weeks, implying that this study does not include how clinical diagnoses, treatment, and behavioral changes over time affect mortality over time. Insight is lacking into the role of clinical diagnoses and symptoms such as pain that might have indirectly contributed to the challenging behavior and/or death. Fourth, while using non-psychotropic drug use as a proxy for somatic disease burden is justified by evidence at the population level (Cossman et al., 2010), we do not know how reliable this is in our relatively small and specific sample. Fifth, some limitations apply to our statistical analyses. For instance, we did not perform a multilevel analysis despite the fact data were derived from different units within different organizations. Given our previous findings that these units are heterogenous in their interventions used (van Voorden et al., 2024), the assumption of independent observations could have been violated. We chose determinants that are known to be related to mortality over time in the prediction model and therefore might be less strongly influenced by this clustering, although this does not apply to the association models. Naturally, our explorative models should be externally validated in the future. Sixth, we did not reach our aim of 200 participants, meaning that our models are less robust than intended. Since the number of events – i.e. deaths – was also higher than expected, we were still able to include four variables. Finally, we collected our data during the Covid-19 pandemic,

which might have influenced our results. Although the number of participants who died directly from Covid-19 was limited (n=2), we do not know to what extent the results were affected by the impacts of the pandemic.

Conclusions and Implications

This explorative observational study has found a high mortality over time in patients with dementia and very severe challenging behavior during their treatment in highly specialized units. Primary causes of death were mainly dehydration with cachexia and pneumonia. Very severe physical aggression was associated with a ninefold increase in mortality over time during a stay. This study underlines the necessity of adequate terminal palliative care in these highly specialized units.

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Supplementary materials

Supplementary Table S1. STROBE statement—checklist of items that should be included in reports of observational studies

	Item no.	Recommendation	Reported under heading, and subheading(s)
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	Abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	Abstract
Introduction			
Background/ rationale	2	Explain the scientific background and rationale for the investigation being reported	- Introduction
Objectives	3	State specific objectives, including any prespecified hypotheses	- Introduction
Methods			
Study design	4	Present key elements of study design early in the paper	- Methods, study design, design
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	- Methods, study, setting - Methods, data sources and data collection (last paragraph)
Participants	6	*Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	Methods, study design, participants
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	- Methods, data sources and data collection - Methods, assessments - Methods, statistical methods
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	- Methods, data sources and data collection - Methods, assessments
Bias	9	Describe any efforts to address potential sources of bias	- Methods, study design
Study size	10	Explain how the study size was arrived at	- Methods, study design, participants
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	- Methods, statistical methods

Supplementary Table S1. Continued

	Item no.	Recommendation	Reported under heading, and subheading(s)
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	- Methods, statistical methods
		(*b*) Describe any methods used to examine subgroups and interactions	- Methods, statistical methods
		(*c*) Explain how missing data were addressed	- Methods, Statistical methods
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed	- Results, patient characteristics and length of stay - Results, Table 1
		(e) Describe any sensitivity analyses	- Methods, statistical methods - Results, prediction mortality with regular determinants - Results, association behavior with mortality
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analyzed	- Results, first paragraph - Results, patient characteristics and length of stay - Supplementary materials Table S1 (of Chapter 4)
		(b) Give reasons for non-participation at each stage	- Results, first paragraph - Results, patient characteristics and length of stay - Supplementary materials Table S1 (of Chapter 4)
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders	- Results, patient characteristics and length of stay - Results, Table 1
		(b) Indicate number of participants with missing data for each variable of interest	- Results, Table 1 - Results, Table 2
		(c) *Cohort study*—Summarise follow-up time (e.g. average and total amount)	- Results, patient characteristics and length of stay - Results, Table 1
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	- Results, patient characteristics and length of stay - Results, Table 1

Supplementary Table S1. Continued

	Item no.	Recommendation	Reported under heading, and subheading(s)
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g.. 95% confidence interval). Make clear which confounders were adjusted for and why they were included (*b*) Report category boundaries when continuous variables were categorized (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	- Results, prediction mortality with regular determinants - Results, Figure 1 - Results, association behavior with mortality - Results, Table 2
Other analyses	17	Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses	- Results, prediction mortality with regular determinants - Results, association behavior with mortality
Discussion			
Key results	18	Summarize key results with reference to study objectives	- Discussion, first paragraph - Discussion, conclusions
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	- Discussion, limitations
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	- Discussion, challenging behavior and mortality - Discussion, Box 1 - Discussion, implications for research
Generalizability	21	Discuss the generalizability (external validity) of the study results	- Discussion, strengths - Discussion, limitations
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	- Title page - Sponsor's role

Supplementary materials 2. Kaplan-Meier survival curves and log-minus-log-plots of categorical variable prediction model

These ten figures of the curves and plots can be found online: https://www.jamda.com/cms/10.1016/j.jamda.2025.105713/attachment/99b18272-d420-4607-9277-0407893207e5/mmc1.docx

Chapter 6. General discussion

This general discussion will start with a summary of the main findings, followed by a reflection. Next, some methodological considerations will be discussed. Finally, implications and recommendations for practice, education, policy, and future research will be discussed.

Summary of the main findings

Chapters 2 and 3 described two mixed-method studies investigating the organizational background of highly specialized units, as well as what (successful) treatment comprises. Chapters 4 and 5 described the results of an observational study of patients with challenging behavior in dementia admitted to a highly specialized unit.

Chapter 2 focused on gaining insights into the organizational characteristics of these units, i.e. admission and discharge characteristics, staffing, the physical environment, and management of severe challenging behavior. The main finding is that these units are pioneering and have strong heterogeneity in the management of severe challenging behavior in dementia. This heterogeneity was demonstrated by the varying degree to which a more intuitive or methodological work-up was used, the broad variety of non-pharmacological interventions used, and the differences in nursing staff hours, nursing staff education levels, length of stay, unit size, and physical environment. Despite these differences, a multidisciplinary team comprising at least an elderly care physician or geriatrician, psychologist, nursing staff members, and other therapists as needed provided the treatment in the units. There were similarities in emphasis on observation with an open attitude, the key role of nursing staff, frequent multidisciplinary meetings, and attention to sensory stimuli. Competences such as reflectiveness on one's own behavior and being able to cope with stressful situations were described as relevant for nursing staff. Investing in a stable nursing staff team was described as important. In the diagnostic phase, observation together with an extensive analysis of the patient's biography was considered essential. In the observation of the physical environment with the OAZIS-dementia (de Boer et al., 2015), the safety theme scored well and domesticity relatively low compared to regular dementia special care units (DSCUs). Patients were admitted from regular DSCUs, home, or a mental health care institution. Most patients were discharged to a regular DSCU, although discharge was often delayed due to specific needs of the patients. For a few patients, the best possible outcome was the manageability of the behavior in the highly specialized unit. The proportion of deaths ranged between 6% and 63% (median 19%) on average per units per year.

Chapter 3 focused on conceptualizing successful treatment of persons with severe challenging behavior in dementia as perceived by professionals. We performed a concept mapping study in which 82 experts in dementia care participated (Kane & Trochim, 2007). Three clusters were identified, the first addressing treatment outcomes and two addressing treatment processes, each divided into sub-clusters: 1) *well-being,* comprising *well-being of the person with dementia* and *all people directly involved*; 2) *multidisciplinary analysis and treatment*, comprising *multidisciplinary analysis, process conditions, reduction in psychotropic drugs,* and *person-centered treatment;* and 3) *attitudes and skills of those involved*, comprising *consistent approach by the team, understanding behavior, knowing how to respond to behavior,* and *open attitudes*. The clusters concerning the treatment process might form prerequisites to ensure the well-being of persons with dementia and people directly involved, such as relatives and nursing staff.

Chapters 4 and 5 focused on general and behavioral characteristics and treatment outcomes—specified as discharge location and mortality—of patients (n=127) admitted to highly specialized units for the treatment of very severe challenging behavior. Eleven units participated in this observational study from December 2020 until December 2022. In these chapters, the treatment outcome 'well-being of the person with dementia' was operationalized by surrogates from Chapters 2 (mortality) and 3 (discharge location).

Nine in ten patients had moderately severe or severe cognitive decline. Although the very severe challenging behaviors were rather heterogeneous, agitation, general restlessness, and verbal aggression were each present in 70% or more of the patients. However, among nursing staff, agitation was rated as severely or extremely distressful in one in four patients. Half of the patients could be discharged to a regular DSCU, one in ten could not be discharged at the time of the follow-up, and one-third died during their stay. The main causes of death were dehydration—often with cachexia—and pneumonia. Explorative Cox models showed that age and the number of somatic drugs most accurately predicted overall mortality. Explorative Cox models of the association between behavior and mortality of participants who died during their stay in a highly specialized unit showed a ninefold increased mortality risk in the ten percent of participants scoring highest on physical aggression.

Reflection on the findings

Challenging behavior and the well-being of all involved

Chapter 3 found that not only the well-being of the person with dementia but also of other persons in their direct environment can be seen as an outcome to evaluate in the treatment of persons with severe challenging behavior in dementia. This finding supports the principles of relationship-centered care, which focuses on the social environment and considers the needs of both family and staff, placing the person with dementia within the context of meaningful relationships (Nolan et al., 2004; Watson, 2019). Therefore, evaluating the treatment of severe challenging behavior is not only about diminishing behavior, but rather the focus should be placed on the well-being of all involved. For example, the impact of very severe challenging behavior on the well-being of nursing staff should also be considered, and admission to a highly specialized unit can relieve them. Consequently, it might prevent absenteeism or the acceptance of being physically injured due to persisting very severe challenging behavior (Veldwijk-Rouwenhorst et al., 2022). Understanding behavior and knowing how to respond to and tolerate it by nursing staff is another indicator of successful treatment, which is probably also a precondition for their well-being (Chapters 2 and 3). Accordingly, providing treatment in a regular DSCU might be hindered when well-being of nursing staff is at stake. Most units have invested in training to cope with physical aggression, and the number of peer consultation groups for nursing staff members in these units has recently increased. Yet, more attention for these skills is probably necessary and might reduce the emotional distress of nursing staff members (Geoffrion et al., 2020); Chapter 4 shows that nursing staff members who work in these units experience the very severe challenging behavior in one in four patients as severe or extremely distressing.

Highly specialized units for very severe challenging behavior in dementia

This thesis has focused on the care and treatment of patients with dementia and severe challenging behavior, with a special focus on highly specialized units in the Netherlands. While the development of these units remains in its initial phase, comparable units have been established in Australia as a part of the Special Dementia Care Program (Department of Health, 2018; Gresham et al., 2021). Furthermore, units where patients with dementia and severe challenging behavior can be admitted to temporarily have been reported in other Western European countries, although the context differs from the highly specialized units in the Netherlands. In the United Kingdom, specialized units are described as part of a specialist hospital setting (Jones et al., 2023). Other specialist medical care units in settings such as a hospital

or psychiatric hospital—albeit outside a nursing home setting—are available in Italy, Germany, France, Greece, Switzerland, and Norway (Cesana et al., 2023). In Belgium, patients with dementia and very severe challenging behavior are also admitted to a psychogeriatric ward in a psychiatric hospital (Van den Bulcke et al., 2024). Other European countries exclude nursing home settings for specialized treatment. The organization of long-term care in the Netherlands is different as specialized physicians—i.e. elderly care physicians—are available and usually employed in the regular nursing home setting, together with a multidisciplinary team of nurse practitioners, physician assistants, (healthcare) psychologists, and other therapists (Koopmans et al., 2017; Zwijsen et al., 2014). By contrast, in Germany and Switzerland, nursing home residents experience difficulties in access to a physician (BIVA-Pflegeschutzbund, 2021; Herrmann et al., 2020; VirchowBund, 2019), and this physician is often a general practitioner in most European countries (Fitzpatrick et al., 2019). In regular DSCUs in the Netherlands—the units within the nursing home setting where most persons with dementia who can no longer live on their own live (Verbeek et al., 2009)—most challenging behavior is manageable. In a few exceptions the behavior is not manageable in this setting. Examples of behavior that is not manageable include situations where it causes serious safety issues or upsets other residents because of extreme vocalizations. For these patients, some organizations have opened the highly specialized units that were studied in this thesis, where expertise in the care and treatment is further developed. Examples of this expertise in staffing include recruiting nursing staff with specific competences and involving a broader range of physicians and therapists compared to a regular DSCU in the Netherlands (Chapter 2). This thesis shows that in 2018 units with individually developed expertise were pioneering in treating this patient group (Chapter 2). The expertise developed in these units was enhanced by an infrastructure of six academic networks that connect nursing home settings with universities that have been in place from 10 to 25 years (Koopmans et al., 2013). Recently, separate expertise networks were developed for seven specific patient groups with low prevalence and high complexity rates (Koopmans et al., 2022). One of these groups is the "D-zep" group, reflecting a Dutch acronym for dementia and very severe challenging behavior. Factors such as multidisciplinary analysis, clear agreements about roles of the multidisciplinary team, a well-supported nursing staff team that knows how to respond to behavior with an open attitude, and facilities to tailor interventions and sensory stimuli were mentioned by professionals as necessary to provide for successful treatment in these units (Chapters 2 and 3).

Severe challenging behavior and mortality

The mortality in persons with dementia and very severe challenging behavior appeared to be high (Chapter 4). In previous research, a higher mortality rate in

the general population of persons with dementia was found when scores on the neuropsychiatric inventory (NPI) were higher (Bränsvik et al., 2021; Connors et al., 2016; Hapca et al., 2018; Mendes et al., 2025; Peters et al., 2015). We found a trend toward higher mortality in patients with apathy, nighttime behavior, and/or eating problems (Chapter 5). Especially in persons with physical aggression, a significantly higher mortality has also been found in other recently published research (Van den Bulcke et al., 2024). A high mortality in persons with dementia and very severe challenging behavior might be due to several factors. Well-known determinants of mortality such as age and somatic disease burden were also found (Chapter 5). Nevertheless, other factors that were not found or included in the models in this study due to the relatively small sample size might also play a role. For example, well-known factors such as cognitive decline and delirium are known to be related to a higher mortality yet were not found in this study (Chapter 5) (Haaksma et al., 2020; Hapca et al., 2018). Moreover, frontotemporal dementia and dementia with Lewy bodies are associated with significantly increased mortality, although they were not included in the models due to the small sample size (Chapter 5) (Connors et al., 2016; Garcia-Ptacek et al., 2014). Although this thesis describes determinants related to death, it does not include intercurrent (somatic) diseases that occurred during stay in a highly specialized unit.

Methodological considerations

Persons with dementia and very severe challenging behavior: How to define this group?

In Chapters 3 and 4, a pragmatic choice was made to include all persons with dementia and very severe challenging behavior *"associated with suffering or danger to the person with [suspected] dementia or people in his or her environment"* (Zuidema et al., 2018) who were admitted to the highly specialized units. A disadvantage of this pragmatic choice is that the group lacks clear operational definitions, specifically regarding characteristics such as symptom severity and dementia type. Agreement on an operational definition of these patients might improve research with and therefore knowledge about these patients. The network of highly specialized units has started with this work in recent years (Knippenberg et al., 2025; Nederlanden, 2024; Plouvier & Gerritsen, 2022; Timmermans et al., 2021). The current definition defines the group as persons with dementia having "*behavior that includes all types of severe challenging behavior which 1) is frequent, persistent and/or unpredictable, 2) causes significant distress for the patient and/or its environment, and 3) does not respond to regular (guideline-based) treatment approaches.*" (Timmermans et al., In preparation). A research report

of the network has recently proposed a first quantitative operationalization of the behavior to enable developing a further definition of the group. The behavior of patients referred for consultation to the team of a highly specialized unit, that nowadays should precede eventual admission, is described in terms of the type, frequency, severity, persistence, and danger of the behavior (Knippenberg et al., 2025). The type of behavior is categorized into physically aggressive, verbally aggressive, physically nonaggressive, and verbally nonaggressive behavior, as well as an open category (Knippenberg et al., 2025). This description should be used together with the clinical judgment of professionals (Knippenberg et al., 2025). These developments influence the interpretation of the findings of this thesis in several ways. First, with further developments, the results might differ when the definition of the group changes. The current definition makes it difficult to compare because experiencing behavior as distressful can be influenced by many factors, which should be defined to enable comparison and investigation. Second, in the observational study, about one-third of the patients were admitted from home, which is no longer the journey that patients make in the Netherlands (Plouvier & Gerritsen, 2022). Further analysis of the data revealed similar mortality risks for the ten percent of participants with the highest physical aggression scores who were not admitted from home.

Design

One strength of this study is that it used mixed methods in a pioneering phase of the highly specialized units in the Netherlands, which enabled describing these units qualitatively and quantitatively. The more qualitative description of the organizational characteristics (Chapter 2) informed the methods, practical organization, and interpretation of the observational study. The perspectives of nursing staff members in Chapter 2 and informal caregivers throughout this study would have enriched the perspectives in this study. Especially with the concept mapping study in Chapter 2, the perspective of informal caregivers would have been valuable in appreciating what successful treatment involves. The overall results were discussed with (representatives of) persons living in nursing homes, who suggested that an extensive discussion and explanation about the added value of these units is necessary with the legal representative prior to relocation. An example of this added value is that the nursing staff in highly specialized units can observe well with a certain tolerance towards challenging behavior that includes looking at the behavior with an open mind. The latter is often at stake in the unit where the person with dementia lives. A final concern for the interpretation of the findings in Chapters 4 and 5 is that data collection took place the COVID-19 pandemic. Although the number of participants who died directly from COVID-19 was limited (n=2), it is unclear how this pandemic has influenced our findings.

Implications and recommendations

Practice

This thesis provides valuable insights into the treatment of persons with dementia and very severe challenging behavior in clinical practice. First, this thesis has underlined the central role of nursing staff members in the treatment of severe challenging behavior in dementia (Chapters 2 and 3). Ideally, nursing staff members in DSCUs and highly specialized units understand the behavior, know how to respond to it, apply this consistently, and have an open attitude (Chapter 3). Nevertheless, in highly specialized units, nursing staff experience severe or extreme distress due to agitation (Chapter 4), and therefore more attention to their well-being is needed. This could be achieved by recruiting and developing appropriate competences, and peer consultation groups might contribute to improving the well-being of nursing staff (Chapters 2 and 3) (Bolt et al., 2020; Piirainen et al., 2021; Wang et al., 2020). Moreover, a framework of relationship-centered care such as the Senses Framework could be used to evaluate the well-being of nursing staff and other persons in the direct environment of a person with dementia (Chapter 3) (Nolan et al., 2006; Nolan et al., 2004). Second, intensive multidisciplinary cooperation is needed for the treatment of very severe challenging behavior. Attention to process conditions of successful treatment is needed, such as agreements about the roles of the professionals involved and facilitation by the organization to implement interventions (Chapters 2 and 3), especially because it is often disregarded (Keenan et al., 2020; Rapaport et al., 2018; Visser et al., 2008). Moreover, the high mortality rate indicates that the care for persons with dementia and very severe challenging behavior often results in terminal palliative care (Chapters 3 and 4) (Bränsvik et al., 2021; Connors et al., 2016; Peters et al., 2015). Especially for those with very severe physical aggression, the likelihood of a pending death and what is important in this final phase of life should be discussed (Chapter 4) (Van den Bulcke et al., 2024). Finally, before opening a highly specialized unit, it is necessary to invest in the physical environment. Safety, a low amount of visual and auditory stimuli, space, and interventions to dose stimuli individually—e.g. deep pressure equipment, enclosure beds and headphones, and a walking circuit—were described in this thesis as interventions that were available but were often missed in regular DSCUs, which delayed discharge back to regular DCSUs (Chapter 2).

Education

This thesis has highlighted the relevance of appropriate competences in knowing how to respond to severe challenging behavior in dementia, as well as the relevance of effective collaboration as a multidisciplinary team. Competences

such as reflectiveness on one's own behavior, the ability to cope with stressful situations like physical aggression, and the capacity to observe well are now integral to the competence profiles of nursing staff in highly specialized units (D-zep kennisnetwerk, 2024). Challenging behavior in dementia has received very little attention in the regular training of certified nursing assistants, who account for the majority of nursing staff in regular DCSUs (Kroezen et al., 2018). This lack of training is also experienced as a problem by nursing staff members themselves in regular Dutch nursing homes, as an inventory of nursing staff members in regular Dutch nursing homes showed that knowledge about the management of challenging behavior was the most pressing need for training (Vilans, 2020). Accordingly, more training in managing challenging behavior and coping with physical aggression is needed, including in regular DSCUs; for example, as a part of implementing the multidisciplinary programs STA OP! protocol (Pieper et al., 2016) or Grip on Challenging Behavior (Zwijsen et al., 2014). Moreover, collaboration among nursing staff members and other multidisciplinary team members is part of successful treatment. The efficacy of this multidisciplinary team is likely enhanced when team members are more interdependent, interactive, and coordinate task processes (Chapter 3) (Kozlowski & Ilgen, 2006). Doing so might enhance understanding of how to respond to behavior in all individuals involved with a person with dementia and challenging behavior among all team members. Finally, efforts should be made to unlock knowledge to a broader public about the treatment of severe challenging behavior in dementia. Sharing knowledge is achieved through consultations initiated by the teams of the highly specialized units to prevent admissions (see below). Furthermore, this sharing of knowledge can be accomplished in collaboration with the network of highly specialized units, the Centre for Consultation and Expertise (CCE), the academic networks that connect nursing home settings and universities, the national center of expertise for long-term care in the Netherlands (Vilans), and the national patient association (Dutch Alzheimer Association/Alzheimer Nederland).

Policy

This thesis has shown that some pioneering highly specialized units started with consultation to prevent admissions (Chapter 2). This is further developed nowadays by the network of highly specialized units and is expected to reduce costs (Athmer & van Eijkel, 2025). The main assumption underlying this expected reduction is that consultation is expected to reduce admissions to highly specialized units now and in the future by increasing the knowledge in regular DSCUs (Athmer & van Eijkel, 2025). It is known that relocations have a negative impact on the well-being and health of persons with dementia (Ryman et al., 2018). Moreover, this thesis has

shown that about one-third die during a stay in a highly specialized unit (Chapters 4 and 5), which underlines that relocations should be avoided where possible. Therefore, more insights are needed into the processes leading to an admission in a regular DSCU. A first study into this subject showed that the increasing burden of the behavior—due to an increase in its severity and an increasing realization that the patients' needs could not be met—led to the nursing staff reaching their limits (Verhees et al., 2023). Second, we found a daily tariff ranged from €241.07 to €548.60 per patient per day in 2018. In a few units, additional agreements on reimbursement were made. These differences are undesirable, and the network of highly specialized units addresses this issue. An investigation into the social return on investment on behalf of the network showed that every euro invested by these units generates about 2.4 times itself in social value (Ketelaar & Hendriks, 2025). Finally, in policymaking, it is essential to recognize that discharge to a regular DSCU from a highly specialized unit was only possible in approximately half of the admissions. Indeed, this group included one in six patients who were subsequently discharged to a so-called "psychogeriatric plus" DSCU. For a small proportion (about one in ten) longer specialized care was needed, i.e., no discharge was possible (yet) at the follow-up nine months after the observational study (Chapter 4).

Research

This thesis has provided more insights into the complexity of the treatment of severe challenging behavior in dementia. We therefore recommend to further develop and evaluate treatment using a framework for complex interventions (Skivington et al., 2021). Most implications for further research are in line with the themes in the research agenda of the highly specialized units (D-zep kennisnetwerk, 2023), namely: 1) operationalization of a definition for the group of patients with dementia and very severe challenging behavior; 2) underlying factors of behavior ranging from personal factors, such as physical factors and biography including trauma, or factors in the social and physical environment; 3) interventions and; 4) improving the well-being of the persons involved (D-zep kennisnetwerk, 2023). The intention is also to investigate the relationship among these themes. Below, some specific topics concerning this thesis that warrant further research are discussed.

Considering the second theme of the research agenda—underlying factors of behavior—this thesis found a high mortality, especially in people with dementia and very severe physical aggression. The background of the relationship between physical aggression and mortality is not yet well understood, although it would be insightful to include intercurrent diseases, pain, delirium, and adverse effects of psychotropic drugs in future research. Moreover, the trend in the association

between apathy, nighttime behavior and/or eating changes and death might be due to cognitive decline, although the role of intercurrent diseases, (not recognized) delirium, and adverse effects of psychotropic drug use—especially antipsychotic drugs—should be included in future research (McInerney et al., 2024; Mok et al., 2024; Mühlbauer et al., 2021). Moreover, as previously mentioned, investigating a larger group will make it possible to discern mortality in more specific patient groups, such as the differences in mortality among dementia types (Garcia-Ptacek et al., 2014). Moreover, the high mortality raises the question concerning how to provide appropriate terminal palliative care for these patients. In line with this, it should be investigated whether it can be predicted which persons will benefit from consultation, who will benefit from admission, as well as which patients should be offered terminal palliative care.

Considering the third theme of the research agenda—interventions—this thesis has shown that several methods are used in the treatment of severe challenging behavior in dementia, with special attention paid to the physical environment, including specific stimuli. Some multidisciplinary programs have shown their value in the management of challenging behavior in regular DSCUs (Pieper et al., 2016; Zwijsen et al., 2014). Moreover, other specific interventions have been used, such as the principles of miMakkus in the contact with a person with advanced-stage dementia (Hendriks, 2017), interventions from sensory integration (Champagne, 2018), enclosure beds (Haynes & Pratt, 2009; Molleman et al., 2015), and the administration of electroconvulsive therapy (Hermida et al., 2019; Stella et al., 2023; Swierkosz-Lenart et al., 2019; van den Berg et al., 2018), which require further investigation. The latter two will be investigated in the recently started Waalbed-V study. Such interventions can be integrated where the social and physical environment is also considered, although whether and how this integration should be undertaken requires further investigation.

The fourth theme of the research agenda—the well-being of all involved—explicates the ethical dimension that often implicitly underlies choices in care and treatment in general (Hunt & Carnevale, 2011; Truog et al., 2015), and broadens this dimension from the person with the disease to all involved. In future research, it might help to make these choices more explicit for several reasons. First, given that treatment choices are no longer self-evident for persons with dementia and severe challenging behavior, it might be insightful not only to investigate *whether* but also *why* a specific form of care or treatment is chosen and seen as beneficial to apply in this situation. To start with, the choice whether to admit to a highly specialized unit has an ethical dimension. A better understanding of who will profit from

admission—in line with the aforementioned research agenda—will add to this. Furthermore, choices in treatment that are influenced by ethical considerations might also affect treatment outcomes. Examples include the decision not to treat an intercurrent pneumonia or the even more subtle balance between psychotropic drug use in severe physical aggression and the sedative side effects that might eventually and unintentionally lead to reduced intake and death. These treatment decisions are complex and can even lead to the decision for palliative sedation (Veldwijk-Rouwenhorst et al., 2021). Finally, complex (palliative) situations—especially in older adult care—are known to increase moral stress in caregivers, which is related to reduced work ability (Selander et al., 2022), contrasting the ideal situation where caregivers can sustain an open attitude; that includes the skills to tailor (re)actions to the person with dementia, look at the behavior with an open mind, and see the behavior as a way of communicating about well-being. Therefore, investigating what might reduce moral stress in caregivers is essential to provide effective care and treatment for persons with dementia and severe challenging behavior in the future.

Conclusion

The Waalbed-IV study investigated the care and treatment of persons with dementia and severe challenging behavior in the Netherlands, with a special focus on highly specialized units where these persons can temporarily stay. This thesis has shown that these units were pioneering in their organization and treatment. Furthermore, the central role of nursing staff members in the treatment has been highlighted. Improving the well-being of all involved is a central theme in the successful treatment of severe challenging behavior, as well as attention for the treatment process. The latter includes multidisciplinary analysis and treatment, as well as the attitudes and skills of all involved. Mortality during stay in a highly specialized unit was 32%, and especially persons with a high physical aggression score had a ninefold increased mortality risk over time. In the future, issues concerning the well-being of all involved, the effect of several interventions that include as well as target the specific context, and how palliative care can be provided for persons with dementia and severe challenging behavior should be given priority in practice and research.

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Chapter 7.

Samenvatting (summary in Dutch)

Datamanagement

Dankwoord (acknowledgements in Dutch)

Curriculum Vitae (in Dutch)

PhD portfolio of Gerrie van Voorden

Information page Donders Graduate School

Inleiding

Hoofdstuk 1 van dit proefschrift beschrijft de achtergrond van de WAALBED (WAAL Behavior in Dementia)-IV studie. Tot 90% van de mensen met dementie vertoont op enig moment probleemgedrag. Dit heeft een grote impact op hun welbevinden en dat van hun omgeving. Mensen met dementie en probleemgedrag verhuizen ook vaker naar een (kleinschalige) woonafdeling voor mensen met dementie van een verpleeghuis. Een kleine groep mensen met dementie ontwikkelt zeer ernstig probleemgedrag wat niet te hanteren is op een reguliere woonafdeling. In Nederland kunnen deze mensen tegenwoordig tijdelijk worden behandeld op een hierin gespecialiseerde afdeling. Deze afdelingen vormen de focus van dit proefschrift.

Probleemgedrag is een overkoepelende term voor zeer verschillende gedragingen die ook kunnen variëren in ernst, frequentie en impact. Probleemgedrag komt meer voor bij gevorderde dementie. In de internationale literatuur en ook binnen Nederland worden verschillende aanduidingen voor probleemgedrag gebruikt. In aansluiting op de huidige richtlijn gebruikt dit proefschrift de term probleemgedrag en hiermee worden gedragingen zoals verbale of fysieke agressie, agitatie, roepgedrag of ander gedrag bedoeld dat *"gepaard gaat met lijdensdruk of gevaar voor de persoon met dementie of voor mensen in zijn of haar omgeving"*, zoals de Nederlandse richtlijn definieert. Probleemgedrag kan worden gerelateerd aan kenmerken van de persoon met dementie maar kan ook (mede) resulteren vanuit de interactie met diens sociale of fysieke omgeving. Hierom is een multidimensionale analyse van probleemgedrag van belang waarbij multidisciplinaire interventies hun meerwaarde hebben bewezen in de reguliere setting. Echter, bij zeer ernstig probleemgedrag schiet in de reguliere setting de behandeling vaak te kort. Voorbeelden waarbij behandeling van probleemgedrag in de reguliere setting van een woonafdeling niet meer mogelijk is zijn wanneer gedrag een gevaar vormt voor de persoon zelf en/of zijn omgeving of wanneer het gepaard gaat met een aanhoudend ernstige belasting voor de persoon zelf en/of de mensen in diens omgeving. Tijdelijke opname op een gespecialiseerde afdeling kan dan aan de orde zijn. Deze gespecialiseerde afdelingen beogen mensen weer te ontslaan naar een reguliere afdeling als het gedrag weer als hanteerbaar op een reguliere afdeling wordt gezien. Gespecialiseerde afdelingen voor deze doelgroep zijn een nieuw fenomeen waaraan een aantal ontwikkelingen hebben bijgedragen: 1) het aantal mensen met dementie neemt toe; 2) het aantal bedden in de psychiatrie in Nederland voor deze patiënten is afgenomen; en 3) mensen met dementie wonen langer thuis en verhuizen pas later naar een woonafdeling waarbij al vaker sprake is van probleemgedrag. Meer inzicht verkrijgen in de behandeling van mensen met dementie en zeer ernstig probleemgedrag op gespecialiseerde

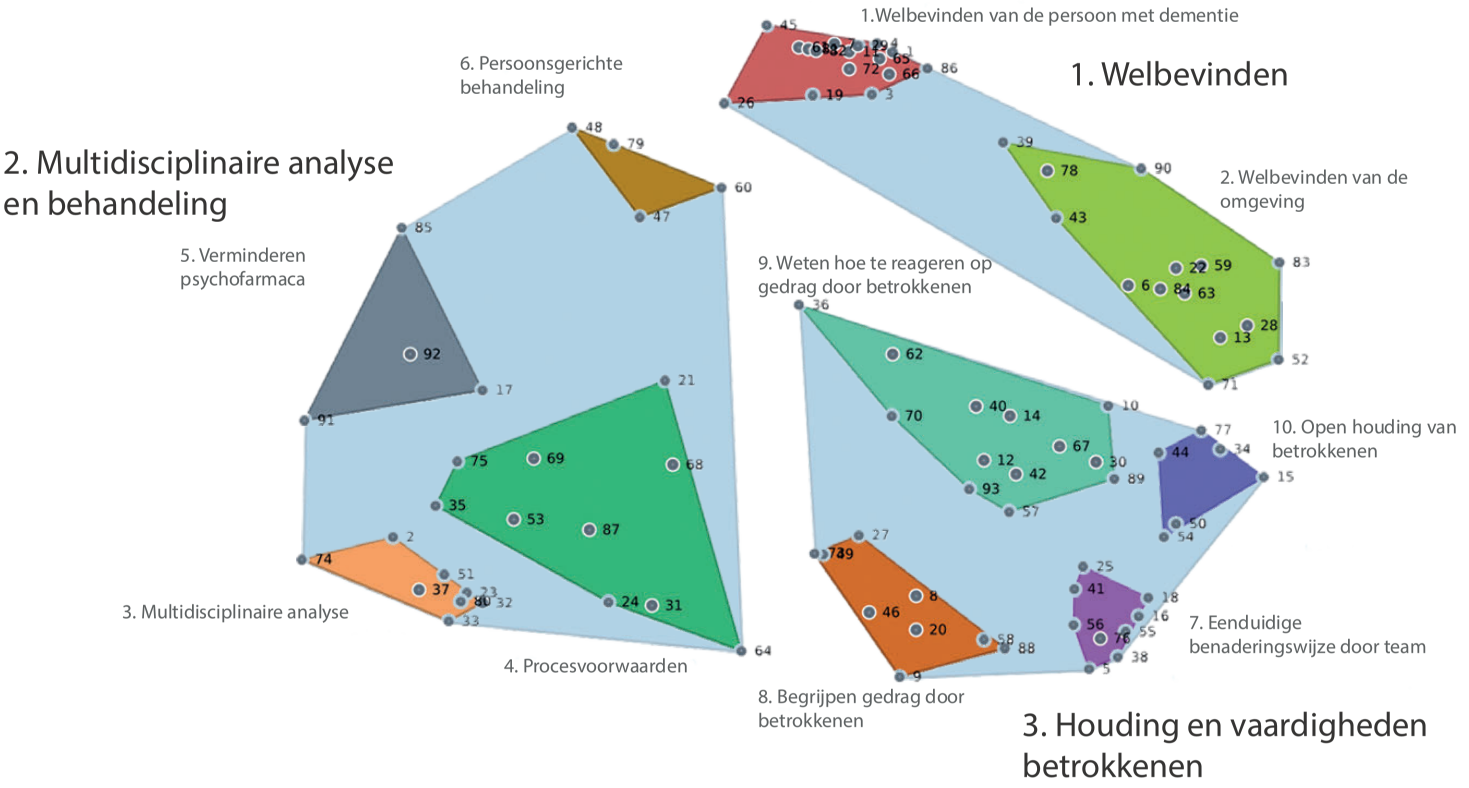
afdelingen is om een aantal redenen van belang: 1) deze afdelingen zijn een nieuw fenomeen waarbij organisatorische en behandelkenmerken kunnen verschillen tussen afdelingen; 2) behandeling volgens de richtlijnen volstaat meestal niet voor deze doelgroep, dus meer inzicht in de behandeling en het effect hiervan op deze gespecialiseerde afdelingen is nodig en; 3) probleemgedrag bij dementie is gerelateerd aan een hoger risico op sterfte.

Om meer te weten te komen over de behandeling van zeer ernstig probleemgedrag bij dementie onderzocht de WAALBED IV studie de volgende zaken: 1) de organisatorische kenmerken van de gespecialiseerde afdelingen wat betreft opname en ontslag, kenmerken van het zorg- en behandelteam en de fysieke omgeving; 2) de kenmerken van behandeling op deze afdelingen; 3) het conceptualiseren van succesvolle behandeling door ervaren professionals in de behandeling van mensen met dementie en ernstig probleemgedrag; 4) patiëntkenmerken – inclusief gedragskenmerken, ontslagbestemming, overlijden en doodsoorzaken – van patiënten opgenomen op deze afdelingen; 5) de samenhang tussen algemeen bekende determinanten van overlijden, en overlijden tijdens opname op deze afdelingen en; 6) de associatie tussen probleemgedrag en overlijden.

Samenvatting van de bevindingen

Hoofstuk 2 beschrijft de organisatorische kenmerken – d.w.z. opname-en ontslag-kenmerken en fysieke omgeving- en behandelkenmerken van gespecialiseerde afdelingen beschreven. Voor dit onderzoek werd gebruik gemaakt van drie vormen van data verzameling: 1) een digitale vragenlijst in te vullen door de afdelingsmanager; 2) een interview met de hoofdbehandelaar en vaak een andere behandelaar en; 3) een observatie van de fysieke omgeving waarbij de OAZIS-dementie, ontwikkeld voor het evalueren van de omgeving van zorginstellingen, gebruikt werd. Beschrijvende statistische analyse werd gebruikt voor kwantitatieve data en thematische analyse voor kwalitatieve data. De belangrijkste bevinding is dat deze afdelingen pionierden en sterk verschillen in de behandeling van zeer ernstig probleemgedrag bij dementie. Deze verscheidenheid kwam tot uiting in een meer intuïtieve of methodologische aanpak, de grote diversiteit aan niet-farmacologische interventies, en de verschillen in beschikbare uren voor zorgmedewerkers, het opleidingsniveau van zorgmedewerkers, de verblijfsduur, de grootte van de afdelingen en in de fysieke omgeving. Naast deze verschillen werd de behandeling altijd verzorgd door een multidisciplinair team dat ten minste bestond uit een specialist ouderengeneeskunde of geriater, een psycholoog en

Figuur 1. Concept map: weergave 93 *statements* (grijze stippen met nummer) in verhouding tot de clusters



een zorgmedewerker, en dat werd aangevuld met andere behandelaren indien nodig. Andere overeenkomsten waren de nadruk op kunnen observeren met een zekere tolerantie voor het probleemgedrag, de sleutelrol van zorgmedewerkers in de behandeling, de hoge frequentie van multidisciplinaire bijeenkomsten en aandacht voor sensorische stimuli. Vaardigheden zoals reflectie op eigen gedrag en in staat zijn om te gaan met stressvolle situaties werden beschreven als relevant voor zorgmedewerkers. Investeren in een stabiel zorgteam werd beschreven als belangrijk. In de diagnostische fase was observatie samen met een uitgebreide analyse van iemands biografie essentieel. Bij de observatie van de fysieke omgeving scoorde het thema veiligheid relatief hoog en het thema huiselijkheid laag vergeleken met reguliere woonafdelingen. Patiënten werden veelal opgenomen vanaf reguliere woonafdelingen, vanuit huis of vanuit de psychiatrie. De meeste patiënten werden ontslagen naar een reguliere woonafdeling alhoewel ontslag vaak was vertraagd door veronderstelde psychiatrische comorbiditeit en moeite om een plek te vinden die bij de behoefte van een patiënt paste. Voor enkele patiënten leek het hoogst haalbare dat het gedrag hanteerbaar was op de gespecialiseerde afdeling. De mediane proportie van sterfte op een afdeling was 19%.

In **Hoofstuk 3** wordt een zogenaamde *concept mapping* studie beschreven waarin met 82 professionals een omschrijving van succesvolle behandeling van ernstig probleemgedrag bij dementie werd ontwikkeld. Professionals die deelnamen werkten op een gespecialiseerde afdeling of waren consulent van het Centrum voor Consultatie en Expertise (CCE). De dataverzameling kende twee fases: 1) een online brainstorm waarbij deelnemers de volgende zinsnede aanvulden: "*De behandeling van mensen met ernstig probleemgedrag bij dementie vind ik succesvol als….*"; 2) het individueel sorteren en waarderen van de in de eerste fase verzamelde *statements*. Vervolgens volgde een data-analyse middels multidimensional scaling gevolgd door hiërarchische cluster analyse resulterend in een *concept map* (Figuur 1). In de visualisatie werden drie clusters gevonden, de eerste adresseert behandeluitkomsten en de andere twee het behandelproces, elk onderverdeeld in sub-clusters: 1) welbevinden, onderverdeeld in welbevinden van de persoon met dementie en welbevinden van de omgeving, 2) multidisciplinaire analyse en behandeling, onderverdeeld in multidisciplinaire analyse, procesvoorwaarden, verminderen psychofarmaca en persoonsgerichte behandeling en, 3) houding en vaardigheden betrokkenen, onderverdeeld in eenduidige benaderingswijze door team, begrijpen van gedrag door betrokkenen, weten hoe te reageren op gedrag door betrokkenen en open houding van betrokkenen. De clusters betreffende het behandelproces kunnen worden gezien als de voorwaarden om het welbevinden van de persoon met dementie en zijn omgeving te verbeteren. Concluderend focust succesvolle

behandeling van ernstig probleemgedrag bij dementie dus op verbetering van welbevinden van de persoon met dementie én zijn omgeving waarbij aandacht voor het behandelproces inclusief procesvoorwaarden essentieel is.

Hoofdstuk 4 en 5 beschrijven een observationele studie waaraan elf gespecialiseerde afdelingen deelnamen. In totaal namen 127 patiënten deel die werden gevolgd vanaf opname. Hiervan werden allerlei kenmerken verzameld: demografische kenmerken, de aanwezigheid van een delier, de ernst van de cognitieve achteruitgang, comorbiditeit, medicatiegebruik inclusief psychofarmacagebruik, gedrag gedurende de eerste weken van opname en ontslagbestemming of overlijden tijdens verblijf op de gespecialiseerde afdeling. Voor het meten van gedrag werden de Neuropsychiatric Inventory Questionnaire (NPI-Q) en de Cohen Mansfield Agitation Inventory (CMAI) gebruikt.

Als afgeleide van de mate van welbevinden van de persoon met dementie werd gekeken naar overlijden (n.a.v. Hoofdstuk 2) en ontslagbestemming (n.a.v. Hoofdstuk 3). Negen van de tien patiënten hadden een matig ernstige of ernstige cognitieve achteruitgang. Hoewel het zeer ernstige gedrag heterogeen was, waren agitatie, algehele rusteloosheid, en verbale agressie elk aanwezig in 70% of meer van de patiënten. Voor zorgmedewerkers was agitatie ernstig of extreem stressvol in een op de vier patiënten. De helft van de patiënten kon naar een reguliere woonafdeling worden ontslagen, een op de tien was tijdens de follow-up na negen maanden nog niet ontslagen, en een derde overleed tijdens opname. De meest voorkomende doodsoorzaken waren uitdroging – vaak met cachexie – en pneumonie. Exploratieve Cox-regressieanalyse liet zien dat leeftijd en het aantal medicijnen voor lichamelijke aandoeningen overlijden het beste voorspelden. Exploratieve Cox-regressieanalyses van de associatie tussen gedrag en overlijden gedurende opname lieten een negenmaal verhoogd risico zien op overlijden voor het percentiel van patiënten dat het hoogst scoorde op fysieke agressie.

Hoofdstuk 6 beschrijft de verdere ontwikkeling van de gespecialiseerde afdelingen en reflecteert op de belangrijkste bevindingen van dit proefschrift.

Gespecialiseerde afdelingen voor de behandeling van mensen met dementie en zeer ernstig probleemgedrag hebben zich verenigd tot een netwerk waarbij kennis wordt gedeeld, kwaliteit wordt ontwikkeld en getoetst, en waarbij het netwerk zich ten doel stelt om bij te dragen aan verder onderzoek. Het is een van de laag volume hoog complexe doelgroepen: de zogenaamde D-zep doelgroep – D-zep is een acroniem voor dementie en zeer ernstig probleemgedrag-. Ook in andere

westerse landen kunnen mensen met dementie en zeer ernstig probleemgedrag tijdelijk worden opgenomen waarbij alleen de setting in Australië lijkt op de Nederlandse setting. In Nederland is op reguliere kleinschalige woonafdelingen voor mensen met dementie, naast een zorgteam, een behandelteam beschikbaar dat in dienst is van de zorginstelling. Het behandelteam bestaat uit een specialist ouderengeneeskunde, verpleegkundig specialist of physician assistant en een (GZ-) psycholoog, en andere behandelaren zoals fysiotherapeuten, ergotherapeuten, diëtisten, logopedisten en vaak ook vaktherapeuten zoals muziektherapeuten. Vanuit deze context hebben veel D-zep afdelingen zich ook ontwikkeld. In bijvoorbeeld Duitsland en Zwitserland hebben verpleeghuizen moeite om artsen te vinden die de behandeling op zich willen nemen en als het lukt zijn het vaak huisartsen. Mensen met dementie en zeer ernstig probleemgedrag worden dan vaak opgenomen op psychiatrische afdelingen.

Een belangrijke bevinding van dit proefschrift is dat het welbevinden van alle betrokkenen een essentieel onderdeel van succesvolle behandeling van ernstig probleemgedrag bij dementie vormt. Dit doet recht aan dat probleemgedrag altijd in een (sociale) context plaatsvindt – en mede kan worden veroorzaakt door die context-. Die context zal dan ook betrokken moeten worden om gedrag hanteerbaarder te maken. Zorgmedewerkers hebben een centrale rol in de behandeling, ook bij mensen met dementie op een reguliere woonafdeling. Aandacht voor hun welbevinden is nodig bij het zorgen voor, en vaak ook uitvoeren van de behandeling van, mensen met dementie en probleemgedrag. Hierbij kan bijvoorbeeld gedacht worden aan faciliteren in het kunnen uitvoeren van de interventies door de organisatie bijvoorbeeld door het beschikbaar stellen van gewenste interventies en scholingen in specifieke interventies, het bieden van agressietrainingen en het organiseren van intervisiegroepen voor zorgmedewerkers. Ook is in de opleidingen van verzorgenden nauwelijks aandacht voor probleem-gedrag, terwijl zorgmedewerkers aangeven hier een grote kennisbehoefte aan te hebben. Het D-zep netwerk heeft zich onder andere ten doel gesteld hun kennis te delen met reguliere afdelingen middels consultatie door hun team. De verwachting is dat hiermee opnames kunnen worden voorkomen in de toekomst.

Wat betreft de mensen met dementie en zeer ernstig probleemgedrag zelf zijn de volgende zaken van belang. Zo laat dit onderzoek zien dat de sterfte tijdens een opname hoog is, zeker bij mensen met ernstige fysieke agressie. Dit geeft aan dat tijdig gedacht moet worden aan palliatieve terminale zorg. Ook roept het vragen op voor verder onderzoek zoals de vraag of het van tevoren te voorspellen is wie zal overlijden, wie belang zal hebben bij consultatie en wie bij opname. De

afdelingen zetten nog veel verschillende interventies in en hun fysieke, sociale en organisatorische contexten kunnen wat verschillen: dit nader onderzoeken is van belang voor de toekomst.

Conclusie

Dit proefschrift laat zien dat gespecialiseerde afdelingen pionieren in de zorg en behandeling van mensen met dementie en zeer ernstig probleemgedrag wat betreft organisatie en behandeling. Zorgmedewerkers vervullen een centrale rol in de zorg en behandeling op deze afdelingen. Het verbeteren van het welbevinden van alle betrokkenen staat centraal in succesvolle behandeling van ernstig probleemgedrag evenals aandacht voor de kwaliteit van het behandelproces. Dit laatste behelst multidisciplinaire analyse en behandeling evenals de houding en vaardigheden van alle betrokkenen. Een derde van de onderzochte groep patiënten overleed tijdens opname op een gespecialiseerde afdeling en met name deelnemers met een zeer hoge score op fysieke agressie hadden een sterk verhoogd risico op overlijden. Het is van belang om in de praktijk en onderzoek speciale aandacht te hebben voor het welbevinden van de persoon met dementie en betrokkenen in de directe omgeving, het effect van verschillende interventies waarbij de specifieke context wordt betrokken, en hoe in passende palliatieve (terminale) zorg kan worden voorzien voor mensen met dementie en zeer ernstig probleemgedrag.

Data management

Ethics and privacy

Medical and ethical approval of the studies

This thesis is based on the results of research involving human participants, which was conducted in accordance with relevant national and international legislation and regulations, guidelines, codes of conduct and Radboudumc policy. The studies were not subject to the Dutch Medical Research Involving Human Subjects Act (WMO). Statements were obtained from the recognized CMO Radboudumc, Nijmegen, the Netherlands (CMO Radboudumc dossier number: 2018-4354. (Chapters 2 and 3) and 2020-6979 (Chapters 4 and 5)).

Privacy of the participants

The privacy of the participants in these studies was warranted using pseudonymization. The pseudonymization key was stored on a secured network drive that was only accessible to members of the project who needed access to it because of their role within the project. The pseudonymization key was stored separately from the research data. Informed consent was obtained from participants to collect and process their data for this research project.

Informed consent

Informed consent was obtained from participants to collect and process their data for this research project. Consent was also obtained for sharing the (pseudonymized) data after research. Participants or their legal representatives were informed about the use and re-use of data in the information letter and could opt-in for the use of the data in scientific research depositories on the informed consent form. The privacy of all participants was warranted by the use of encryption and unique individual subject codes (pseudonymization). These codes were stored separately from the study data. Technical and organizational measures were followed to safeguard the availability, integrity and confidentiality of the data (these measures include the use of pseudonymization, access authorization and secure data storage).

Data collection and storage

Data collection for Chapter 2 has three variants and several formats: 1) A survey for which LimeSurvey within the secured Radboudumc environment was used. Data were converged from LimeSurvey to SPSS; 2) interviews that were tape-recorded, pseudonymized and transcribed verbatim in Microsoft Word. Transcripts were entered into Atlas.ti (version 8.3.16) for data analyses; 3) assessment scales

administered using paper questionnaires (hardcopy) that were entered into SPSS. Paper (hardcopy) data and informed consent forms for the interview of participants are stored in the locked archive of the Department of Primary and Community Care of the Radboud university medical center, namely Verkroost Archiefservices. For the observational study (Chapter 4 and 5), the informed consent forms were stored at the participating units except for some units that delegated this task to the research team. Pseudonymized data were stored on the department server and are only accessible by project members working at the Radboudumc.

Data for Chapter 3 was collected pseudonymized using groupwisdom™, i.e. participants logged in with a pseudonym which was given to them by an email invitation and analyzed within groupwisdom™. In this way, groupwisdom™ had never access to personal data. Data and results of analyses were downloaded and stored on the department server and are only accessible by project members working at the Radboudumc.

Data for Chapter 4 and 5 was obtained by using Case Report Forms (eCRF) and secured online questionnaires Castor EDC. Data were converged from Castor EDC to SPSS. Pseudonymized data were stored on the department server and in Castor EDC and are only accessible by project members working at the Radboudumc.

Data sharing according to the FAIR principles

Our datasets can be found in the Radboud Data Repository:

Data acquisition collection (raw data): https://doi.org/10.34973/tycb-4s61

Research documentation collection (processed data and documentation): https://doi.org/10.34973/y601-xf89

Data is not available open access here. The data underlying Chapters 2 and 3 are available with restricted access due to pseudonymization. Moreover, some of the data of Chapter 2 contain confidential content. The data of the observational study, Chapters 4 and 5, are pseudonymized and will be made available with restricted access from the Radboud Data Repository after use in the Waalbed-V study. We used Castor EDC for the data collection of Chapter 4 and 5 because of the interoperability it provides for. We used interoperable file formats where possible.

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En dan is het nu zover: dit onderzoekstraject zit erop. Toen ik hieraan begon vertelde Raymond mij: "Je weet toch nooit echt waar je aan begint." En dat is waar. Maar ik had al zo'n vermoeden dat het de moeite waard zou zijn en dat was het. Ondanks dat de laatste loodjes wel even een lange adem vroegen, kijk ik dankbaar terug op alle mensen die ik hierdoor heb leren kennen en wat het me gebracht heeft.

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Geertje: op afstand in Ethiopië leefde je mee met dit traject. Omdat je vertrouwd bent met veel analysemethoden was het leuk met je hierover te sparren. Grappig genoeg had je serieuze plannen voor een PhD, maar ging manlief JD er opeens een doen. Maar je volgt vast wel een keer of niet: genoeg mooie dingen om op te zetten.

Lieve Hanneke: wat was het een bijzondere tijd toen we als twee nichten samen gingen wonen in jouw klushuis in Zwolle -sorry, ik wilde deze grap nog één keer maken-. Dank voor je kritische en opbouwende blik. Ik heb veel geleerd van jouw doorzettingsvermogen in dat klushuis. Je wilt de wereld mooier maken en maakt daar werk van. Je deed dit ook voor deze studie: je ontwierp het studie-logo, hielp met de flyer en tekende de concept map. Inmiddels ben je getrouwd met Wienand, en mama van Sam en Sera, maar zien en spreken we elkaar nog geregeld waarbij het met Lei erbij goed klikt.

En dan mijn paranimfen. Marthe: ik leerde je kennen bij de GRZ als mede-AIOS. We hadden een hoop lol en verwondering, zullen we het maar noemen. Dank voor je steun tijdens deze laatste periode en voor alle wandelingen bij ons in de buurt. Nadine: je gaat al heel lang mee en had zelf gepromoveerd kunnen zijn in de oogheelkunde met je uit de hand gelopen wetenschapsstage in Boston. Maar daar heb je natuurlijk niet zoveel meer aan als inmiddels bevlogen MDL-arts. Dank voor alle (telefonische) bijpraatmomenten.

Pap en mam, broers en schoonzussen -Elbert, Nineke, Gert, Mark en Esther-: dank dat ik altijd bij jullie terecht kan. Jullie grote zus is soms een beetje raar in wat ze allemaal doet, maar gelukkig kunnen jullie ermee leven. Veel liefs voor jullie en natuurlijk ook voor Levi, Sarah, Ted en Tommy.

En tot slot: Lei, dankjewel voor alle keren dat jij me op onze vrije dagen moest missen omdat ik boven zat met de laatste loodjes van dit onderzoek. En dat je dan vaak lunch voor me maakte. Ik hou van jou.

Curriculum Vitae (in Dutch)

Gerrie van Voorden werd geboren op 26 maart 1989 in Woerden. Zij behaalde haar atheneumdiploma aan het Driestar College in Gouda in 2007.

Tijdens het laatste jaar van het atheneum begon zij met een bijbaan als zorgassistent in het plaatselijke verzorgingshuis in Woerden. Na de zorgstage tijdens het eerste jaar geneeskunde aan de Universiteit Leiden verruilde zij deze rol voor verzorgende. In deze jaren maakte zij kennis met deze gemoedelijke werksetting.

Tijdens haar studie zocht Gerrie een wetenschapsstage met de mogelijkheid om kwalitatief onderzoek te doen en deze vond zij bij het VUmc. Zij interviewde tijdens deze wetenschapsstage artsen van een geheugenpoli over hun ervaring met euthanasie bij beginnende dementie. Deze ervaring bracht haar later veel in de eerste jaren als dokter en liet haar zien dat onderzoek doen heel verrijkend kan zijn. Tijdens de coschappen zocht Gerrie naar een generalistisch vak wat bij haar paste. Zij liep o.a. een keuze coschap kindergeneeskunde in Hawassa, Ethiopië. Tijdens haar semi-artsstage bij de interne ouderengeneeskunde in het Diaconessenhuis in Leiden realiseerde zij zich dat ze verder wilde in de ouderengeneeskunde.

Na haar afstuderen als arts in 2013 ging Gerrie werken bij Argos Zorggroep in Schiedam. Eind 2014 startte zij bij Alrijne Zorggroep in Leiderdorp waar zij werkte op de geriatrische neurologische revalidatie unit, een afdeling somatiek en op psychogeriatrische afdelingen. Van 2016 tot 2019 werkte zij eerst als basisarts en later als arts in opleiding tot specialist ouderengeneeskunde bij Zorgverlening Het Baken in Elburg en omstreken waar zij eveneens op revalidatie, somatiek en psychogeriatrische afdelingen werkte. Zij combineerde de opleiding tot specialist ouderengeneeskunde met een promotietraject bij de afdeling Eerstelijnsgeneeskunde van het Radboudumc. Deze Waalbed-IV studie heeft geresulteerd in dit proefschrift. Sinds oktober 2024 werkt Gerrie als specialist ouderengeneeskunde bij IJsselheem en heeft zij van IJsselheem de mogelijkheid gekregen haar promotieonderzoek af te ronden.

Gerrie is getrouwd met Lei Hendriks. Samen met hun kat en twee kippen wonen zij in Dedemsvaart.

PhD portfolio of Gerrie van Voorden

Department:	The Department of Primary and Community Care, Radboudumc
PhD period:	01/03/2018 – 01/10/2025
PhD Supervisors:	prof. dr. R.T.C.M. Koopmans, prof. dr. D.L. Gerritsen, prof. dr. M. Smalbrugge, prof. dr. R.C. Oude Voshaar

Training activities

Courses		**Year**	**ECTS**
• Basic course in legislation and organization for clinical researchers (BROK), and update	NFU	2018, 2022	1.5
• Management for PhD candidates	Radboud University	2018	2
• Scientific Writing for PhD candidates	Radboud University	2019	3
• Qualitative Research Methods and Analysis	Radboud University	2019	3
• Statistics for PhD's using SPSS	Radboud University	2019	2
• Epidemiological research: key principles (test result 8.5)	EpidM	2022	4
• Regression techniques (test result 8.0)	EpidM	2024	4
• Elective module Leadership and Organization	SOON	2023	2.5
• Graduate School Introduction Day	Donders Graduate School	2018	
• Graduate School Day	Donders Graduate School	2019	
• Graduate School Day 2	Donders Graduate School	2022	
• Scientific Integrity Course	Donders Graduate School	2020	

Conferences

Oral presentations

• Afdelingen voor patiënten met dementie en ernstig probleemgedrag: een beschrijving van hun organisatie en behandeling	Verenso	2019
• Characteristics of specialized units for people with dementia and very severe challenging behavior in the Netherlands: a mixed method study	IPA (virtual)	2021
• Welbevinden, een multidisciplinaire aanpak en een vaardig team: de drie kernzaken voor een succesvolle behandeling van ernstig probleemgedrag bij dementie	SANO	2022
• Welbevinden, een multidisciplinaire aanpak en een vaardig team: de drie kernzaken voor een succesvolle behandeling van ernstig probleemgedrag bij dementie	Verenso	2023
• Kenmerken van patiënten die worden behandeld op afdelingen voor dementie en zeer ernstig probleemgedrag (D-zep)	Verenso	2024

Poster presentations		
• Characteristics of specialized units for people with dementia and very severe challenging behavior in the Netherlands: a mixed method study	EuGMS	2021
• Well-being, multidisciplinary work and a skillful team: essential elements in successful treatment in severe challenging behavior in dementia	EuGMS	2022
Other		
• Attendance at various conferences including Verenso, UKON, Vilans, EuGMS, and IPA webinars.		
Teaching activities		
Supervision of internships/other		
• Supervising the thesis of a resident in elderly care medicine		2023
• Supervising an academic traineeship of a resident in elderly care medicine		2024
Interviews		
• Mijn hart ligt bij het verpleeghuis	Verenso	2020
• Onderzoek naar zeer ernstig probleemgedrag bij dementie	ZonMw	2023
Prizes		
Jan Stoopprijs	Verenso	2025
Other publications other than outlined in this thesis		
• Hora-est: Specific Care on the Interface of Mental Health and Nursing Home (SpeCIMeN)	Tijdschrift voor Ouderengeneeskunde	2020

Information page Donders Graduate School

Donders Graduate School

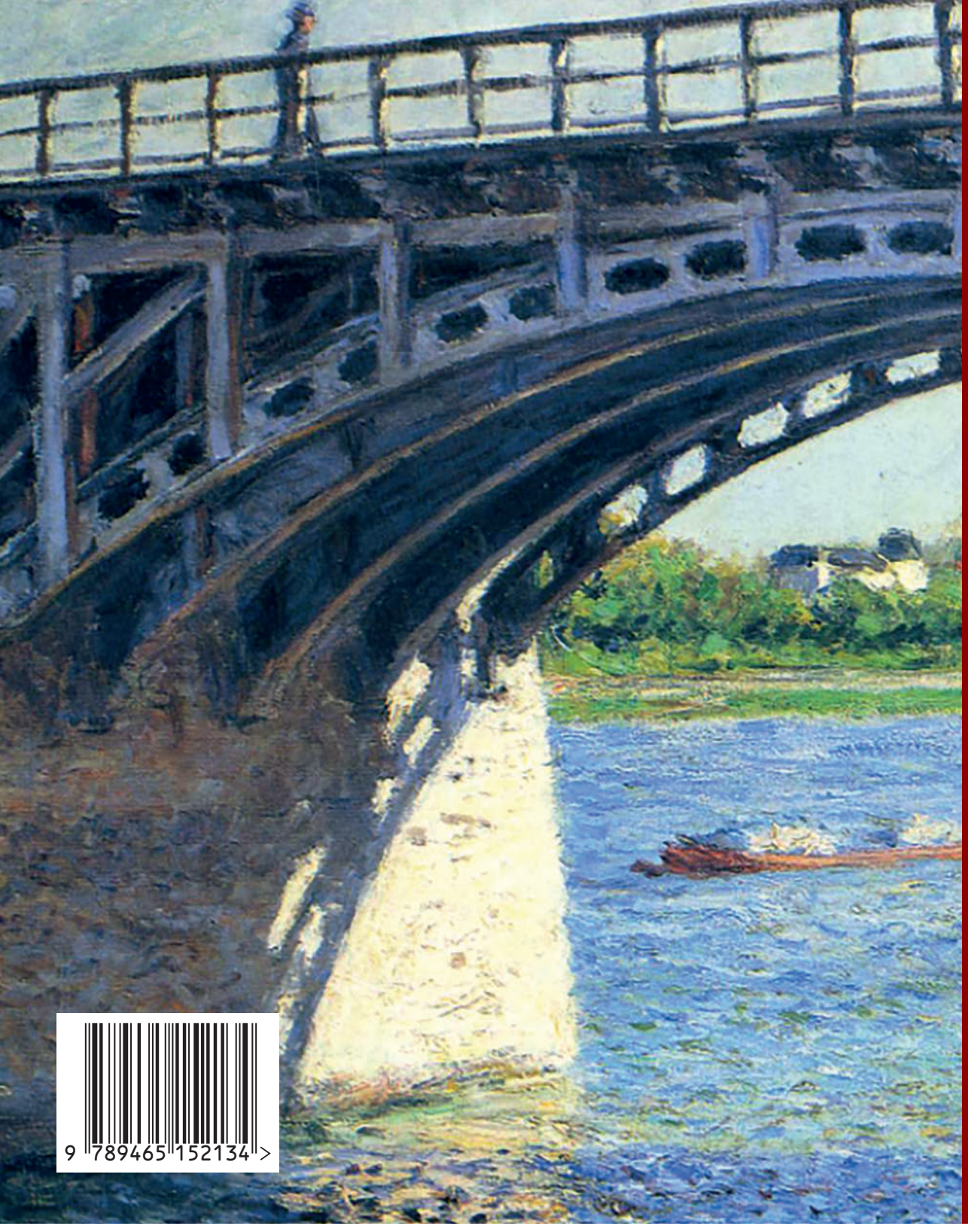
For a successful research Institute, it is vital to train the next generation of scientists. To achieve this goal, the Donders Institute for Brain, Cognition and Behaviour established the Donders Graduate School in 2009. The mission of the Donders Graduate School is to guide our graduates to become skilled academics who are equipped for a wide range of professions. To achieve this, we do our utmost to ensure that our PhD candidates receive support and supervision of the highest quality.

Since 2009, the Donders Graduate School has grown into a vibrant community of highly talented national and international PhD candidates, with over 500 PhD candidates enrolled. Their backgrounds cover a wide range of disciplines, from physics to psychology, medicine to psycholinguistics, and biology to artificial intelligence. Similarly, their interdisciplinary research covers genetic, molecular, and cellular processes at one end and computational, system-level neuroscience with cognitive and behavioural analysis at the other end. We ask all PhD candidates within the Donders Graduate School to publish their PhD thesis in de Donders Thesis Series. This series currently includes over 750 PhD theses from our PhD graduates and thereby provides a comprehensive overview of the diverse types of research performed at the Donders Institute. A complete overview of the Donders Thesis Series can be found on our website: https://www.ru.nl/donders/donders-series

The Donders Graduate School tracks the careers of our PhD graduates carefully. In general, the PhD graduates end up at high-quality positions in different sectors, for a complete overview see https://www.ru.nl/donders/destination-our-former-phd. A large proportion of our PhD alumni continue in academia (>50%). Most of them first work as a postdoc before growing into more senior research positions. They work at top institutes worldwide, such as University of Oxford, University of Cambridge, Stanford University, Princeton University, UCL London, MPI Leipzig, Karolinska Institute, UC Berkeley, EPFL Lausanne, and many others. In addition, a large group of PhD graduates continue in clinical positions, sometimes combining it with academic research. Clinical positions can be divided into medical doctors, for instance, in genetics, geriatrics, psychiatry, or neurology, and in psychologists, for instance as healthcare psychologist, clinical neuropsychologist, or clinical psychologist. Furthermore, there are PhD graduates who continue to work as researchers outside academia, for instance at non-profit or government organizations, or in pharmaceutical companies. There are also PhD graduates

who work in education, such as teachers in high school, or as lecturers in higher education. Others continue in a wide range of positions, such as policy advisors, project managers, consultants, data scientists, web- or software developers, business owners, regulatory affairs specialists, engineers, managers, or IT architects. As such, the career paths of Donders PhD graduates span a broad range of sectors and professions, but the common factor is that they almost all have become successful professionals.

For more information on the Donders Graduate School, as well as past and upcoming defences please visit: http://www.ru.nl/donders/graduate-school/phd/



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