



Fighting until the end

Nursing home residents with dementia and very severe or extreme challenging behavior: starting points for optimizing care

Annelies Veldwijk-Rouwenhorst

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Colofon

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challenging behavior: starting points for optimizing care

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Anne Elizabeth Rouwenhorst
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Promotoren:

Prof. dr. R.T.C.M. Koopmans

Prof. dr. S.U. Zuidema (Universitair Medisch Centrum Groningen)

Prof. dr. D.L. Gerritsen

Prof. dr. M. Smalbrugge (Amsterdam Universitair Medisch Centrum)

Manuscriptcommissie:

Prof. dr. H. Vermeulen

Prof. dr. R.C. Oude Voshaar (Universitair Medisch Centrum Groningen)

Prof. dr. D.J.A. Janssen (Maastricht University)

Jij strijdt
Een strijd
Met jezelf
En de wereld

Je bevecht
Jouw gevecht
Met je lichaam
En geest

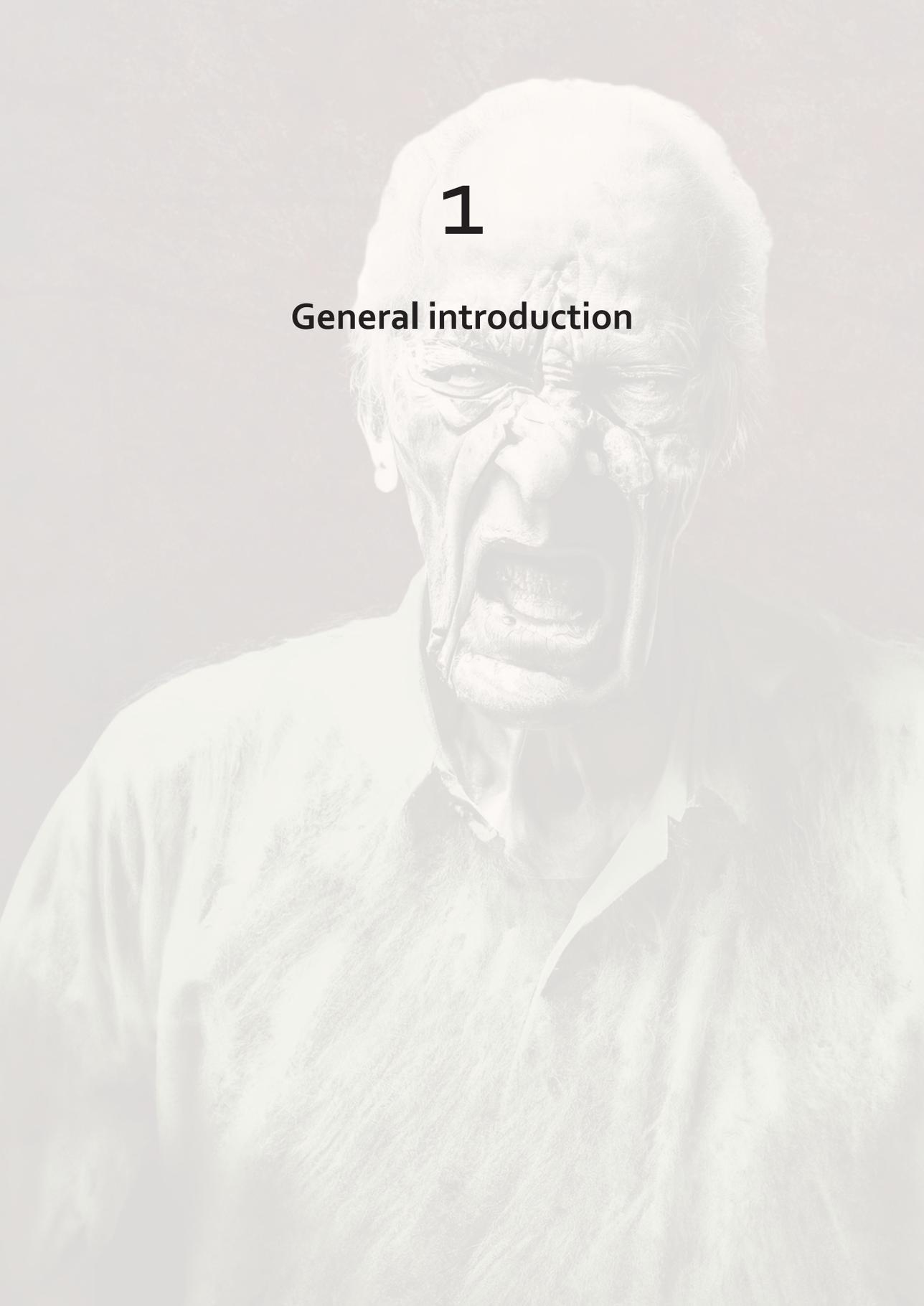
Je roept
Je slaat
Je bent verloren
En opgesloten

Je mist jezelf
Ver van wie je bent geweest

Uit 'Gedicht zonder titel', De Lachende Traan, website Alzheimer Nederland

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1

General introduction

Globally, 55 million people have dementia, which is a progressive syndrome characterized by a deterioration in cognitive function beyond what might be expected from the usual consequences of biological ageing.¹ The rate of cognitive decline varies among different types of dementia, of which dementia due to Alzheimer's disease is the most common form, contributing to 60-70% of cases.^{1,2} Other common types are vascular dementia, frontotemporal dementia and dementia with Lewy Bodies.³ Dementia has a great impact on those it affects. People with dementia face a very uncertain, unpredictable and ambiguous period of life and experience a loss of cognitive, functional and behavioral abilities.³ Furthermore, carers and families of those living with dementia are often over-burdened and may experience a deterioration of their own mental health.^{4,5} Lastly, dementia has a major impact on society.¹ In the Netherlands, 290.000 people live with dementia. Out of all conditions, it results in the highest health care costs.⁴ To reduce these costs, policy focuses on supporting people with dementia to live at home for as long as possible and appeals to informal caregivers to achieve this.⁶ Currently, in the Netherlands, 79% of the people with dementia live at home.⁴

When care at home for a person with dementia becomes insufficient due to increasing care intensity, worsening limitations in daily functioning and/or the complexity of the disease, 24-hour care in a nursing home (NH) becomes necessary. NHs are facilities with a domestic-style environment that provide 24-hour functional support and care for people who require assistance with daily living, and who often have complex healthcare needs and increased vulnerability.⁷ Currently, 80.000 people with dementia live in NHs across the Netherlands⁴, where care and treatment are provided in dementia special care units by multidisciplinary teams. These multidisciplinary teams consist of care staff (with certified primary nurse assistants, nurse assistants and vocationally-trained registered nurses), treatment staff (typically an elderly care physician, psychologist, physiotherapist, speech therapist, dietician, music therapist and occupational therapist) and, occasionally, a unit manager. This care environment is unique in the world, as all of these professionals are employed by the NH organization and elderly care medicine is an official medical specialty in the Netherlands, involving a three-year training program.⁸

More than 80% of NH residents with dementia show one or more types of challenging behavior, also known as neuropsychiatric symptoms or Behavioral and Psychological

Symptoms of Dementia (BPSD).⁹⁻¹¹ These include, for example, agitation, aggression, vocalizations, apathy and anxiety. Frequently, challenging behavior is the reason for admission to a NH, often because of the burden on informal caregivers.¹² In the NH, this behavior can cause distress in the NH resident themselves, with an impaired quality of life¹³ and more rapid cognitive and functional decline.^{14, 15} Furthermore, it causes burden and distress in other residents and (informal) caregivers.¹⁶⁻²⁰ Due to the Dutch policy that people with dementia live at home for as long as possible, at NH admission they already present with more severe and complex challenging behaviors than a decade ago. As a result, these residents have more complex care needs, which requires NH staff to have extra skills to achieve a good quality of treatment and care.

Sometimes, challenging behavior can become very severe or extreme and even refractory, where none of the conventional treatments are effective, fast-acting enough and sometimes accompanied by unacceptable side-effects.²¹⁻²³ In some cases, this may lead to an untenable situation or impasse in which NH staff feel that they are out of (treatment) options.^{24, 25} In these situations, life on the resident's unit is often disrupted, for instance the resident's behavior causes an increase in stimuli on the unit or the behavior requires much time and support from the NH staff. Moreover, this extreme behavior has an impact on the quality of life of the resident and other NH residents, for example due to (self-) injuries.^{26, 27} NH staff members may also get injured, become mentally distressed or dejected due to a lack of power to act.^{27, 28} From clinical practice, we know that NH residents with dementia and very severe or extreme challenging behavior constitute a small group. In a seven-tiered model of BPSD, Brodaty et al. categorized very severe and extreme BPSD and estimated that 10% of people with dementia can be categorized as very severe, while 1% have extreme BPSD. However, these percentages are not based on empirical data.²⁹ Moreover, this group of NH residents has not yet been operationally defined within the literature. To our knowledge, at the start of this study in 2014, no international literature existed on the prevalence rates and characteristics of NH residents with dementia and very severe or extreme challenging behavior. Potential associated factors for very severe or extreme challenging behavior were also unknown, as well as the experiences of NH staff with situations of very severe or extreme challenging behavior in residents with dementia. Furthermore, practice-based experience told us that in exceptional cases in which the extreme challenging behavior is refractory, continuous palliative sedation (CPS) is

administered. However, the process of decision-making that leads to CPS, the trajectory itself and the experiences of those involved had not been previously explored. To contribute to the optimal care and treatment of NH residents with dementia and very severe or extreme (refractory) challenging behavior, to improve their quality of life and for the development of guidelines for professionals, identification of these residents is necessary. Exploring the characteristics of these residents, correlates of their behavior and experiences of NH staff with situations of very severe or extreme challenging behavior in residents with dementia can be important starting points for optimizing care.

Aims and research questions of this thesis

The overarching goal of the WAALBED (WAAL Behavior in Dementia)-III study is to achieve more insight into the group of NH residents with dementia and very severe or extreme challenging behavior by characterizing them, and exploring the experiences of NH staff with situations of very severe or extreme challenging behavior and/or in which CPS was applied as a final solution.

The aims of this thesis are:

1. To study the prevalence and characteristics of NH residents with dementia and very severe or extreme challenging behavior.
2. To explore distinctive correlates for very severe or extreme challenging behavior.
3. To gain insight into the experiences of NH staff with situations of very severe or extreme challenging behavior in residents with dementia.
4. To explore situations in which CPS was applied because of refractory challenging behavior.

The aims are operationalized into the following research questions:

- What are the differences in prevalence and characteristics of NH residents with dementia with very severe or extreme challenging behavior and of NH residents with dementia and less severe challenging behavior?
- What are distinctive correlates for very severe or extreme challenging behavior?

- Why are situations of very severe or extreme challenging behavior of NH residents with dementia experienced as an impasse and what are contributing factors to this?
- How does the process of decision-making and the trajectory of CPS in NH residents with dementia and extreme challenging behavior take place and what are the experiences of those involved?

Outline of this thesis

To answer the first and second research questions, **Chapter 2 and Chapter 3** describe the results of a cross-sectional study which compared NH residents with very frequent agitation, very frequent physical aggression or very frequent vocalizations with residents who showed these behaviors less frequently. It used combined data of 2074 NH residents from four studies, collected from 119 dementia special care units in 26 Dutch NHs. Correlates for very frequent agitation, very frequent physical aggression and very frequent vocalizations were identified using univariate and multivariate multilevel logistic regression analyses.

Chapter 4 answers the third research question by exploring situations of very severe or extreme challenging behavior in NH residents with dementia that are experienced as an impasse by those involved. A qualitative, multiple case study was performed with individual interviews and focus group discussions. Interviewees were elderly care physicians, psychologists, care staff members, unit managers and relatives (n=42) who were involved with NH residents with dementia and extreme challenging behavior living on dementia special care units in the Netherlands. The reasons behind experiencing such situations as an impasse, as well as contributing factors, were identified.

In **Chapter 5** the results of a qualitative explorative study into the process of decision-making and the trajectory of CPS in NH residents with dementia and extreme challenging behavior are presented, thereby answering the fourth research question. Interviews were held with relatives, elderly care physicians and other staff members involved with three NH residents with dementia and refractory and extreme challenging behavior who had received continuous palliative sedation.

Finally, in **Chapter 6** the main findings and conclusions of this thesis are summarized and discussed, alongside several methodological considerations. Furthermore, implications and recommendations for practice, health care policy, education and future research are described.

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“Het (gedrag) is een soort veenbrand, dus het komt ergens weer omhoog en je weet niet waar en wanneer het omhoog komt, in welke hevigheid het omhoog komt.”

Specialist ouderengeneeskunde in individueel interview



2

Nursing home residents with dementia and very frequent agitation: a particular group

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Annelies E. Veldwijk-Rouwenhorst

Martin Smalbrugge

Roland B. Wetzels

Hans Bor

Sytse U. Zuidema

Raymond T.C.M. Koopmans

Debby L. Gerritsen

Abstract

Objective: Although many nursing home residents with dementia show agitation, hardly any literature is published about very frequent agitation. The WAALBED-III study focuses on the 2-week prevalence and correlates of very frequent agitation in these residents.

Design: Cross-sectional study using combined data of four studies.

Setting: One hundred nineteen dementia special care units in twenty-six nursing homes in the Netherlands.

Participants: Two thousand seventy-four residents with dementia.

Measurements: We operationally defined very frequent agitation as having a score of 6 (several times a day) or 7 (several times an hour) on at least five items of the Cohen Mansfield Agitation Inventory (CMAI) combined with a CMAI total score above the 90th percentile. To assess the association of demographic and behavioral characteristics with very frequent agitation, we performed a multivariate multilevel logistic regression analysis.

Results: The 2-week prevalence of very frequent agitation was 7.4% (95% CI: 6.374–8.634). Correlates for very frequent agitation were age (OR: 0.967, 95% CI: 0.942–0.992), dementia severity (GDS 6 = OR: 3.636, 95% CI: 1.929–6.875; GDS 7 = OR: 2.951, 95% CI: 1.321–6.588), delusions (OR: 2.480, 95% CI: 1.555–3.956), anxiety (OR: 1.904, 95% CI: 1.259–2.881), euphoria (OR: 3.712, 95% CI: 2.171–6.337) and irritability (OR: 4.411, 95% CI: 2.854–6.816).

Conclusions: To our knowledge, this study is the first to report prevalence data and correlates about nursing home residents with very frequent agitation. We found several correlated factors for very frequent agitation. Still, further research is needed for a better understanding of the behavior of this group, and to identify good treatment options.

Key Words: Agitation, dementia, very frequent, nursing home, residents

Introduction

Agitation is an important reason for nursing home (NH) admission among residents with dementia.¹ It is one of the most prevalent neuropsychiatric symptoms,^{2,3} with an estimated prevalence in NHs of 79% (range: 70%- 86%) according to the most recent review article.²

Agitation is often persistent during the NH stay.³ It occurs in several types of dementia,^{4,5} and habitually coexists with other neuropsychiatric symptoms.^{6,7} Furthermore, agitation manifests particularly in middle and later stages of dementia.⁸ Reported consequences of agitation are burden in family caregivers⁹ and in professional caregivers,¹⁰ more rapid cognitive and functional decline,^{11,12} and impaired quality of life.¹³ Causes of agitation may be internal (e.g. unmet needs, anatomical/physiological changes)¹⁴⁻¹⁶ and/or external (e.g. sound level on a unit).¹⁷ The multifactorial origin makes treatment of agitation complex, requiring a biopsychosocial treatment approach.

According to the most recent definition, agitation is excessive motor activity, verbal aggression, and/or physical aggression, which are consistent with emotional distress and produce excess disability on various domains.¹⁸ This definition of agitation is based on expert consensus, rather than on research. Moreover, this definition does not incorporate differences in severity of agitation.

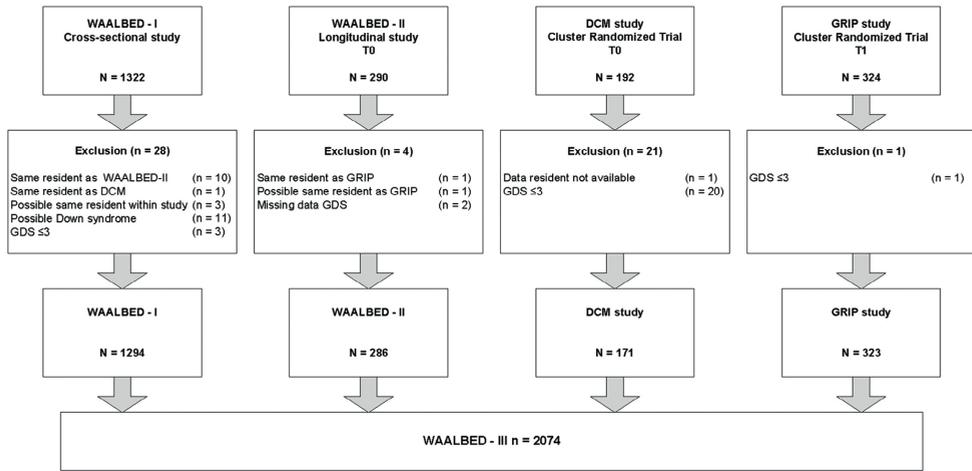
We know from clinical practice that there is a small group of NH residents with very frequent agitation.¹⁹ For example, practice reports illustrate that very frequent agitation in a NH resident frequently leads to a disruption of life on the care unit.¹⁹ Despite this impact, there are no studies that report on the prevalence of very frequent agitation. Therefore, exploration of the characteristics and behavior of a group of NH residents with very frequent agitation could provide relevant clues for improving NH care and perhaps the quality of life of these residents. For this reason, our WAALBED (WAAL Behavior in Dementia)-III study aims to study 1) the 2-week prevalence of very frequent agitation within the population of NH residents; and 2) the factors that distinguish NH residents with very frequent agitation from those with less frequent agitation.

Methods

Study design and subjects

We used the data of four existing studies in NH residents with dementia: the WAALBED-I study (cross-sectional study; N = 1319),²⁰ the WAALBED-II study (longitudinal; N = 290),²¹ the Dementia Care Mapping (DCM) study (randomized controlled trial, longitudinal; N = 434),²² and GRIP on challenging behavior study (randomized controlled trial, stepped wedge design; N = 659).²³ The data were combined into one data set. The studies recruited residents in the following periods: WAALBED-I study: 2003, WAALBED-II study: between 2006 and 2008, DCM: between 2010 and 2012, and GRIP: between 2011 and 2012. In all four studies, residents were considered for inclusion provided they: a) met the criteria for dementia according to the Diagnostic and Statistical Manual of Mental Disorders, fourth edition;²⁴ b) had no life-threatening disease at the time of inclusion; and c) had resided in the NH for at least 4 weeks. Residents who participated in more than one of the studies were included only once: data of the most recent study were used. Furthermore, residents who had Down syndrome and those with a score on the Global Deterioration Scale (GDS)²⁵ of 3 or lower, or a missing GDS score, were excluded. Of all studies, the only or first measurement was used, except for the GRIP study. Here, the second measurement was used, because data on quality of life (which we examine in another part of our study) were not collected at baseline.²³ Further, from the GRIP study only residents who were in the control condition at the second measurement were included. As a result of these exclusion criteria, 54 residents were excluded from the original merged data set. In addition, one resident was excluded because the majority of data was missing. This resulted in a dataset of 2074 residents (see Figure 1) from 26 NHs situated throughout the Netherlands. These NH residents were living in 119 different dementia special care units.

Figure 1. Flowchart of the included residents.



Notes: DCM: Dementia Care Mapping study; GDS: Global Deterioration Scale; WAALBED: WAAL Behavior in Dementia.

Data

Operationalization of very frequent agitation

We used the Cohen Mansfield Agitation Inventory (CMAI) to operationally define very frequent agitation.²⁶ The CMAI is the most widely used assessment scale for measuring the frequency of agitation and aggression. It consists of 29 items, each rated on a 7-point frequency scale (1 to 7) ranging from “never” to “several times an hour”. CMAI items can be summed into a total score with a possible range from 29 to 203.²⁶ In three studies the CMAI was administered by a research assistant interviewing the care staff member who was the most involved in the daily care of the resident. In one study (DCM) an Internet application was used for administering the CMAI. In all four studies, the care staff member was asked to use the 2-week period before the assessment date as reference period for their answers. We operationally defined very frequent agitation as having a score of 6 (several times a day) or 7 (several times an hour) on at least five CMAI-items combined with a CMAI total score above the 90th percentile.

Demographic characteristics

Information about age, sex, marital status, and duration of stay was present in all four data sets and therefore included. Other characteristics were not included because they were not present in all four data sets.

Dementia severity

Information about dementia severity was assessed using the GDS.²⁵ This scale ranges from normal cognition (GDS stage 1) to very severe cognitive decline (GDS stage 7).

Neuropsychiatric symptoms

Neuropsychiatric symptoms, other than agitation, were assessed with the Neuropsychiatric Inventory-Nursing Home version (NPI-NH). The NPI-NH was administered in the same way as the CMAI. The NPI-NH rates the frequency (F) and severity (S) of each symptom on a four-point (1–4) and three-point (1–3) Likert scale, respectively. By multiplying this frequency and severity scores, a separate score (F x S score) can be calculated, with values ranging from 0 (the symptom does not exist) to 12 for each symptom. Clinically relevant neuropsychiatric symptoms (F x S score ≥ 4) were used in the analyses.²⁷ Only the NPI items that were conceptually distinct from agitation were included. For example, the NPI item night-time behavior was excluded because of the overlap of some of its subquestions with the CMAI item wandering. As a result, we only used the following seven NPI items: delusions, hallucinations, anxiety, euphoria, apathy, irritability, and eating change.

Psychotropic drug use

Total psychotropic drug use (PDU) and the use of several PD-groups was measured according to the Anatomical Therapeutic Chemical classification²⁸ and grouped into antipsychotics, antidepressants, hypnotics, anxiolytic drugs, antiepileptics, and cholinesterase inhibitors. To quantify PDU, we used dichotomous categories of either 'present' or 'absent' per drug group in the analyses. Drugs that were taken as needed were discarded.

Data analysis

For the analyses SPSS 22.0 (IBM, Armonk, NY) was used. For the different studies the mean, standard deviation (SD), and range of the means of the NPI and CMAI scores for the care units within each study were described. Furthermore, the intraclass correlation coefficient was calculated, assessing how much of the variance of NPI and CMAI was explained by the clustering of NH residents within care units. Descriptive statistics were used to summarize the characteristics. The 2-week prevalence of very frequent agitation and a 95% score (Wilson) confidence interval were calculated. After that, based on the

severity of agitation, the data set was divided into three groups; one group of NH residents with very frequent agitation, a group of NH residents with less frequent agitation, and a group without agitation (CMAI total score of 29). Because of our focus on the factors that distinguish NH residents with very frequent agitation from those with less frequent agitation, the group without agitation was excluded from our analyses. Characteristics of NH residents with very frequent agitation and of residents with less frequent agitation were displayed. To take into account the hierarchical structure of the data (NH level and residents within care units), we used multilevel multivariate logistic modeling to assess the independent correlation of the characteristics with very frequent agitation.

Results

Residents

Table 1 provides the mean and range of the mean CMAI scores and the mean NPI scores of the care units for the four different studies, as well as the intraclass correlation coefficients of these mean scores. The mean CMAI scores of the GRIP study were higher than those of the other three studies; for the NPI, the mean scores for the WAALBED-II study and DCM study were lower.

Table 1. Characteristics: mean CMAI and NPI scores for the care units from the four studies.

Number of residents N = 2074				
Study Name (No. of Care Units)	CMAI Total Score ^a	ICC	NPI Total Score ^a	ICC
WAALBED-I (58)	47.9 (6.6; 34.4–64.5)	0.108	22.0 (8.3; 4.0–40.9)	0.158
WAALBED-II (14)	44.5 (6.1; 36.8–58.9)	0.113	19.3 (9.0; 9.1–44.6)	0.199
DCM (33)	47.2 (8.9; 32.5–68.0)	0.082	13.7 (7.0; 1.3–32.0)	0.056
GRIP (14)	55.4 (10.5; 47.9–89.6)	0.241	26.2 (10.6; 14.1–56.1)	0.199

Notes: DCM: Dementia Care Mapping study; ICC: intraclass correlation coefficient; WAALBED: WAAL Behavior in Dementia study.

^aMean (SD; min–max).

The characteristics of the NH residents in the merged data set are depicted in Table 2. The mean age was 83.0 years. The majority of the residents was female and in GDS stage 6. Antipsychotic drugs were prescribed most often. Of the NPI items, irritability had the highest prevalence. We found a 2-week prevalence of very frequent agitation of 7.4% (95% score [Wilson] CI: 6.374 – 8.634).

At the CMAI-item level, the residents with very frequent agitation had the highest scores on the items general restlessness, pacing and aimless wandering, and performing repetitious mannerisms (see Table 3). We elucidate the characteristics of the NH residents with very frequent agitation in Table 4. Multivariate multilevel logistic regression analysis showed that the odds for very frequent agitation were significantly lower in residents who were older and in residents with a NH stay of 12 to 60 months (compared with NH residents with a NH stay of 0 to 3 months). In contrast, the odds for very frequent agitation were significantly higher in residents with a GDS score of 6 or 7 (see Table 5). Moreover, the odds for very frequent agitation were significantly higher in residents who had delusions, anxiety, euphoria, and irritability. The odds for very frequent agitation did not differ significantly from 1 for the use of the various psychotropic drugs.

Table 2. Resident characteristics of the WAALBED-III study.

	Total (N = 2074)
Age at time CMAI measurement, y ^a	86.0 (7.6; 36 – 102)
Sex (% female) ^b	77.7% (1611)
Marital status ^{b,c}	
Married/ civil partnership/unmarried but living together/ living together	21.5% (369)
Divorced/unmarried	12.4% (212)
Widow(er)	66.1% (1133)
Duration of institutionalization ^{a,d}	28.9 (27.0; 0.0 – 219.3)
0-3 months	8.3% (172)
3-12 months	23.2% (479)
12-60 months	55.9% (1155)
>60 months	12.5% (259)
GDS ^b	
GDS 4	3.9% (80)
GDS 5	19.2% (399)
GDS 6	51.1% (1059)
GDS 7	25.8% (536)
Psychotropic drug use ^{b,e}	
Total	63.0% (1267)
Antipsychotic	34.6% (695)
Antidepressant	27.5% (553)
Hypnotic	13.6% (273)
Anxiolytic	15.8% (317)
Antiepileptic	5.9% (118)
Antidementia	2.8% (56)
CMAI total score ^a	48.0 (16.9; 29 – 154)
NPI-NH Symptoms ^{b,f}	
Delusions ^d	13.8% (284)
Hallucinations ^g	7.5% (155)
Anxiety ^h	21.7% (449)
Euphoria ^h	7.0% (145)
Apathy ⁱ	30.0% (622)
Irritability ^j	31.7% (656)
Eating change ^k	21.8% (422)

Notes: CMAI: Cohen Mansfield Agitation Inventory; GDS: Global Deterioration Scale; NPI-NH: Neuropsychiatric Inventory Nursing Home version.

^a Mean (SD; min-max).

^e Missing data n = 63.

^h Missing data n = 3.

^b % (n).

^f F x S scores ≥ 4 .

ⁱ Missing data n = 1.

^c Missing data n = 360.

^g Missing data n = 7.

^j Missing data n = 4.

^d Missing data n = 9.

^k Missing data n = 48.

Table 3. Percentages of the scores 6/7 of the CMAI items for NH residents with very frequent agitation.

CMAI Item	Score = 6 (several times a day) on this item	Score = 7 (several times an hour) on this item
	% (N)	% (N)
Pacing and aimless wandering	29.2 (45)	39.0 (60)
Inappropriate dressing or disrobing	16.2 (25)	5.2 (8)
Spitting	6.5 (10)	0.0 (0)
Cursing or verbal aggression	28.6 (44)	7.1 (11)
Constant unwarranted request for attention or help	29.2 (45)	32.5 (50)
Repetitive sentences or questions	29.9 (46)	27.3 (42)
Hitting	11.7 (18)	0.6 (1)
Kicking	6.5 (10)	0.0 (0)
Grabbing onto people or things inappropriately	35.7 (55)	8.4 (13)
Pushing	10.4 (16)	0.6 (1)
Throwing things	7.1 (11)	0.0 (0)
Making strange noises	20.1 (31)	16.9 (26)
Screaming	14.9 (23)	6.5 (10)
Biting	2.6 (4)	0.0 (0)
Scratching ^a	8.8 (13)	3.3 (5)
Trying to get to a different place	29.2 (45)	13.0 (20)
Intentional falling	1.3 (2)	0.6 (1)
Complaining	29.9 (46)	7.8 (12)
Negativism	29.2 (45)	8.4 (13)
Eating or drinking inappropriate substances	2.6 (4)	0.6 (1)
Hurting self or other	9.7 (15)	2.6 (4)
Handling things inappropriately	28.6 (44)	7.8 (12)
Hiding things ^a	14.4 (22)	3.3 (5)
Hoarding things	18.8 (29)	5.8 (9)
Tearing things or destroying property	6.5 (10)	0.0 (0)
Performing repetitious mannerisms	34.4 (53)	29.2 (45)
Making verbal sexual advances	1.9 (3)	0.6 (1)
Making physical sexual advances or exposing genitals	1.9 (3)	0.6 (1)
General restlessness	42.2 (65)	46.1 (71)

Notes: CMAI: Cohen Mansfield Agitation Inventory.

^aMissing data n = 1.

Table 4. Characteristics of NH residents with very frequent agitation and less frequent agitation (N = 1858).

	Very Frequent Agitation (N = 154)	Less Frequent Agitation (N = 1704)
Age at time CMAI measurement, years ^a	80.8 (7.3; 55–94)	83.2 (7.6; 36–102)
Sex (% female) ^b	77.9% (120)	77.4% (1319)
Marital status ^{b,c}		
Married/civil partnership/unmarried but living together/living together	22.2% (26)	21.0% (294)
Divorced/unmarried	62.4% (73)	66.7% (934)
Widow(er)	15.4% (18)	12.3% (173)
Duration of institutionalization ^{a,d}	26.0 (24.2; 0.0–175.2)	28.3 (26.0; 0.0–1914.2)
0–3 months	10.4% (16)	8.0% (136)
3–12 months	24.0% (37)	23.6% (401)
12–60 months	57.8% (89)	56.4% (956)
>60 months	5.6% (12)	12.0% (203)
GDS ^b		
GDS 4	1.3% (2)	3.8% (65)
GDS 5	8.4% (13)	19.8% (338)
GDS 6	73.4% (113)	50.8% (865)
GDS 7	16.9% (26)	25.6% (436)
Psychotropic drug use ^{b,e}		
Total	78.1% (118)	64.5% (1061)
Antipsychotic	52.3% (79)	35.7% (588)
Antidepressant	37.7% (57)	27.6% (454)
Hypnotic	15.9% (24)	14.2% (233)
Anxiolytic	27.8% (42)	15.9% (261)
Antiepileptic	6.6% (10)	5.9% (97)
Antidementia	4.0% (6)	2.7% (44)
NPI-NH symptoms ^{b,f}		
Delusions ^d	41.6% (64)	12.8% (217)
Hallucinations ^g	19.5% (30)	7.2% (122)
Anxiety ^h	49.4% (76)	20.9% (355)
Euphoria ^h	24.7% (38)	5.9% (101)
Apathy ⁱ	39.0% (60)	29.7% (505)
Irritability ^j	76.0% (117)	31.4% (533)
Eating change ^k	33.3% (51)	21.1% (351)

Notes: GDS: Global Deterioration Scale; NPI-NH: Neuropsychiatric Inventory Nursing Home version.

^aMean (SD; min–max).

^b% (n).

^cMissing data n = 340.

^dMissing data n = 8.

^eMissing data n = 61.

^fF × S scores ≥ 4.

^gMissing data n = 6.

^hMissing data n = 3.

ⁱMissing data n = 1.

^jMissing data n = 4.

^kMissing data n = 44.

Table 5. Correlates for very frequent agitation in NH residents with dementia.

Number of Residents N = 1750 (complete case analysis)	Odds Ratio	95% CI	p value
Age	0.967	0.942–0.992	0.012
Sex ^a	0.938	0.585–1.505	0.791
Duration of institutionalization ^b			
3–12 months	0.591	0.278–1.257	0.172
12–60 months	0.488	0.242–0.987	0.046
>60 months	0.372	0.138–1.003	0.051
GDS ^c			
GDS 6	3.636	1.929–6.875	<0.001
GDS 7	2.951	1.321–6.588	0.008
Psychotropic drug use			
Antipsychotic ^d	1.419	0.942–2.137	0.094
Antidepressant ^d	0.968	0.631–1.484	0.881
Hypnotic ^d	0.948	0.549–1.636	0.848
Anxiolytic ^d	1.479	0.923–2.372	0.104
Antiepileptic ^d	0.832	0.377–1.836	0.649
Antidementia ^d	1.487	0.534–4.139	0.448
NPI-NH symptoms			
Delusions ^e	2.480	1.555–3.956	<0.001
Hallucinations ^e	1.454	0.820–2.585	0.200
Anxiety ^e	1.904	1.259–2.881	0.002
Euphoria ^e	3.712	2.174–6.337	<0.001
Apathy ^e	1.398	0.916–2.133	0.121
Irritability ^e	4.411	2.854–6.816	<0.001
Eating change ^e	1.336	0.859–2.077	0.199

Notes: GDS: Global Deterioration Scale; NPI-NH: Neuropsychiatric Inventory Nursing Home version. Multivariate multilevel logistic regression F (20.1729) = 8.130, p ≤ 0.001.

^aRef Female.

^bRef 0–3 months.

^cRef GDS 4 and 5.

^dRef without this type of drug.

^eRef without this NPI item.

Discussion

To our knowledge, this study is the first to report prevalence rates of NH residents with very frequent agitation. We found a 2-week prevalence of very frequent agitation of 7.4%. Odds for very frequent agitation were significantly lower in residents who were older and who stayed in the NH for more than 12 months and less than 60 months, yet were higher for residents with more severe dementia, psychotic symptoms, euphoria, or irritability.

Because studies about very frequent agitation are lacking, we can only compare our findings with figures of less frequent agitation in NH residents with dementia. On the one hand, these studies-which in general were performed in patients with Alzheimer disease-found similar results regarding the association with psychotic symptoms.²⁹⁻³¹ Also, these studies demonstrate a relationship with severe dementia⁸ and anxiety.³² On the other hand, to our knowledge, some of the found associations have never been studied before, like the relationship between duration of stay and agitation.

There are several possible explanations for the association between delusions and very frequent agitation. First, frontal lobe dysfunction plays an important role in the origin of delusions³³ as well as of agitation.¹⁵ Second, a study in patients with mild cognitive impairment and Alzheimer disease describes a significant association of neocortical atrophy with the onset of psychosis (including agitation, hallucinations, and delusions).³⁴ Finally, agitation, psychosis, and frontal disinhibition often appear together.³⁵ Concerning the association of anxiety with very frequent agitation, earlier studies have proposed some explanations. For instance, agitation has been considered the expression of underlying anxiety.³⁶ Moreover, the alterations of functional connectivity in the brain are the same for anxiety and agitation.³⁷ In the same way, the association between irritability and very frequent agitation can be explained by an underlying biological mechanism, as poorer white matter integrity has been associated with an increased likelihood to exhibit irritability and agitation.³⁸ The role of neurological deficits in the origin of the symptoms mentioned here is supported by a review by Zwijsen et al.³⁹ They conclude that the way people with dementia recognize, interpret, and respond to the world around them might be influenced by neuropsychological functioning in dementia and they call for further research.³⁹

The suggestion that very frequent agitation and correlated neuropsychiatric symptoms may stem from alterations in similar areas of the brain are important. As is known, very frequent agitation can be an expression of unmet needs,¹⁴ but perhaps there are cases in which it is caused by brain damage alone. Also, very frequent agitation may be an expression of another underlying neuropsychiatric symptom, like anxiety.³⁶

Although it is questionable whether different underlying causes of very frequent agitation can be separated clinically, a combination of particular symptoms, like very frequent agitation with delusions and anxiety, may point towards a biological cause. Still, we cannot justify this assumption with existing studies. The possible explanations of our results signify the importance of performing research into the relationships between different neuropsychiatric symptoms- including agitation- and between neuropsychiatric symptoms and neurological deficits in NH residents with dementia.

Our study has several strengths. First, we used a large sample of 2074 NH residents. As such, it was possible to perform logistic regression analyses applying multiple possible confounders. Second, our sample was representative, because of the participation of a large number of NHs from many regions of the Netherlands.

One of the limitations of this study is that PDU may have decreased the 2-week prevalence rate of very frequent agitation because of its possible effect on this symptom. This may have weakened the relationships between the correlates found and very frequent agitation. Another limitation is that we could not address dementia subtypes, because no pertaining data were available. Would that have been the case, we could have investigated, for instance, whether the relationship between delusions and very frequent agitation was stronger in NH residents with frontotemporal dementia. A third possible limitation is that marital status was not included in the multivariate logistic regression analysis, because the GRIP study did not collect data about marital status of the NH residents. This would have resulted in many missing values in our total WAALBED-III data set, whereas we expect the importance of marital status to be limited in agitation of institutionalized residents with dementia. Fourth, because we were limited by the available data of the four studies, unfortunately we could not include other potentially interesting variables in the analysis, like pain, function, or depressive symptoms. This would be interesting for further research.

Fifth, although the CMAI scores of the DCM study did not differ significantly, the NPI-NH scores in the DCM study were lower than in the other three studies. Given the difference in administration of the NPI-NH (self-assessment versus interview-based), these results may suggest that the mode of administration is a relevant aspect when interpreting these questionnaires' results.

A final limitation is the operationalization of very frequent agitation. To start with, we defined very frequent agitation based on the frequency of symptoms above a certain threshold value. This operational definition may not be appropriate or restrictive enough. Although the fact that we combined two criteria (a score of 6 or 7 on at least five CMAI items combined with a CMAI total score above the 90th percentile) contributes to a refinement of the operationalization of very frequent agitation, by using the second criterion we partially determined the 2-week prevalence beforehand. It would be interesting to determine prevalence and correlates in another sample using the same cutoff criteria. Furthermore, for the operationalization of very frequent agitation, we used the CMAI. Given the use of four existing data sets that only included the CMAI and NPI for challenging behavior, we were not able to use other measures to define very frequent agitation. In our view, it is more appropriate to use the CMAI for defining agitation than the NPI, because the CMAI specifically targets agitation and is very comprehensive. It might have been more optimal to also take severity or disruptiveness into account. Nevertheless, given the findings of Cohen-Mansfield,⁴⁰ that frequency and disruptiveness of behavior were highly correlated, our group of residents with very frequent agitation could very well be comparable to the residents with the most disruptive behavior. To fully grasp a concept of severe or extreme agitation, however, it may not only be necessary to include other aspects of the resident's agitated behavior into account such as whether it is directed towards other people, but also aspects of the context in which the agitation occurs. For instance, the environment of NH a unit or the care approach of the NH staff may be even more important factors for explaining why agitation is considered very frequent than the demographic and behavioral characteristics of the pertaining resident. That is the reason why describing this context should be the next step in research and in understanding very frequent agitation, next to exploring the characteristics of the behavior more broadly and in depth.

Conclusion

In conclusion, this study of a large sample of NH residents with dementia showed a 2-week prevalence of very frequent agitation of 7.4%. These residents differ significantly from residents with less frequent agitation on several aspects, like psychotic symptoms, euphoria, and irritability. Nevertheless, much about very frequent agitation remains unclear. Therefore, further research is needed to establish a comprehensive definition of very frequent agitation, to investigate the relationship of neurological deficits with very frequent agitation and correlated neuropsychiatric symptoms, and to explore the context of this behavior. More insight into NH residents with dementia showing very frequent agitation may lead to better treatment. Subsequently, the severity of agitation might become less frequent and the quality of life of these residents may improve.

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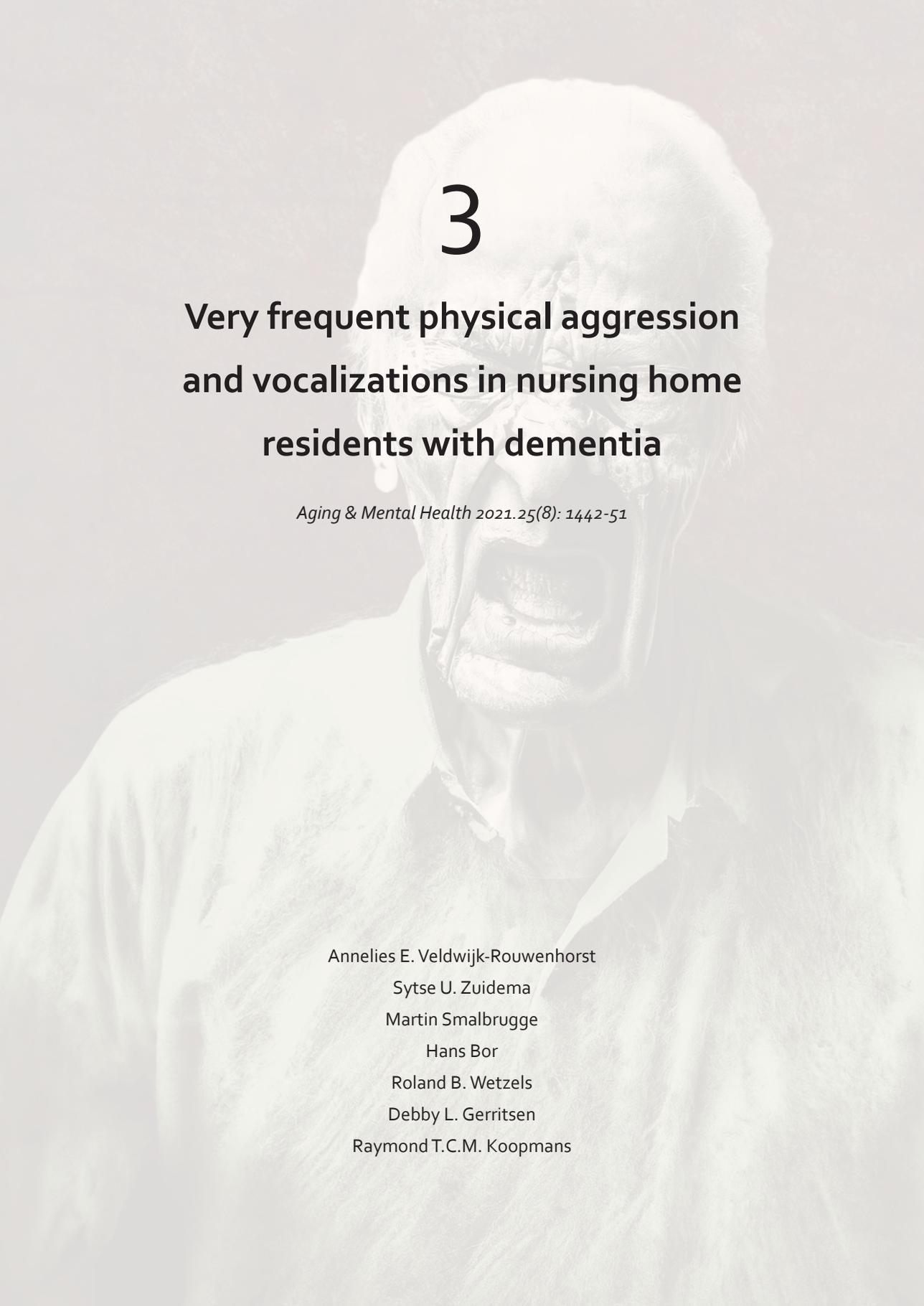
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“Als je er geen grip op krijgt, dat vind ik heel moeilijk. Dat ik naar mijn idee eigenlijk van alles geprobeerd heb en het gedrag blijft dan. Dan sta je wel eens voor je gevoel met je rug tegen de muur.”

Eerst verantwoordelijk verzorgende in individueel interview



3

Very frequent physical aggression and vocalizations in nursing home residents with dementia

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Annelies E. Veldwijk-Rouwenhorst

Sytse U. Zuidema

Martin Smalbrugge

Hans Bor

Roland B. Wetzels

Debby L. Gerritsen

Raymond T.C.M. Koopmans

Abstract

Objectives: We investigated the 2-week prevalence and correlates of very frequent physical aggression (PA) and vocalizations in nursing home (NH) residents with dementia.

Method/Design: This cross-sectional study used combined data of 2074 NH residents from four studies, collected from 119 dementia special care units in 26 Dutch NH. Very frequent PA was defined as scoring 6 or 7 on the items 'hitting', 'pushing', 'biting' and 'kicking' of the Cohen Mansfield Agitation Inventory; very frequent vocalizations as scoring 6 or 7 on 'screaming' and 'making strange noises'. We compared NH residents with very frequent PA or vocalizations with residents with less frequent PA or vocalizations, assessing correlates using univariate and multivariate multilevel logistic regression analyses.

Results: We found a 2-week prevalence of 2.2% (95% confidence interval (CI): 1.63–2.89) of very frequent PA and 11.5% of very frequent vocalizations (95% CI: 10.23–12.98). Very frequent PA was only associated with apathy (odds ratio (OR) = 1.93, 95% CI: 1.04–3.61). Correlates of very frequent vocalizations were age (OR = 0.97, 95% CI: 0.951–0.998), dementia severity (overall *p*-value 0.020), antipsychotic drug use (OR = 1.56, 95% CI: 1.08–2.26), antiepileptic drug use (OR = 2.75, 95% CI: 1.34–5.68) and euphoria (OR = 2.01, 95% CI: 1.22–3.31).

Conclusion: Characteristics of NH residents with very frequent PA or very frequent vocalizations differ from those of NH residents with less frequent PA or vocalizations. Frontal lobe damage, boredom, pain and/or external factors may explain several of the found associations, but further research is necessary. Our findings may contribute to better care for these residents and thereby to improving their quality of life.

Introduction

Physical aggression (PA) and vocalizations are behaviors of nursing home (NH) residents with dementia that are experienced as challenging and complex. They cause distress and burden in the NH resident self, other residents and (informal) caregivers.¹⁻⁵ PA (e.g. hitting, pushing, scratching)⁴ can be directed towards nursing staff⁶ or other NH residents.^{6,7} Previous cross-sectional studies have suggested that causes of (physical) aggression or vocalizations (e.g. screaming, excessively loud and/or repetitive verbal utterances)^{2,8} could be internal (i.e. physical, cognitive/neurobiological or psychological);^{3,9-12} or external (i.e. environmental).^{6,13,14} However, these studies were mostly small and did not focus on very frequent PA or vocalizations.

The multifactorial etiology and complexity mean that treatment and care for NH residents with PA or vocalizations are challenging. These behaviors may result in the prescription of psychotropic drugs^{15,16} and PA has been shown to lead to the use of physical restraints.¹⁶ Prevalence rates of 6–21% (PA)¹⁶ and 11–30% (vocalizations)¹⁰ have been reported in NHs.

Several correlates have been described for PA and vocalizations, such as higher age,^{4,10} more dementia severity,^{4,17} psychotropic drug use (PDU),^{4,16} and positive associations with other neuropsychiatric symptoms, e.g. depression and psychotic disorders,^{13,18} whereas conflicting results have been found for sex.^{4,10,16}

PA and vocalizations in NH residents can be extremely severe and very frequent. Although suggested prevalence rates of NH residents with very frequent PA or very frequent vocalizations are low,^{4,29} anecdotal information from daily practice shows that these extreme behaviors cause suffering in the pertaining residents, have a great impact on people involved including co-residents, and lead to difficulties in managing the behaviors among NH staff. Resident-to-resident aggression is considered a widespread but disregarded phenomenon²⁰ and can result in serious injuries and even death in co-residents.^{7,21} Furthermore, NH staff can get injured and experience mental distress as a consequence of very frequent PA or very frequent vocalizations.^{22,23}

Acquiring insight into the prevalence and characteristics of residents with these extreme behaviors is highly relevant; on the one hand to obtain points for improvement in the care and quality of life for these residents, on the other hand to diminish the impact of these behaviors on the people involved. We reported data about NH residents with dementia and very frequent agitation in a previous paper describing the WAALBED (WAAL Behavior in Dementia)-III study.²⁴ Agitation, however, encompasses several types of behavior which may differ in prevalence and relevant associated characteristics. Therefore, in this paper, we focus on two specific behaviors often considered to be part of agitation²⁵ and regarded as especially challenging.^{3,3,5} The primary aim of this article was to explore the 2-week prevalence of NH residents with very frequent PA or very frequent vocalizations in a sample of NH residents. Furthermore, this article is a first attempt to investigate whether NH residents with very frequent PA or very frequent vocalizations are different from those with less frequent presentations of these behaviors by exploring if there are distinctive correlates for these very frequent behaviors. This would provide NH staff insight into which NH residents will be at risk of very frequent PA or vocalizations. We hypothesize that these groups have distinct characteristics compared to NH residents with less frequent PA and less frequent vocalizations.

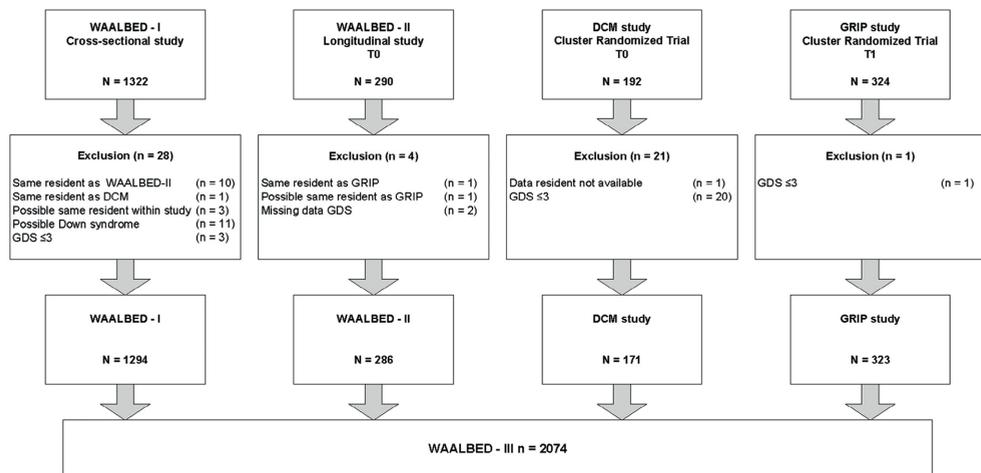
Methods

Study design and subjects

As previously described²⁴ we combined data from four studies in NH residents with dementia: WAALBED-I study (cross-sectional study; N = 1319, 2003),²⁶ WAALBED-II study (longitudinal study; N = 290, 2006–2008),²⁷ Dementia Care Mapping (DCM) study (randomized controlled trial, cluster randomized; N = 434, 2010–2012)²⁸ and GRIP on challenging behavior study (randomized controlled trial, stepped wedge design; N= 659, 2011–2012).²⁹ All studies were conducted according to the principles of the Declaration of Helsinki (version 2013, www.wma.net). The regional Medical Ethics Committees for Arnhem/Nijmegen and Amsterdam reviewed the study protocols. Informed consent was obtained from the primary legal representative or legal guardian in all studies.

We considered residents for inclusion if they: (a) met the criteria for dementia according to the Diagnostic and Statistical Manual of Mental Disorder, fourth edition,³⁰ (b) had no life-threatening disease at the time of inclusion; and (c) had resided in the NH for at least 4 weeks. The sole/baseline measurement was used from the first three studies. We only included data from residents in the control condition at the second measurement from the GRIP study. In another part of our study we aim to examine data on quality of life of NH residents with dementia and very frequent behavior. Because data on quality of life were not collected at baseline in the GRIP study, we used the second measurement of that study.²⁹ Where residents had participated in more than one of the four studies we only included data from the most recent study. Residents with a Global Deterioration Scale (GDS)³¹ score of 3 or lower, or a missing GDS score, were excluded as well as residents who had Down syndrome. In addition, we excluded one resident because the majority of data was missing. These criteria resulted in the exclusion of 54 residents from the original merged data set, leaving a data set of 2074 residents (see Figure 1) from 119 different dementia special care units in 26 NHs situated throughout the Netherlands. Because of this large sample, it was possible to perform logistic regression analyses applying multiple possible confounders.

Figure 1. Flowchart of the included residents.



Notes: DCM: Dementia Care Mapping study; GDS: Global Deterioration Scale; WAALBED: WAAL Behavior in Dementia.

Data

Operationalization of very frequent physical aggression and very frequent vocalizations

We assessed PA and vocalizations with the Dutch version of the Cohen Mansfield Agitation Inventory (CMAI).³² The CMAI is the most widely used instrument for measuring the frequency of agitation and aggression in NH residents.³³ It consists of 29 items, each rated on a 7-point frequency scale (1–7) ranging from 'never' to 'several times an hour' and can be summed into a total score with a possible range from 29 to 203.³³ In all four studies, the care staff members most involved in the daily care of the resident completed the CMAI. In three studies this were licensed vocational nurses who had been specifically assigned to individual residents and thus knew them well.^{26,27,29} In the DCM study these data were not available.²⁸ In that study the CMAI was administered using a web-based application. In all four studies, the 2-week period before the assessment date was used as reference period for their observations.

Very frequent PA was defined as having a score of 6 (several times a day) or 7 (several times an hour) on the items 'hitting', 'pushing', 'biting' and 'kicking' of the CMAI. In order to interpret correlates, we decided to only include items which in terms of content could be unambiguously labeled as PA and directed towards other people. Therefore, the items 'spitting', 'hurting self or others', 'tearing things or destroying property' and 'scratching' were not included.

Very frequent vocalizations were defined as having a score of 6 or 7 on the items 'screaming' and 'making strange noises' of the CMAI. Like with PA, we decided to only include items which in terms of content could be clearly labeled as vocalizations. The choice of selecting items for the definition of very frequent vocalizations was based on the first type of vocalizations described in Table 1 in the article of von Gunten et al.,³⁴ but without the prerequisite that the vocalizations caused disruption as this is very difficult to operationalize. Additionally, we did not include the item 'cursing or verbal aggression' of the CMAI because this item may regard aggression more than vocalizations. If it was not possible to determine to which group a NH resident belonged due to missing relevant CMAI items, we excluded that resident from the analyses.

Other measurements

We included the demographic characteristics: age, sex, marital status and duration of institutionalization. Dementia severity was assessed with the GDS, which ranges from normal cognition (GDS stage 1) to very severe cognitive decline (GDS stage 7).³¹ Neuropsychiatric symptoms were assessed with the Dutch version of the Neuropsychiatric Inventory-Nursing Home version (NPI-NH).^{35,36} With this assessment-instrument, frequency (F) and severity (S) of each symptom are rated on a four-point (1–4) and three-point (1–3) Likert scale, respectively. A separate score (F x S score) can be calculated by multiplying the frequency and severity scores. This results in values ranging from 0 to 12 for each symptom. The NPI-NH was administered in the same way as the CMAI.

In the analyses, we used clinically relevant neuropsychiatric symptoms, commonly defined as an F x S score of ≥ 4 .³⁷ We excluded NPI-items that were conceptually similar to PA or vocalizations. For PA\ this applied to the items aggression/agitation, irritability and disinhibition, and concerning vocalizations to the item aggression/agitation.

PDU was classified and grouped into several PD-groups (antipsychotics, antidepressants, hypnotics, anxiolytic drugs, antiepileptics and cholinesterase inhibitors) by using the Anatomical Therapeutical Chemical-classification.³⁸ We used dichotomous categories of either 'present' or 'absent' per drug group in the analyses to quantify PDU and discarded drugs which were taken as needed.

Data analysis

SPSS 22.0 (IBM, Armonk, NY) was used for the analyses. We calculated the 2-week prevalence of very frequent PA and very frequent vocalizations including a 95% (Wilson) confidence interval.

Since we were interested in correlates that can help to identify NH residents with a risk of very frequent behavior, only those with very frequent (scoring 6 or 7 on the selected CMAI items) and less frequent PA and vocalizations (scoring 2–5 on the selected CMAI items) were included for the analysis. We did not include residents without the behavior (a score of 1 on the selected CMAI items), because, given the generally high prevalence of agitation in NH residents, comparing NH residents with very frequent behavior with residents

without PA or vocalizations would not result in finding correlates that are specifically relevant for identifying those with very frequent behavior.

To take the hierarchical structure of the data into account (NH residents within care units), we used multilevel modeling with a mixed model including a random intercept varying across the care unit level. For selecting variables for multivariate analysis, univariate multilevel logistic regression analysis was used to exploratively assess the relationship of characteristics (age, sex, duration of institutionalization, dementia severity, PDU and other neuropsychiatric symptoms) with very frequent PA and with very frequent vocalizations. To assess the independent relationships of correlates with the outcomes we included variables with $p < 0.25$ in the univariate analyses in a multivariate logistic model.³⁹

Results

Very frequent physical aggression

Due to missing relevant CMAI items in two residents, the total sample of NH residents was 2072. We found a 2-week prevalence of 2.2% (95% CI: 1.63–2.89) for very frequent PA (N = 45) and a 2-week prevalence of 24.0%, (95% CI: 22.24–25.92) for less frequent PA (N = 498). The majority of NH residents with very frequent PA were female (77.8%). Mean age of these residents was 81.6 (SD 8.6) years and ranged from 47 to 93 years. Most NH residents were in a moderately severe stage of dementia (GDS 6, 48.9%) (see Table 1). Antipsychotic drugs (55.8%) were prescribed most often in these residents. Apathy was the NPI item with the highest prevalence in this group (55.6%) (see Table 2). In the univariate multilevel analysis, dementia severity, the use of antipsychotics and having apathy were correlated with very frequent PA, based on a p-value of < 0.25 (see Table 3). Multivariate multilevel logistic regression analysis with these variables showed that the odds for very frequent PA were statistically significantly higher in residents who had apathy (OR 1.93, 95% CI 1.04-3.61) (see Table 3).

Table 1. Demographic data of NH residents with dementia with very frequent physical aggression (PA) and less frequent PA (Total N = 2072) as well as NH residents with dementia with very frequent vocalizations and less frequent vocalizations (Total N =2073).

	Very frequent PA	Less frequent PA	Very frequent Vocalizations	Less frequent Vocalizations
	N = 545	N = 498	N = 239	N = 392
	Prevalence 2.2%	Prevalence 24.0%	Prevalence 11.5%	Prevalence 18.9%
Age at CMAI measurement, mean (SD), y	81.6 (8.6)	83.1 (7.6)	81.5 (8.4)	84.1 (7.3)
Gender, n (%)				
Female	35 (77.8)	373 (74.9)	188 (78.7)	317 (80.9)
Male	10 (22.2)	125 (25.1)	51 (21.3)	75 (19.1)
Marital status, ^a n (%)				
Married/ civil partnership/ unmarried but living together/ living together	13 (37.1)	85 (23.0)	39 (20.3)	59 (19.2)
Divorced/unmarried	3 (8.6)	46 (12.5)	34 (17.7)	33 (10.7)
Widow(er)	19 (54.3)	238 (64.5)	119 (62.0)	215 (70.0)
Duration of institutionalization, ^b mean (SD)	27.0 (26.1)	31.6. (25.2)	34.2 (28.7)	34.0 (28.2)
months, n (%)	5 (11.1)	22 (4.5)	12 (5.0)	16 (4.1)
months, n (%)	8 (17.8)	81 (16.3)	48 (20.1)	69 (17.6)
months, n (%)	26 (57.8)	336 (67.7)	140 (58.6)	247 (63.2)
months, n (%)	6 (13.3)	57 (11.5)	39 (16.3)	59 (15.1)
GDS, n (%)				
4	2 (4.4)	9 (1.8)	4 (1.7)	10 (2.6)
5	1 (2.2)	67 (13.5)	26 (10.9)	47 (12.0)
6	22 (48.9)	271 (54.4)	113 (47.3)	217 (55.4)
7	20 (44.4)	151 (30.3)	96 (40.2)	118 (30.1)

Notes: SD: standard deviation; GDS: Global Deterioration Scale.

^aMissing data n = 360.

^bMissing data n = 9.

Table 2. Psychotropic drug use and neuropsychiatric symptoms of NH-residents with dementia with very frequent physical aggression (PA) and less frequent PA (Total N= 2072) as well as NH-residents with dementia with very frequent vocalizations and less frequent vocalizations (Total N= 2073).

	Very Frequent PA N = 45 Prevalence 2.2%	Less Frequent PA N = 498 Prevalence 24.0%	Very Frequent Vocalizations N = 239 Prevalence 11.5%	Less Frequent Vocalizations N = 392 Prevalence 18.9%
Psychotropic drug use, ^a n (%)				
Total	33 (76.7)	323 (67.3)	171 (73.7)	254 (66.7)
Antipsychotic	24 (55.8)	202 (42.1)	114 (49.1)	147 (38.6)
Antidepressant	17 (39.5)	146 (30.4)	78 (33.6)	110 (28.9)
Hypnotic	5 (11.6)	54 (11.3)	33 (14.2)	48 (12.6)
Anxiolytic	8 (18.6)	108 (22.5)	57 (24.6)	77 (20.2)
Antiepileptic	5 (11.6)	31 (6.5)	27 (11.6)	15 (3.9)
Antidementia	0 (0.0)	15 (3.1)	9 (3.9)	11 (2.9)
NPI-NH Symptoms, ^b n (%)				
F x S scores ≥ 4				
Delusions ^c	11 (24.4)	115 (23.1)	45 (18.9)	79 (20.3)
Hallucinations ^d	7 (15.6)	60 (12.0)	66 (27.6)	94 (24.2)
Depression ^e	11 (24.4)	114 (22.9)	11 (27.6)	114 (22.9)
Anxiety ^e	13 (28.9)	142 (28.5)	85 (35.6)	120 (30.8)
Euphoria ^e	6 (13.3)	62 (12.5)	50 (20.9)	49 (12.6)
Apathy ^f	25 (55.6)	169 (33.9)	92 (38.5)	146 (37.3)
Disinhibition ^g			80 (33.5)	121 (31.0)
Irritability ^g			118 (49.4)	187 (47.9)
Aberrant motor behavior ^e	21 (46.7)	191 (38.4)	108 (45.2)	140 (35.8)
Night time behavior ^h	10 (22.2)	93 (19.0)	51 (21.7)	71 (18.5)
Eating change ⁱ	14 (32.6)	133 (27.3)	62 (26.7)	90 (24.0)

Notes: NPI-NH: neuropsychiatric inventory-nursing home version; F x S: Frequency x Severity.

^aMissing data n = 63.

^dMissing data n = 7.

^gMissing data vocalizations n = 4.

^bNormal range 0-144.

^eMissing data n = 3.

^hMissing data n = 45.

^cMissing data n = 9.

^fMissing data n = 1.

ⁱMissing data n = 48.

Table 3. Univariate^a and multivariate^b multilevel logistic regression analysis of demographic characteristics of NH residents with very frequent physical aggression compared to NH residents with less frequent physical aggression.

		Univariate Association OR (95% CI) ^c	<i>p</i> -value ^d	Multivariate Association OR (95% CI) ^e	<i>p</i> -value ^e
Age		0.98 (0.94–1.02)	.284		
Gender	Female	Reference	.719		
	Male	0.88 (0.43–1.79)			
Duration of institutionalization ^f					
0–3		Reference	.311		
3–12	months	0.45 (0.14–1.51)			
12–60	months	0.37 (0.13–1.05)			
>60	months	0.48 (0.13–1.72)			
GDS	4 and 5	Reference	.189	Reference	.587
	6	1.61 (0.54–4.75)		1.41 (0.47–4.24)	
	7	2.46 (0.82–7.42)		1.76 (0.56–5.49)	
Psychotropic drug use ^g					
Antipsychotic	No	Reference	.142	Reference	.133
	Yes	1.58 (0.86–2.92)		1.60 (0.87–2.95)	
Antidepressant	No	Reference	.289		
	Yes	1.41 (0.75–2.65)			
Hypnotic	No	Reference	.949		
	Yes	1.03 (0.40–2.69)			
Anxiolytic	No	Reference	.625		
	Yes	0.83 (0.38–1.79)			
Antiepileptic	No	Reference	.252		
	Yes	1.79 (0.66–4.88)			
Antidementia	No	Reference	.445		
	Yes	0.31 (0.01–6.46)			
NPI-NH Symptoms					
F x S scores ≥ 4					
Delusions	No	Reference	.861		
	Yes	1.07 (0.53–2.14)			
Hallucinations	No	Reference	.550		
	Yes	1.29 (0.56–3.01)			
Depression	No	Reference	.840		
	Yes	1.08 (0.53–2.17)			

Table 3. (continued).

		Univariate Association OR (95% CI) ^c	<i>p</i> -value ^d	Multivariate Association OR (95% CI) ^e	<i>p</i> -value ^e
Anxiety	No	Reference	.964		
	Yes	1.02 (0.52–1.97)			
Euphoria ^h	No	Reference	.887		
	Yes	1.07 (0.44–2.59)			
Apathy	No	Reference	.014	Reference	.038
Aberrant Motor Behavior	Yes	2.11 (1.16–3.84)		1.93 (1.04–3.61)	
	No	Reference	.350		
Night-time Behavior ^f	Yes	1.33 (0.73–2.43)			
	No	Reference	.647		
Eating change ^l	Yes	1.19 (0.57–2.46)			
	No	Reference	.525		
	Yes	1.24 (0.64–2.39)			

Notes: GDS: Global Deterioration Scale; NPI-NH: neuropsychiatric inventory-nursing home version; F x S: Frequency x Severity.

^aVery physical aggression *n* = 45, less frequent physical aggression *n* = 498.

^b*N* = 523.

^cOdds ratio modeling the probability of very frequent physical aggression. Includes a random intercept for care unit to account for clustering of residents within care units.

^dOverall fixed effects *p*-value; values are highlighted, that are below the .250 level and these characteristics were included in the multivariate model.

^eOverall fixed effects *p*-value; values are highlighted, that are below the .05 level.

^fMissing data univariate analysis *n* = 2.

^gMissing data univariate analysis *n* = 20.

^hMissing data univariate analysis *n* = 1.

ⁱMissing data univariate analysis *n* = 8.

^lMissing data univariate analysis *n* = 12.

Very frequent vocalizations

The total sample of NH residents was 2073, due to missing relevant CMAI items in one resident. We found a 2-week prevalence of very frequent vocalizations (*N* = 239) of 11.5% (95% CI: 10.23–12.98) compared with a 2-week prevalence of 18.9% (95% CI: 17.28–20.65) for less frequent vocalizations (*N* = 392). NH residents with very frequent vocalizations had a mean age of 81.5 (SD 8.4) years. Most of these NH residents were female (78.7%), were in a moderately severe stage of dementia (GDS 6, 47.3%) (see Table 1) and had the highest prescription rates for antipsychotic drugs (49.1%). Irritability was the NPI item with the highest prevalence in this group (49.4%) (see Table 2). In univariate multilevel analyses, age, severity of dementia and the use of antipsychotics, antidepressants, anxiolytics and

antiepileptics were significantly associated with very frequent vocalizations. Furthermore, the odds for very frequent vocalizations were significantly higher in NH residents who had anxiety, euphoria, aberrant motor behavior or night-time behavior (see Table 4). In multivariate multilevel analyses (see Table 5), a correlate for very frequent vocalizations was age (OR 0.97, 95% CI: 0.951–0.998), which means that NH residents with a lower age were more likely to develop very frequent vocalizations. Other correlations were the use of antipsychotic drugs (OR 1.56, 95% CI 1.08–2.26), antiepileptic drugs (OR 2.75, 95% CI 1.34–5.68) and having euphoria (OR 2.01, 95% CI 1.22–3.31). Dementia severity was, again, a correlate when considered overall: NH residents with a GDS score of 6 were less likely to have very frequent vocalizations than those with a GDS score of 4/5 (reference category). NH residents with a GDS score of 7 were more likely to have very frequent vocalizations than those with a GDS score of 4/5 (GDS 6 OR 0.86, 95% CI 0.49–1.52; GDS 7 OR 1.54, 95% CI 0.85–2.78, the overall p -value was .020).

Table 4. Univariate^a and multivariate^b multilevel logistic regression analysis of demographic characteristics of NH residents with very frequent vocalizations compared to NH residents with less frequent vocalizations.

		Univariate Association OR (95% CI) ^c	p-value ^d	Multivariate Association OR (95% CI) ^c	p-value ^e
Age		0.96 (0.94 – 0.98)	.000	0.97 (0.951 – 0.998)	.032
Gender	Female	Reference	.406		
	Male	1.19 (0.79 – 1.78)			
Duration of institutionalization ^f					
0-3	months	Reference	.709		
3-12	months	0.92 (0.39 – 2.17)			
12-60	months	0.75 (0.34 – 1.66)			
>60	months	0.88 (0.37 – 2.10)			
GDS	4 and 5	Reference	.034	Reference	0.20
	6	1.00 (0.60 – 1.66)		0.86 (0.49 – 1.52)	
	7	1.59 (0.93 – 2.72)		1.54 (0.85 – 2.78)	
Psychotropic drug use ^g					
Antipsychotic	No	Reference	.015	Reference	.017
Antidepressant	Yes	1.52 (1.09 – 2.12)		1.56 (1.08 – 2.26)	.
Hypnotic	No	Reference	.201	Reference	.363
Anxiolytic	Yes	1.26 (0.88 – 1.81)		1.20 (0.81 – 1.77)	
Antiepileptic	No	Reference	.552		
Antidementia	Yes	1.16 (0.71 – 1.88)			
	No	Reference	.208	Reference	.741
	Yes	1.29 (0.87 – 1.93)		1.08 (0.70 – 1.66)	
	No	Reference	.001	Reference	.006
	Yes	3.15 (1.62 – 6.09)		2.75 (1.34 – 5.68)	
	No	Reference	.487		
	Yes	1.38 (0.55 – 3.45)			

Table 4. (continued).

		Univariate Association OR (95% CI) ^c	p-value ^d	Multivariate Association OR (95% CI) ^c	p-value ^e
NPI-NH Symptoms					
F x S scores ≥4					
Delusions ^h	No	Reference	.684		
Hallucinations ⁱ	Yes	0.92 (0.60 – 1.39)			
Depression ⁱ	No	Reference	.258		
Anxiety ^j	Yes	1.32 (0.82 – 2.13)			
Euphoria ^j	No	Reference	.289		
Apathy ^a	Yes	1.23 (0.84 – 1.78)			
Disinhibition ^j	No	Reference	.175	Reference	.830
Irritability ^j	Yes	1.27 (0.90 – 1.81)		1.04 (0.71 – 1.54)	
Aberrant Motor Behavior ^f	No	Reference	.006	Reference	.006
Night-time Behavior ^k	Yes	1.87 (1.20 – 2.91)		2.01 (1.22 – 3.31)	
Eating Change ^l	No	Reference	.669		
	Yes	1.08 (0.77 – 1.51)			
	No	Reference	.445		
	Yes	1.15 (0.81 – 1.63)			
	No	Reference	.753		
	Yes	1.05 (0.76 – 1.47)			
	No	Reference	.014	Reference	.057
	Yes	1.24 (0.64 – 2.39)		1.44 (0.99 – 2.09)	
	No	Reference	.202	Reference	.570
	Yes	1.31 (0.87 – 1.98)		1.14 (0.72 – 1.81)	
	No	Reference	.373		
	Yes	1.19 (0.81 – 1.75)			

Notes: GDS: Global Deterioration Scale; NPI-NH: neuropsychiatric inventory-nursing home version; F x S: Frequency x Severity.

^a Very frequent vocalizations n = 239, less frequent vocalizations n=392.

^b N = 602. ^c Odds ratio modeling the probability of very frequent vocalizations. Includes a random intercept for care unit to account for clustering of residents within care units.

^d Overall fixed effects p-value; values are highlighted, that are below the .250 level and these characteristics were included in the multivariate model.

^e Overall fixed effects p-value; values are highlighted, that are below the .05 level.

^f Missing data univariate analysis n = 1.

^g Missing data univariate analysis n = 18.

^h Missing data univariate analysis n = 4.

ⁱ Missing data univariate analysis n = 3.

^j Missing data univariate analysis n = 2.

^k Missing data univariate analysis n = 13.

^l Missing data univariate analysis n = 24.

Discussion

As far as we know, this is the first study to explore the 2-week prevalence and correlates of NH residents with very frequent PA and very frequent vocalizations in a large sample of NH residents with dementia. A 2-week prevalence of 2.2% was observed for very frequent PA. NH residents with apathy were more likely to have very frequent PA. The 2-week prevalence of very frequent vocalizations was 11.5%. NH residents with a higher age, more severe dementia, having euphoria or using antipsychotics and antiepileptics were more likely to have very frequent vocalizations.

Very frequent physical aggression

The prevalence for very frequent PA is comparable with the findings by Voyer et al.⁴ In that study, fewer than 3% of the older adults in long-term care facilities displayed PA often or always.⁴ The association with apathy may seem remarkable, because the definition of apathy in the NPI encompasses diminished initiative and indifference, which seem to conflict with the acting out behavior seen in PA.⁴⁰ A possible explanation for the relationship found could be the executive dysfunction syndrome.⁴³ In people with the executive dysfunction syndrome, damage in one or more of the three involved brain circuits originating in the frontal lobes (dorsolateral prefrontal circuit, lateral orbitofrontal circuit and anterior cingulum circuit) can lead to co-occurrence of apathy and aggression.^{43,42} In addition, damage to the same structures may also cause disinhibition.⁴³ A second explanation for the relationship of apathy with PA could be boredom in the NH resident, which may initially cause apathy followed by PA.⁴⁴ A third explanation for this association could be pain; chronic pain in a NH resident may lead to apathy or unexpected outbursts of aggression.⁴⁵ A fourth explanation of the correlation of apathy with physical aggression could lie in external factors, like staff ratio; perhaps a low staff ratio leads to apathy in NH residents due to insufficient attention for these residents, which consecutively may lead to aggression.⁴⁶ Unfortunately, we could not include these variables in the analysis because we were limited by the available data of the four studies. Finally, the correlation can be a result of suboptimal validity of the apathy measurement.⁴⁷ It may be difficult to observe apathy in more severe dementia. Associations of PA with older age, male sex, antipsychotic drug use, mild or severe cognitive impairment,⁴ delusions and hallucinations¹⁸ have been described in other studies regarding less frequent PA. We did not find these associations

for very frequent PA. Perhaps this could partly be explained by the fact that the definition of PA was (slightly) different and prevalences for PA were higher in these studies.

Very frequent vocalizations

Cohen-Mansfield et al.⁴⁸ described a prevalence rate of 15% for residents screaming at least once or twice per day, which is in line with the prevalence rate we found in our study. A higher prevalence of 25% of disruptive vocalizations (> 20 times per day shift) was reported in the study by Cariaga et al., probably due to the inclusion of more types of vocalizations (e.g. abusive language (profanities) and negativism) compared with our study.⁴⁵ Regarding the correlates for very frequent vocalizations, we could only find studies about less frequent vocalizations to compare our results with. Associations with the use of antiepileptic drugs or with euphoria have not been described in the literature. Again, as with aggression, frontal lobe damage may be a possible explanation for the association of euphoria with very frequent vocalizations. One of the brain circuits involved with executive dysfunction, the anterior cingulum circuit, is important for mood and emotion, especially in the preservation of positive mood.^{43,49} Additionally, as described above, this anterior cingulate circuit may cause disinhibition,⁴³ and has been shown to be involved in voluntary initiation and suppression of vocalizations.^{49,50} On the one hand, associations we found for age,¹⁰ the use of antipsychotic drugs,⁵¹ and dementia severity^{10,52} are consistent with other studies in NH residents with less frequent vocalizations. On the other hand, some studies found associations with depression, anxiety and irritability, which we could not confirm.⁵³⁻⁵⁸ Possible reasons for this are the differences in the study populations (like male-female distribution), settings, sample sizes and the use of different measurement instruments. Although we did not include other emotional or environmental factors in our analyses, it is possible that these factors play a role in the occurrence of vocalizations. Namely, several studies describe a relationship of premorbid personality (having a history of introversion, rigidity, emotional control, and (dis)agreeableness) with vocalizations.⁵⁹⁻⁶¹ Furthermore, associations are reported of vocalizations with the environment in general⁵¹ and specific factors such as temperature.⁶² A higher awareness of these associations might positively influence the practice of NH staff. Finally, earlier studies show that the way of providing care, NH staff attitudes and care staff characteristics all influence the behavior of NH residents.^{63,64} For example, less challenging behavior occurs in NH residents with dementia

when NH staff has a more hopeful attitude towards them.⁶⁴ It would have been interesting if we had data about these factors, to confirm the findings of these studies.

Strengths and limitations

Our study has several strengths. It used a large and representative sample of NH residents, resulting from the participation of a large number of NHs from many regions of the Netherlands. Additionally, since the same assessment instruments were used in the four combined studies, it was straightforward to merge and interpret the data.

This study also has some limitations. First, the 2-week prevalence rates found may be influenced by PDU, which may have weakened the relationships between the correlates and very frequent PA or very frequent vocalizations. Second, because of its cross-sectional design, our findings should not be interpreted as causal relationships. As an example, for PDU, the high frequency of the behavior may lead to the use of psychotropic drugs instead of PDU leading to very frequent behavior. Besides this, possible causes for the behaviors (severity of dementia) and possible consequences of these behaviors (PDU) were combined in the same statistical model, which could have influenced our findings. Third, the most important methodological consideration of our study is the operationalization of very frequent PA and very frequent vocalizations. To begin with, as we used the CMAI to define very frequent PA and very frequent vocalizations, the items of this assessment instrument restricted the operationalization of these behaviors. This way, we have also partly predetermined the prevalence rates of these behaviors by our unambiguous, but consequently narrow definitions. Maybe the prevalence rates we found could be considered an underestimation. Another limitation is the fact that the CMAI only reports frequency and not intensity or severity of distress like the NPI-NH. Behavior which is very frequent but less intense can be well tolerated by people involved, while behavior which is less frequent but intense can have a great impact. Furthermore, although we tried to operationalize very frequent PA and vocalizations by aligning with existing operationalizations in previous studies, this appeared to be more complex than expected. In the current literature, differences in the use of terminology of (physical) aggression^{6,65,66} and vocalizations^{2,10,34,65} were observed and various measurement instruments were used to operationalize PA and vocalizations.^{53,66,67} In consequence, diverging and overlapping classifications exist for the same behaviors.^{2,47,66} Additionally, the fact that frequencies of

the behaviors were not further specified in several articles was another difficulty in operationalizing. As a consequence, these difficulties in aligning with other studies imply difficulties in comparing our findings with those from other studies. As already mentioned earlier in the discussion, a final limitation concerns the fact that comparison with other studies is limited due to differences in study populations (like male-female distribution), settings and sample sizes.

Yet, our definition and operationalization of very frequent PA and vocalizations could facilitate replication and comparison with other studies in future research. Nevertheless, further studies are needed to define and operationalize very frequent PA and vocalizations, especially by incorporating the context in which these behaviors occur. The influence of the care environment as a cause of these behaviors is important, like the interaction with NH staff. Finally, although further exploring subtypes of PA or vocalizations would have been interesting, it was not possible to perform these analyses because the groups became too small for analysis or comparison.

Conclusion

To conclude, in this study we found a 2-week prevalence of 2.2% for very frequent PA and of 11.5% for very frequent vocalizations. Characteristics of NH residents with very frequent PA or very frequent vocalizations are different from NH residents with less frequent PA or vocalizations. Boredom, pain and factors according to environment may be explanations for the association of apathy with very frequent PA. Furthermore, executive dysfunction needs attention in the scientific study of very frequent challenging behavior as it may be a possible explanation for both the association of apathy with very frequent PA and the association of euphoria with very frequent vocalizations. Our findings contribute to gaining insight into these two types of behaviors and may improve the care and quality of life of NH residents. Simultaneously, it may increase the quality and safety of the working experience of NH staff. However, although we could identify correlates for very frequent PA and very frequent vocalizations, further research is needed to confirm and extend our findings. New studies should consider the validity of measurements and fully consider this in their choice for a certain data collection method. Moreover, a straightforward definition

of very frequent PA and vocalizations is needed that incorporates the context of the behaviors. This may eventually result in a better understanding, treatment and quality of life of NH residents with very frequent PA and very frequent vocalizations.

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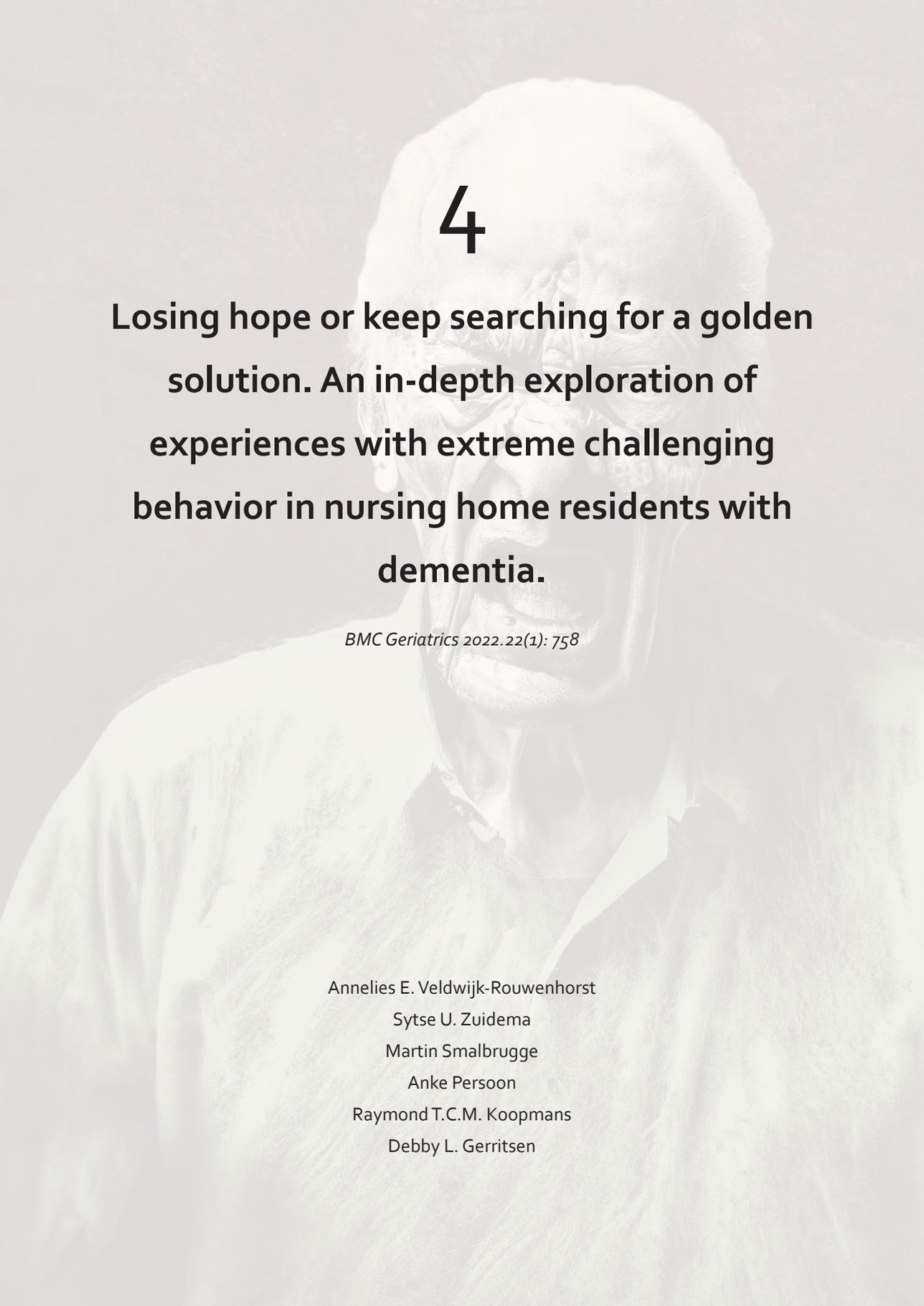
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“Je ziet het lijden en het mensonwaardige eigenlijk, maar toch blijf je hopen dat je iets vindt dat het (gedrag) omkeert en dat iemand zich weer beter voelt..... je blijft iedere wisseling van medicatie, iedere nieuwe benadering blijf je de hoop hebben dat je het ei van Columbus hebt uitgevonden.”

Verpleegkundige in individueel interview



4

Losing hope or keep searching for a golden solution. An in-depth exploration of experiences with extreme challenging behavior in nursing home residents with dementia.

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Annelies E. Veldwijk-Rouwenhorst

Sytse U. Zuidema

Martin Smalbrugge

Anke Persoon

Raymond T.C.M. Koopmans

Debby L. Gerritsen

Abstract

Background: Situations of extreme challenging behavior such as very frequent and/or severe agitation or physical aggression in nursing home (NH) residents with dementia can be experienced as an impasse by NH staff and relatives. In this distinct part of our WAALBED (WAAL-Behavior-in-Dementia)-III study, we aimed to explore these situations by obtaining the experiences and perspectives of NH staff and relatives involved. This can provide a direction in providing tools for handling extreme challenging behavior of NH residents with dementia and may improve their quality of life.

Methods: Qualitative multiple case study with individual interviews and focus group discussions. Interviewees were elderly care physicians, psychologists, care staff members, unit managers and relatives ($n = 42$). They were involved with NH residents with dementia and extreme challenging behavior living on dementia special care units in the Netherlands. For these residents, external consultation by the Centre for Consultation and Expertise was requested. Audio-recordings of the interviews were transcribed verbatim and analyzed with thematic analysis, including conventional content analysis.

Results: Seven cases were included. Forty-one individual interviews and seven focus group discussions were held. For six stakeholder groups (resident, relative, care staff, treatment staff, NH staff, and the organization), three main factors could be identified that contributed to experiencing a situation of extreme challenging behavior as an impasse: 1) characteristics and attitudes of a stakeholder group, 2) interaction issues within a stakeholder group and 3) interaction issues among (groups of) stakeholders. The experienced difficulties with the resident's characteristics, as well as suboptimal interdisciplinary collaboration and communication among the NH staff are remarkable. NH staff kept searching for a golden solution or lost hope.

Conclusions: This study offers important insights into situations of extreme challenging behavior in NH residents with dementia and offers caregivers targets for improving care, treatment and interdisciplinary collaboration, such as working uniformly and methodically.

Key Words: Challenging behavior, dementia, nursing home, qualitative research

Introduction

In nursing homes over 80% of residents with dementia show challenging behavior, which encompass a broad spectrum of behaviors and become more severe as the dementia progresses.¹⁻³ A minority of cases consist of extreme challenging behavior, which is severe and/or occurs frequently.⁴⁻⁷ In their seven-tiered model of the severity and prevalence of challenging behavior, Brodaty et al. categorize extreme challenging behavior as Tier 7, with an estimated prevalence described as rare.⁴ In our WAALBED (WAAL-Behavior-in-Dementia)-III study, similar two-week prevalence rates of 7.4% of very frequent agitation, 2.2% of very frequent physical aggression and 11.5% of very frequent vocalizations were found.^{5,6}

Previous studies have shown that challenging behavior has a great influence on the residents and their environment (relatives, nursing home (NH) staff and other residents), especially in case of aggression.⁸⁻¹⁰ Extreme challenging behavior has an even greater impact on the resident, such as self-injury and the application of physical and chemical restraints, both influencing the quality of life of the resident negatively.¹¹ Furthermore, challenging behavior like severe physical aggression leads to injuries to other residents, which possibly influences their quality of life. Also, the extreme challenging behavior can lead to injuries, mental distress and even burnout among care staff or it can influence their decision to start looking for another job.^{8,12}

The high impact of the behavior, together with its extreme severity and frequency, can lead to a situation in which an impasse is reached,^{4,13} in which NH staff feels that they are out of (treatment) options and relatives feel powerless. This impasse is often preceded by a long trajectory of searching for the 'right' solution.¹⁴ It is still unclear why a situation of extreme challenging behavior is experienced as an impasse by NH staff and relatives. To our knowledge, there is no theoretical framework in literature which already explains this. Although earlier literature describes that NH staff's beliefs influence their attitudes, which in turn influence their response to the resident's behavior itself,^{15,16} the reasons why they experience a particular situation as an impasse are yet unknown but may be useful for breaking such a situation.

Therefore, this qualitative study tries to answer the following research question: “Why are situations of extreme challenging behavior of NH residents with dementia experienced as an impasse by NH staff and relatives?” It aims to provide insight into experiences of NH staff (including their beliefs and attitudes) and to unravel contributing factors. Hereby we hope to provide tools for handling this behavior and to improve the care for and quality of life of NH residents with dementia and extreme challenging behavior.

Methods

Study aim, design, setting and participants

This explorative, qualitative study was performed as a distinct part of the WAALBED-III study that focused on NH residents with dementia and extreme challenging behavior.^{5,6,14} Because of the lack of a theoretical frame to explain why situations of extreme challenging behavior in NH residents with dementia are experienced as an impasse, we decided to apply qualitative methods in this study. Hereby we were able to provide complex textual descriptions.¹⁷ We used the Consolidated criteria for Reporting Qualitative studies (COREQ) to conduct and report the study. A detailed description of the applied methodology is presented in Supplementary material table 1.

In the Netherlands, care for people with dementia and extreme challenging behavior is mainly provided in dementia special care units by multidisciplinary teams of which the members are all employed by the NH (see Table 1). In the following text, we will use the word NH staff for this, by which we mean the entire group of professionals.

Table 1. Setting of the study.

Members nursing home staff	<ul style="list-style-type: none"> ● Care staff: certified primary nurse assistants, nurse assistants, vocational trained registered nurses. ● Treatment staff <ul style="list-style-type: none"> – elderly care physician – psychologist – physiotherapist – speech therapist – dietician – music therapist – occupational therapist ● Unit manager: manager of the unit where the resident lives.
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For this study, we included cases of NH residents with dementia and extreme challenging behavior for which external consultation from the Centre for Consultation and Expertise (CCE)²⁸ was requested. The CCE is a supplementary service to standard healthcare services which is funded by the Dutch government and provides expertise and support in the long-term care (including extreme challenging behavior) in people with dementia and intellectual disabilities. CCE works with independent experts in order to provide customized advice and support and accepts applications for consultation when there are serious concerns about a resident's quality of life.

Consecutive sampling was used to select cases, which means cases were selected in order of sign up according to their appropriateness for inclusion.²⁹ Cases were assessed for inclusion by two coordinators of the CCE, and by AV and DG through verification of the inclusion criteria: a) the resident had dementia and extreme challenging behavior which affected their quality of life according to the professionals who reported the case to the CCE; b) there was no obvious easily treatable cause for the challenging behavior; c) the behavior was experienced as very difficult to cope with by the involved NH staff and they had been unable to treat the challenging behavior satisfactorily; d) the challenging behavior consisted of aggression and/or vocally disruptive behavior and/or agitation; e) the resident had no acute life-threatening diseases; and f) they had been staying in the NH for at least 4 weeks. When a case was deemed appropriate for inclusion by the elderly care physician and the unit manager of the NH, intensively involved NH staff members (as mentioned in Table 1) and the relative were asked for consent to participate in the study. For consent a written consent form was used.

Data collection

Several data were obtained from the residents' medical files: demographical characteristics, duration of institutionalization, and prescribed medications. This explorative, qualitative study used individual interviews and focus group discussions to explore experiences of NH staff with situations of extreme challenging behavior of NH residents with dementia and to unravel contributing factors.^{17,20,21} As mentioned before, these applied qualitative methods allow us to provide complex textual descriptions of how people experience a given research issue.¹⁷ Topic lists for the interviews with professionals, relatives and focus group discussions were prepared by AV and discussed with the co-authors (see Supplementary material tables 2 and 3). The following topics were addressed: 1) nature and course of the behavior, 2) actions undertaken, 3) factors contributing to an impasse, 4) the impact of the situation on NH staff and relatives and 5) collaboration among NH staff. Six interviews per case were performed; one each with the involved elderly care physician, psychologist, certified primary nurse assistant, unit manager, another care staff member familiar with the resident, and one with a relative of the resident.

The individual interviews with NH staff were held during April–December 2016 in the NH of the resident, while interviews with relatives took place during April–October 2016 at their own home (N = 4) or in the NH (N = 3). In addition, for each case a focus group discussion was held with the same interviewees of the individual interviews, except the relatives. Other care/treatment staff members could join the focus group discussion if they wished. The reason for performing six interviews per case and to conduct focus group discussions was to achieve data source triangulation and thereby to increase the validity and reliability of the results of the study.^{20,21} Moreover, with the focus group discussions we were able to collect a broad range of views, to examine the information obtained from the interviews and to further explore the cases.¹⁷ The focus group discussions with NH staff were held during April 2016–January 2017 in the NH of the resident.

Data analysis

All interviews and focus group discussions were transcribed verbatim and identifying information was removed. Transcriptions were analyzed with thematic analysis, an iterative process involving several steps.²² This included conventional content analysis^{23,24} with the application of inductive coding (deriving codes from the data, modifying them

throughout the coding process and providing an explanation of the data) and deductive coding (identification of potential categories and sub-categories as codes)²² (AV, AP, EV, MW and KM). We coded on attributes and content.²⁵ For the attribute coding, we coded by (groups of) stakeholders: resident, relative, care staff, treatment staff (including unit manager), NH staff (care staff and treatment staff) and organization.

We started with a thorough analysis of the first case to develop a viable procedure for subsequent coding. A coding tree was developed after grouping new codes into categories and combining them with existing codes and categories (AV, AP). After analysis of first case, codes, categories and the coding tree were discussed in two separate meetings and a modified version was used for analysis of the other cases. During the coding process, the coding tree was altered. After analysis of the last case, the most recent version of the coding tree was used for re-coding the previous transcripts to improve accuracy of the analysis (MW).

For within-case analyses, a mind map was created (EV, AV) and for cross-case analysis, a mind map constituting all other mind maps together was made (AV). Mind maps are “visual, non-linear representations of themes and sub-themes and their relationships”.^{26,27} For each case, consensus meetings took place with the data coders (AV, AP, EV, MW, KM) and one of the authors (DG). In all cases, AV was one of the coders. In these meetings, the mind map was discussed. All mind maps were further discussed in meetings with all of the authors. These discussions led to the refinement of categories into definitive main and sub-factors.

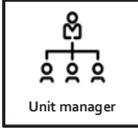
Results

We expected to include ten cases, but stopped inclusion after interviewing for seven as we had reached data saturation, as determined by all authors. For the seventh case, no new codes were added to the coding tree.²⁸ We conducted 41 individual interviews with a total of 42 interviewees (one interview had two interviewees) and seven focus group discussions with a total of 52 interviewees (in six focus group discussions extra NH staff members

attended who did not participate in the residents consisted of extreme physical and/or verbal aggression and/or agitation individual interviews).

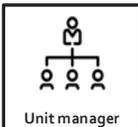
Background information of the interviewees is displayed in Figs. 1 and 2. The majority of the interviewees were women and their age varied between 20 and 63 years.

Figure 1. Characteristics of the included interviewees of the individual interviews (gender and age (years))

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7
 Primary licensed practical nurse	Woman, 37	Woman, 24	Woman, 47	Man, 25	Woman, 49	Woman, 44	Woman, 40
 Care staff member	Woman, 30	Woman, 39	Woman, 43	Woman, 47	Woman, 53	Woman, 41	Woman, 60
 Psychologist	Woman, 61	Woman, 33	Woman, 51	Woman, 40	Woman, 63		Woman, 28 Woman, 32
 Unit manager	Woman, 58	Woman, 53	Woman, 54	Woman, 59	Woman, 53	Woman, 46	Woman, 52
 Elderly care physician	Woman, 37 Elderly care physician in training	Man, 57	Man, 59	Man, 56	Woman, 60	Man, 45	Man, 37
 Relative	Wife	Daughter	Wife	Daughter	Daughter	Wife	Daughter
	N = 6	N = 6	N = 6	N = 6	N = 6	N = 5	N = 7
	N = 42						

Notes: Interviewees depicted in bold type also participated in the focus group discussions.

Figure 2. Characteristics of the included participants of the focus group discussions (gender and age (years))

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7
 Primary licensed practical nurse	Woman, 37	Woman, 24	Woman, 47	Man, 25	Interim Woman, 38		Woman, 40
 Care staff member	Woman, 24 Woman, 25 Woman, 30 Man, 59	Woman, 22 Woman, 33 Woman, 60 Woman, 60	Woman, 20 Woman, 23 Woman, 26 Woman, 28 Woman, 29	Woman, 30 Woman, 43 Woman, 47 Woman, 54 Woman, 56	Woman, 53	Woman, 22	Woman, 41 Woman, 44 Woman, 45 Woman, 55 Woman, 60 Woman, 60
 Psychologist		Woman, 33	Man, 25	Woman, 40	Woman, 63		Woman, 28
 Unit manager	Woman, 58	Woman, 53	Woman, 54		Woman, 53	Woman, 46	Woman, 52
 Elderly care physician		Man, 57	Man, 59	Man, 56	Woman, 60	Man, 45	Man, 37
 Nurse			Woman, 26			Woman, 42	
 Social worker					Woman, 52		
	↓	↓	↓	↓	↓	↓	↓
	N = 6	N = 8	N = 10	N = 8	N = 6	N = 4	N = 10
	↓						
	N = 52						

Notes: Interviewees depicted in bold type also participated in the individual interviews.

The challenging behavior of the residents consisted of extreme physical and/or verbal aggression and/or agitation (see Table 2). Sometimes the behavior was unpredictable. Psychosocial interventions, as well as prescription of multiple psychotropics and, in certain cases, compulsory treatment had been applied to treat the challenging behavior.

"Regarding care, every time you got hit, even though it was on your arm, you always got hit by him (the resident) There are several colleagues including me, who got truly hard blows in the face ... Or a punch in the stomach." (Case 6, Certified primary nurse assistant in individual interview)

"You are attempting all kinds of medication and ways of interaction with the resident ... Well on a certain moment we have tried so many things all of us together. In addition, actually she (the resident) had all kinds of medication which you can prescribe for this kind of challenging behavior.. we tried so many things, also regarding psychological support, stimulating senses was tried very often in the living room ... we have been so intensively involved with this behavior." (Case 7, Unit manager and elderly care physician in focus group discussion)

It appeared that factors contributing to experiencing these situations of extreme challenging behavior as an impasse could best be structured according to the six (groups of) stakeholders through attribute coding. Furthermore, three general factors could be identified using content coding: 1) characteristics of a stakeholder group, 2) interaction issues within a stakeholder group and 3) interaction issues with other (groups of) stakeholders. For some (groups of) stakeholders, only one or two of these general factors were applicable. Moreover, numerous main factors and sub-factors could be identified. These factors are of a different nature; the general factors and main factors provide structure and are broad and overarching, the sub-factors predominantly contain the content. The general, main and sub-factors are described in Table 3 and in the following text, illustrated with quotes. Additional quotes are displayed in Supplementary material table 4. In the following text of the results section we will use the term "all groups of stakeholders" when the results are based on interviews of all groups of stakeholders and the term "interviewees" when they are based on some of the stakeholder groups.

Table 2. Background information of each case.

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7
Gender, age	Man, 75 years old	Woman, 87 years old	Man, 78 years old	Woman, 89 years old	Woman, 89 years old	Man, 81 years old	Woman, 86 years old
Duration of institutionalization	22 months	21 months	18 months	24 months	27 months	29 months	18 months
Department	Psychogeriatric unit, small-scale	Psychogeriatric unit, small-scale	Psychogeriatric unit, small-scale	Psychogeriatric unit, small-scale	Psychogeriatric unit, small-scale	Psychogeriatric unit, small-scale	Psychogeriatric unit, small-scale
Medical problems	Parkinson's dementia Morbus Parkinson Atrial Fibrillation Lower urinary tract symptoms	Dementia Heart failure Hypertension Osteoporosis Depressive disorder	Dementia with leukoencephalopathy Depressive disorder (2007) Rectal bleeding	Dementia Hip fracture (2016)	Vascular dementia COPD Heart failure Hypertension Atrial Fibrillation	Vascular dementia Hypertension Kidney failure Transient ischemic attack	Alzheimer's disease Several transient ischemic attacks Hypothyroidism Osteoporosis
					Cerebrovascular incident (2010) Recurrent urinary tract infections		

Table 2. (continued)

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7
Description of behavior	Unpredictable moments of transgressive behavior and aggression (hitting, pushing, kicking, grabbing firmly) directed towards care staff and other residents	Yelling and screaming accompanied by fear and sadness Angriness	Verbal (yelling) and physical aggression (hitting, kicking, spitting, throwing with feces, squeezing breasts of care staff) directed towards care staff especially during personal care	Agitation Restlessness Attention seeking behavior (experienced as agitation) accompanied by fear and sadness Aggression directed towards care staff and other residents	Restlessness and yelling during the nights	Physical (hitting, kicking, grabbing) and verbal (cursing, insulting) aggression directed towards care staff, volunteers, family and other residents	Restlessness and angeriness Beating on doors and windows Hitting directed towards other residents or care staff Slamming on tables Making noises

Table 2. (continued).

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7
Interventions described in the medical files	Family consultation	Family consultation	Family consultation Involving family in behavioral consult	Family recording with family	Family consultation	Family member	Family consultation
	Resident Personal care with as little stimuli as possible and dosing stimuli by decreasing activities and offering more rest	Resident Offering rest (in living room) Changing the place at the table Offering personal attention, physical contact and safety by volunteers and trainees	Resident	Resident Offering adequate stimuli and familiar voices and noises Distraction Offering personal Attention Giving foot baths	Resident Offering rest in the afternoon (in bed) Displaying picture of the resident's wife in the resident's room to create feeling of safety Giving tea or warm milk in the evenings Structurally notifying the resident of performed actions during care Structured day program Offering daily activities	Resident Personal care with as little stimuli as possible Offering rest (in the resident's room) Structured day program Offering personal attention Offering personal attention (also during meals) and physical contact Singing songs with the resident Handing a doll or a cuddle cat Offering multisensory stimulation ('snoezelen') Aromatherapy Transfer to another, quieter ward	Resident Offering time-outs and rest by separating the resident from other residents Offering personal attention (also during meals) and physical contact Singing songs with the resident Handing a doll or a cuddle cat Offering multisensory stimulation ('snoezelen') Aromatherapy Transfer to another, quieter ward

Table 2. (continued).

Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7
Nursing home staff	Nursing home staff	Nursing home staff	Nursing home staff	Nursing home staff	Nursing home staff	Nursing home staff
Behavioral consult and crisis intervention plan by psychologist	Behavioral consult and crisis intervention plan by psychologist	Behavioral consult by psychologist	Behavioral consult by psychologist	Behavioral consult by psychologist	Behavioral consult by psychologist	Behavioral consult by psychologist
Self-defense course care staff	Video-recordings of the behavior	Using wrist guards during personal care	Expressive therapy	Advice regarding Stimuli	and functional analysis of the behavior	and behavioral consult by psychologist
Multidisciplinary team meetings	Advice regarding sitting comfortably	Training using video-feedback	Recruiting a nurse	Education and skill training of care staff	through the care programme 'Grip on challenging behavior' ²⁹	Changing medication
Changing medication	Consulting internal consultation team	Observing colleagues during care provision	An employee working in the living room	about dementia and depression	Consult of an expressive therapist to be in line with the resident's level of alertness	
	External consultation psychiatrist	Rotation of care staff involvement of occupational therapist	Deployment of extra staff	Changing medication	Deployment of extra staff	
	Deployment of extra staff	Multidisciplinary meetings	Changing medication holiday	Applying intermittent palliative sedation	Changing medication	
	Moral deliberation session	Changing medication				

Table 2. (continued).

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7
Relevant medication (name, dosage)	Clozapine 25 mg bid Levodopa/ carbidopa 50/12.5 mg bid Valproic acid 300 mg bid Clonazepam 0.5 mg as needed	Midazolam 15 mg qd Mirtazapine 15 mg qd Oxazepam 10 mg qd Oxazepam 5 mg qd Oxazepam 5 mg qd Oxazepam 5 mg as needed Venlafaxine 37.5 mg bid	Clozapine 50 mg qd Escitalopram 10 mg qd Mirtazapine 30 mg qd	Haloperidol 2 mg/ml 5 drops qid Oxazepam 10 mg as needed Citalopram 10 mg qd	Levetiracetam 500 mg bid Oxazepam 10 mg as needed	Pipamperone 40 mg bid Citalopram 20 mg qd Memantine 5 mg qd Temazepam 10 mg as needed	Haloperidol 2mg bid Citalopram 20mg qd Pregabalin 75mg bid Oxazepam 5mg as needed

Table 3. Overview of (groups of) stakeholders with general, main and sub-factors.

STAKEHOLDER GROUP	GENERAL FACTORS	MAIN FACTORS	SUB-FACTORS
RESIDENT	CHARACTERISTICS	PERSON BEHAVIOR	<ul style="list-style-type: none"> Unlike other residents Nature of the behavior Course of the behavior Severity of the behavior Unpredictability of the behavior Unclear triggers of the behavior Behavior considered as (partly) on purpose Behavior differs from personality before diagnosis of dementia
	INTERACTION ISSUES WITH OTHER (GROUPS OF) STAKEHOLDERS	WITH OTHER RESIDENTS	<ul style="list-style-type: none"> The resident's behavior causes inconveniences and danger for the other residents Reactions of other residents negatively affect the resident's behavior The resident not understanding verbal requests The resident giving short answers/minimal reaction The resident not wishing to/not making any contact
		WITH NURSING HOME STAFF	<ul style="list-style-type: none"> Inability of nursing home staff to read the resident's emotions Nursing home staff not understanding the resident's behavior and having no control over the behavior
		WITH CARE STAFF SPECIFICALLY	<ul style="list-style-type: none"> Not noticing signs of escalation of the resident's behavior in a timely manner Positive moments with the resident are scarce Paying attention to the resident takes a lot of time Undertaking pleasant activities with the resident is problematic Applying compulsory treatment is difficult

Table 3. (continued).

STAKEHOLDER GROUP	GENERAL FACTORS	MAIN FACTORS	SUB-FACTORS
RELATIVE	CHARACTERISTICS	PERCEPTIONS	Having a different perception of the behavior, treatment and care
	INTERACTION ISSUES WITH OTHER (GROUPS OF) STAKEHOLDERS	WITH NURSING HOME STAFF	Finding it hard to accept that usual care could not always be provided
			Nursing home staff insufficiently informs/involves relatives
			Relative has limited trust in (certain) care staff members
			Relative criticizes actions of care staff
			Relative crosses personal boundaries of care staff members
			Relative is ambivalent/uncommunicative about emotions and wishes for treatment
CARE STAFF	CHARACTERISTICS	PERSONALITY ISSUES	Different approaches and interactions with the resident due to different personalities of care team members
		SKILLS ISSUES	Having insufficient knowledge and experience
			Reports are of an insufficient quality
			Reflects insufficiently on own actions and feelings
		ATTITUDE ISSUES	Having a wait-and-see attitude/refraining from taking the initiative
			Not asking for help/asking for help too late
			Refraining from complying with the behavioral management approach that was agreed on
			Having a fatalistic attitude
			Differences in views on the behavior, approaches in dealing with the resident's extreme challenging behavior and experiences of the behavior due to a difference in working shifts (day/night) and number of working hours
			Difference in opinions about appropriate care
			Difference in the extent to which the resident's behavior is accepted

Table 3. (continued).

STAKEHOLDER GROUP	GENERAL FACTORS	MAIN FACTORS	SUB-FACTORS
TREATMENT STAFF	INTERACTION ISSUES WITHIN STAKEHOLDER GROUP	WITHIN CARE STAFF	<p>Little opportunity for formal and informal exchange of information Giving each other feedback is difficult New ideas from care staff members often receive a negative response from other care staff members Communication takes place indirectly</p>
	CHARACTERISTICS	BEING AT BAY	<p>Missing the whole picture of the situation and the resident's behavior Only present during office hours</p>
		TREATMENT ISSUES	<p>Difficult to develop and implement a treatment plan Treatment plans have no effect/temporary effect The situation often needed to end as soon as possible Difficulties with prescribing medication</p>
		SKILLS ISSUES	<p>Having insufficient knowledge and experience Making treatment plans which are outdated/ impractical/unachievable/not feasible Unable to detect the needs of the care staff, meet their expectations or support them properly Involving external expertise too late</p>
		ATTITUDE ISSUES	<p>Being indecisive/taking little responsibility Undertaking too few actions Not informing themselves properly about the (severity of) the behavior Unaware of the expertise of care staff</p>

Table 3. (continued).

STAKEHOLDER GROUP	GENERAL FACTORS	MAIN FACTORS	SUB-FACTORS
	INTERACTION ISSUES WITHIN STAKEHOLDER GROUP	WITHIN TREATMENT STAFF	Different perceptions as to everyone's responsibilities pertaining to the situation
NURSING HOME STAFF	INTERACTION ISSUES WITHIN STAKEHOLDER GROUP	QUALITY OF INTERDISCIPLINARY COMMUNICATION	Not enough formal and informal exchange of information between the psychologist and elderly care physician Limited exchange of information due to few meetings No room for reflection No room for giving each other feedback No room for an extensive analysis of the behavior Care staff members not communicating their needs, wishes and actions taken with the treatment staff Care staff members share incomplete and unclear information Treatment staff members insufficiently involving care staff in their plans
		INEFFICIENT WORK PROCESSES	Care and treatment staff not taking each other seriously or not listening to each other's ideas/rationalizations for approaching the problem Indirect communication between care and treatment staff Inefficient communication due to a missing working agreement
ORGANIZATION	CHARACTERISTICS	STAFFING ISSUES	Short staffing and staff-turnover Excessive workload
		UNIT	Size of the unit
		ORGANIZATIONAL NORMS	Acceptance of the behavior by considering it as part of the dementia or the resident's personality
		ROLE OF MANAGEMENT	Management staff insufficiently investing in solutions to improve the situation for the resident Management staff making decisions interfering with the clinical situation

Resident

Characteristics

According to interviewees, it was challenging that the resident was unlike the other residents. This was mainly related to the resident being physically stronger and less cognitively impaired.

"He (the resident) is just completely unlike all of the other residents we have. Which almost makes my stomach ache. That I think, imagine that we have placed that man (the resident) in a psychogeriatric ward while he is not as demented as everybody thinks he is." (Case 3, Unit manager in focus group discussion)

Furthermore, the resident's behavior was considered highly complex and particularly challenging, due to its nature (e.g. aggression), course (constantly present or varying in frequency), severity, unpredictability and triggers remaining unclear. Sometimes the behavior was considered as (partly) on purpose, which lowered its acceptability. In other cases, interviewees reported that the resident's behavior differed greatly from their personality before the diagnosis of dementia, and that it was therefore difficult for them to understand the behavior.

"But what I noticed was that it was very taxing on the care team. That when she (the resident) pulled a care team member away with her, continually asked for their attention, that if the care team had to do something that required their focus, like distributing medication, yes, then it is impossible with her (the resident) standing beside you like that." (Case 4, Psychologist in individual interview)

"It (the behavior) is just very fckle... That is what makes it so difficult." (Case 7, Care staff member in individual interview)

"It (the behavior) is like a peat fire, so it arises somewhere and you don't know where and when it will arise, or how fierce it will be when it arises." (Case 4, Elderly care physician in individual interview)

Interaction issues with other (groups of) stakeholders

The resident's interaction with other residents was considered problematic by the interviewees; the resident's behavior caused inconveniences and dangerous situations for the other residents and the responses of other residents triggered the resident's behavior.

"Also the stimuli that she (resident) receives from other residents...I feel that she should be in a low-stimulus environment... And of course she is here with other residents who also do all sorts of things... which end up being an extra trigger, so to speak." (Case 2, Care staff member in individual interview)

The interaction of the resident with the NH staff was also considered challenging, which was mostly attributed to the resident experiencing communication difficulties, delusions, diminished hearing or medication side-effects. The resident was often unable to understand verbal requests or express themselves when communicating with the NH staff, which contributed to the appearance of extreme challenging behavior and in experiencing the situation as an impasse. Occasionally the resident responded to NH staff with only a short answer or a minimal reaction and sometimes the resident did not make, or did not wish to make, any contact with them.

"He (the resident) literally stands very close to you, with a story you could not make heads or tails of, you know, so that makes him angry too, or he pinches you or pushes you away, but also that look in his eyes, he doesn't see you anymore." (Case 6, Unit manager in focus group discussion)

Furthermore, in some cases, NH staff were not able to make contact with the resident or understand the resident's emotions, making it difficult for them to understand and have a grip on the behavior.

"If you cannot get a hold on it (the behavior), that is what I find difficult. When I believe that I have tried everything and the behavior remains. Then you feel like your back is up against the wall." (Case 7, Certified primary nurse assistant in individual interview)

Several difficulties regarding the interaction of the resident with the care staff specifically were reported by NH staff and relatives. In three cases, care staff members did not notice signs of escalation of the extreme challenging behavior in time, leading to outbursts. Due to the extreme challenging behavior, caring for the resident could be very intense, contained scarce positive moments and required close attention and time, sometimes at the expense of the other residents.

"When you are very busy with her (the resident), the other residents, say, pale in significance sometimes, because you constantly focus on her (the resident), by making sure that she remains calm. While there are another six people there who need attention too." (Case 2, Care staff member in focus group discussion)

In most cases, it was difficult to engage in pleasant activities with the resident and to provide care without the behavior occurring. In three cases, compulsory treatment was applied, such as putting the resident in a jumpsuit. This resulted in a heavy burden for the care staff members; the application of compulsory treatment conflicted with their norms and values, but it was considered necessary to ensure safety.

"He did wear a jumpsuit for a while because he had smeared feces on himself. Well, he thought it was horrible to put the thing on and it was a hopeless job to get it on. Then I think, who are we doing this for? Since it is a disaster to get it off again. You trigger him even more then, yes, what exactly is this all for?" (Case 3, Certified primary nurse assistant in individual interview)

Relative

Characteristics

According to NH staff, relatives often had a different perception of the resident's behavior and the required treatment and care. NH staff of three cases said that relatives were not aware of the severity of the behavior or trivialized it. Furthermore, it was difficult for the relatives to accept that usual care could not always be provided due to the resident's resistance to care and the severity of the behavior.

"Things were sometimes played down too (by the relative), perhaps out of self-preservation, I always used to think, like when you were told that he (the resident) had been very aggressive.

But, oh, never mind, fortunately you are all thick-skinned or it wasn't too bad." (Case 1, Care staff member in individual interview)

Interaction issues with other (groups of) stakeholders

Both NH staff and relatives mentioned that care and treatment staff informed and involved relatives insufficiently, which led to dissatisfaction.

"That family conversation revealed that we were not as well informed about certain issues, that something had gone wrong in the communication." (Case 7, Relative in individual interview)

On occasions, NH staff expressed the feeling that they could not do anything right as relatives had limited trust in them. Interviewees said that relatives crossed personal boundaries of care staff by demanding specific care activities, such as dressing the resident despite the resident's resistance to care. This led care staff to feel that the relatives did not acknowledge the resident's problematic behavior. Moreover, several relatives were ambivalent or uncommunicative about their emotions and wishes for treatment. Therefore, it was difficult for NH staff to gain support for their care and treatment plans, which sometimes led to a delay in executing the planned care.

"You thought, okay, she (the relative) understands, she got my message and, when the family conversation was finished or maybe half a day later, she (the relative) said something completely different... The fact that she (the relative) wasn't always consistent, that also made it difficult to get her to support the multidisciplinary team and support the agreements." (Case 1, Psychologist in individual interview)

Care staff

Characteristics

Interviewees experienced that the variety of characteristics and personalities of care staff resulted in different approaches with the resident. For example, a care staff member who was male or perceived as busy could trigger the resident's behavior. In one case this meant that only a limited number of care staff members were able to prevent behavioral outbursts from the resident.

"In any case, it has to do with whether people have a certain calm. For instance, care staff members who tend to come down on residents if they resist. Well, if you have done that to him (the resident) once, you are forever in his bad books." (Case 3, Elderly care physician in individual interview)

Furthermore, skills issues of care staff emerged as another sub-factor in experiencing the situation as an impasse. All groups of stakeholders highlighted that the care staff had insufficient skills and knowledge of extreme behavior.

"And sometimes I think that we were not trained to support and supervise this gentlemen (the resident) in the progress of his illness. Just where knowledge is concerned. This is one of these extreme cases." (Case 3, Care staff member in individual interview)

Another commonly mentioned difficulty concerned reporting by care staff. It was noted that care staff members often did not report the challenging behavior or that reports were of an insufficient quality. This was attributed to reporting not being possible or time consuming, the resident's behavior being considered 'usual', difficulty in expressing the severity of the behavior in words and not wanting to upset the relatives as they had access to the digital reports. Due to these issues regarding reporting, interviewees felt the severity of the behavior was registered insufficiently and was therefore presented to the treatment staff much too late.

"But at night, you feel like, well it is so busy now and it has been for weeks that I have to rush off to the next bell in a moment, I will write it later and there comes a time you don't write it at all." (Case 5, Care staff member on the nightshift in individual interview)

"It is difficult to report, like, I was hit and backed into a corner, because you know that family will read that too... then you feel like you want to play it down." (Case 1, Unit manager in individual interview)

Interviewees including care staff members of six cases mentioned that care staff rarely reflected on their own actions and feelings regarding the resident's behavior, due to a lack of skills or time.

"Don't assume that somebody else (other care staff members) might not know or does not have the relevant knowledge and so just really ask, like, how do you experience it and what do you run up against and what do you feel is difficult with this?" (Case 3, Certified primary nurse assistant in individual interview)

"To influence the behavior yourself, then I think there is a lot to win in that respect, that you have to critically assess, like, how do you deal with that behavior, what is my own role in that." (Case 7, Elderly care physician about the care staff in individual interview)

Finally, several care staff attitude issues played a role in experiencing the situation as an impasse. In the majority of cases, interviewees perceived that several care staff members had a wait-and-see attitude and they refrained from taking their role or from complying with the behavioral management approach that was agreed upon. Interviewees noted that care staff members found it difficult to ask for help, partly due to a fear of failure, meaning that they sometimes did not ask or asked much too late. Care staff reported that they felt alone and that their voice was not heard by the treatment staff.

"I do find it difficult to say to an elderly care physician or a psychologist, like, listen, we all find this difficult, could you provide us with a little more guidance? It feels like there is a threshold you are crossing." (Case 1, Certified primary nurse assistant and care staff member in focus group discussion)

"What would you need? From the elderly care physician, from the psychologist?" (Interviewer)
"Well, that they hear and listen to us... that your opinion is also heard." (Case 3, Care staff member in individual interview)

From the interviewees' perspective, care staff members often had a fatalistic attitude towards the resident and held negative views about their behavior. As a result, it required greater effort for them to care for the resident and perform certain job tasks, such as reading reports about the resident's behavior.

"At a certain moment you become prejudiced, you enter the room (of the resident) with apprehension, you have to dig really deep to find empathy... Because at a certain moment you

already have the feeling, like, I do not want to help him (the resident) anymore, for it always ends up being wrong anyway. And that is not fair to him, since he doesn't have a fair chance that way." (Case 7, Care staff member in individual interview)

Not all of the care staff members experienced the situation as an impasse, which seemed to be related to a difference in working shifts (e.g. day versus evening shift) and in the number of working hours. Moreover, care staff member's views, approaches and experiences with the challenging behavior differed. For example, a certified primary nurse assistant said that she did not pick up on the signals highlighted by other care staff members about the severity of the behavior, which led to a delay in involving the treatment staff. According to the interviewees, various views were expressed about the appropriate care among care staff members which led to different approaches with the resident. For instance, some reassured a particular resident by crawling into bed with them, whereas others would not. Furthermore, care staff members differed in the extent to which they accepted the resident's behavior; sometimes they let their personal boundaries be crossed.

"Everyone has their limits, of course, and with some people the limit is this and with others the limit is that and I think that some have gone on longer than was good for them." (Case 2, Care staff member in focus group discussion about care team members in general)

Interaction issues within stakeholder group

Interviewees noted that too few care team meetings were held and that in these meetings relevant topics, such as how to deal with the behavior, were often not discussed. As a consequence, several care staff members had insufficient insights into the behaviors and how to address them. Furthermore, giving each other feedback about one's actions was considered difficult, as care staff members were quickly offended and avoided confrontation. New ideas often received a negative response from other care staff members.

"Because sometimes you leave after certain situations that someone went through with that gentleman (the resident), you go home, you're still completely full of emotions or with feelings that you didn't even have at the time during work. And are unable to just share it with each other, what happened now, what did that do to you?" (Case 6, Nurse in focus group discussion)

Interviewees felt that there was a lack of dialogue between the care staff members about different attitudes, experiences and views regarding the situation due to indirect communication. Communication was further hampered between care staff members on different shifts.

"There's a powerlessness that I can't explain things properly to the night shift care staff or that it doesn't get through to them (night shift care staff) as to why we are not using medication right now. I often felt that I had to defend Ms ... (name resident) to the night shift care staff." (Case 5, Certified primary nurse assistant in individual interview)

Treatment staff (including unit manager)

Characteristics

To begin with, treatment staff members were said to miss the whole situation as they were only present during office hours and therefore at bay. They themselves mentioned to experience difficulties in treating the resident optimally. The complexity of the resident's behavior slowed the development and implementation of a treatment plan that often also did not work, or only worked temporarily. The severity of the behavior and its consequences for the other residents and NH staff often required a swift resolution, which prohibited an extensive analysis of the behavior. Moreover, difficulties with medication prescribed were reported. Medication was frequently prescribed instantly, which interfered with the developed treatment plan. Finding appropriate medication was difficult given the phasing out, side-effects and delicate balance between under-and over-sedation.

"And then you reach the point of yet trying another medication with consequences, she (the resident) becomes very drowsy again, she starts falling more, she doesn't get involved in the home community anymore, yes, you don't want that either, you want to be able to give her a dignified existence too." (Case 7, Unit manager in individual interview)

Two other main factors in experiencing the situation as an impasse concerned skills issues and attitude issues of the treatment staff. Interviewees similarly believed that treatment staff members had insufficient knowledge of and experience with extreme behavior. Treatment staff members made treatment plans which were outdated, impractical, unachievable and/or unfeasible in four cases. Furthermore, interviewees experienced that

treatment staff members were unable to detect the needs of care staff members, meet their expectations or support them properly. In addition, treatment staff members insufficiently informed the care staff. All groups of stakeholders mentioned that, in retrospect, treatment staff repeatedly tried several interventions and involved external expertise, such as a geriatric psychiatrist or the CCE, only at the very last moment. Moreover, interviewees said that treatment staff members were indecisive and took little responsibility for the situation, undertook too few actions and did not inform themselves properly about the situation by visiting the unit or talking to care staff members. Finally, they were unaware of the care staff's expertise.

"It took me quite a while to see the seriousness of the problem. That is my personal opinion, at least. That afterwards I say, like: maybe I should have been a little more on top of it at the start." (Case 3, Elderly care physician in focus group discussion)

"I think sometimes they don't realize enough just how much expertise the care staff already has and what they all did before they (the psychologist and elderly care physician in training) arrived." (Case 1, Unit manager in individual interview)

Interaction issues within stakeholder group

Treatment staff members indicated that they had different perceptions as to everyone's responsibilities pertaining to the situation and that there was not enough formal and informal exchange of information between the psychologist and elderly care physician.

"And in addition, I've found it difficult to really find a team feeling with him (the elderly care physician), I've felt like a lot was done individually despite initiatives to do more together." (Case 7, Psychologist in individual interview)

Nursing home staff

Interaction issues within stakeholder group

According to all groups of stakeholders, a prominent main factor regarding the interaction within the nursing staff concerned the interdisciplinary communication. Several issues were similar to those within the care staff and treatment staff, such as the limited exchange of information due to few meetings, little time for reflection, giving each other feedback or

performing an extensive analysis of the behavior. Additional issues concerned care and treatment staff not involving each other beyond those meetings. From the interviewees' perspectives, care staff members did not communicate their needs, wishes and actions taken with the treatment staff. The scarce information they did share was incomplete and unclear as it was difficult for them to express the severity of the behavior.

"We (care staff) didn't show enough that we needed help. We thought it would be fine." (Case 3, Care staff member in individual interview)

"But in the beginning, I actually didn't get any signals from the care staff that they had a problem with it... I think they share it mainly with each other and maybe don't even make it very clear to the psychologist just how bad it is." (Case 3, Psychologist in individual interview)

Contrastingly, it was felt that treatment staff members insufficiently involved care staff in their plans.

"A while back there was also something to do with the gentleman (the resident), I was on duty that day but I was not asked about it. Then it seemed like the elderly care physician, the psychologist, my unit manager and the quality nurse sat down and decided for us." (Case 3, Care staff member in individual interview)

Furthermore, interviewees felt that care and treatment staff did not take each other seriously or did not listen to each other's ideas and rationalizations when approaching the problem.

"The care staff also felt that they were not taken seriously and what they were very often told by the elderly care physician was 'Yes I don't have any miracle pills', but that is not the question, we are asking for him to help us, pay attention, listen, shadow us for a moment... help us carry the load." (Case 6, Unit manager in individual interview)

"We (care staff) did have some frustration as a team and also personally. He (the elderly care physician) still doesn't consider it a crisis, while we've had concerns about that for a year with

Ms ... (name resident)... by that point, we actually felt disrespected." (Case 2, Care staff member in individual interview)

A second main factor concerned inefficient work processes. Similar to the situation among care staff, indirect communication between care and treatment staff was an issue. Face-to-face discussions often did not take place. For example, communication occurred through an intermediary, such as a nurse, as care staff members were not allowed to contact the elderly care physician without involving an intermediary.

"Suppose there is an escalation and we need the elderly care physician at that moment, then there is a nursing station in between, so we actually have to call them first before an elderly care physician comes... That is yet another threshold you have to cross. Basically, we feel that the nurse does not know the resident, but we do." (Case 1, Nurse in focus group discussion)

Moreover, interviewees said that communication was inefficient due to a lack of a working agreement on how to contact each other. Occasionally, care staff members shared information about the resident with the psychologist and elderly care physician on separate occasions, with differing information. It was difficult for treatment staff to get a clear and complete picture about the behavior because they mostly spoke with only one care staff member, which was usually the same person, every time (commonly the certified primary nurse assistant) or rather, with a different care staff member each time. Moreover, there were occasions when they did not speak with the correct person (e.g. a trainee care staff member).

"When you come, you talk to one care staff member and the next time you talk to another care staff member and they just have a slightly different opinion or a different perception or a different feeling... you then assume that such a care staff speaks with one voice, that's quite difficult." (Case 4, Elderly care physician in focus group discussion)

Consequences of interaction issues within nursing home staff

Due to the abovementioned issues regarding communication and work processes among NH staff, experiences with and views on the resident's behavior differed, which could lead to disagreements about the developed plans. In dealing with the behavior, feelings of

powerlessness and failure prevailed. However, a number of staff members did not give up hope and continued with their search for a solution to manage the extreme behavior. Others gave up hope and resigned themselves to the situation, which sometimes even led to care staff members accepting that they were physically injured by the resident. Both of these coping mechanisms led to prolonged decision-making processes.

"You have hope that it (the behavior) will get better. At some point you think that maybe it's because of a certain reason, or that it's an incident, after some time you think well maybe it (the behavior) will stay like this." (Case 1, Elderly physician in training in individual interview)

"Yes, at some point you shut up about it too, yes, let's all just do it. And I do think that this has happened. That we all think, well let's just do it, because we won't manage it (the behavior) anyway." (Case 4, Certified primary nurse assistant in individual interview)

Organization

Characteristics

Staffing issues was mentioned by interviewees as one of the difficulties in experiencing the situation as an impasse. All participating units were short-staffed and their staff turnover was a barrier for optimal resident care. Moreover, care staff members highlighted not having enough time for particular residents or others due to an excessive workload.

"And occasionally you'll just ignore her (the resident), because then the workload is such that you think, well, I have to go to the others (other residents) first... that you don't actually have enough time to sit quietly with her." (Case 5, Care staff member in individual interview)

In all cases, the size of the resident's unit was mentioned as a problem by the interviewees. Six residents lived on a small-scale unit where one care staff member had to divide their attention across them. Care staff members did not receive a clear and complete overview of the resident's behavior. In one case, the resident lived on a large-scale unit and was therefore easily triggered by a variety of stimuli stemming from the other residents.

"She (the resident) cannot be attended to 24 hours a day, she also walks around the unit and sometimes there is one care staff member who has six or seven other residents. That care staff

member is not standing there all the time checking what she (the resident) is doing.” (Case 4, Elderly care physician in individual interview)

Furthermore, organizational norms and values in five of the seven cases led to acceptance of the behavior by considering the extreme behavior as part of the dementia or the resident’s personality, rendering it more acceptable.

“It has become part of the culture though, the idea that we think that it (the behavior) is becoming normal.” (Case 4, Care staff member in individual interview)

“You notice that they (the care staff) often put up with things and think things are normal for quite a long time. Under the guise of, well, that’s just part of the pathology and you can’t blame him (the resident). But they are still being beaten and pinched.” (Case 1, Psychologist in individual interview)

Finally, interviewees described the role of the management of the NH as a main difficult factor. The interviewees reported that the management staff of the NH insufficiently invested in solutions to improve the situation regarding residents with extreme behavior, such as making funds available to invest in environmental adjustments to influence the resident’s behavior. In one case, the management staff made decisions which interfered with the clinical situation.

“And that has more to do with the fact that management has started to interfere with the content of the case, which really does not please me.” (Case 6, Elderly care physician in individual interview)

Discussion

This is the first study in which an in-depth exploration of situations of extreme challenging behavior concerning NH residents with dementia was conducted. We found that several characteristics and attitudes of NH staff, as well as their interactions, contributed to their experience of the situation as an impasse. In particular, the resident’s characteristics,

together with suboptimal mono-and interdisciplinary communication and collaboration were experienced as the greatest difficulties. NH staff members kept searching for a solution to manage the resident's extreme challenging behavior or lost hope. In the end, they did not know how to cope with the situation any longer and consulted external expertise.

Part of our findings are in line with earlier studies such as the difficulties experienced by the NH staff with the nature, extremity and persistency of the behavior, developing a clear treatment plan and prescribing medication.^{11,30} Moreover, the disparity in views and attitudes of the staff and their need for more knowledge is a familiar theme across NH care.³⁰⁻³³

A conflicting result with our study concerns a review in which a positive influence of small-scale units on the residents' behavior was described,³⁴ compared to the negative influence found in our study. It is possible that small-scale units can contribute to a general reduction of challenging behavior, but are not suitable for residents exhibiting extreme behaviors. It is also possible that the limited use of mono-and interdisciplinary meetings on these units is also a factor, which play a greater role for residents with extreme behaviors.

Several of our findings are connected to the NH staff's professional attitude. It appeared to be difficult for staff members to reflect on their own and others' behavior, which was further complicated by the circumstances, such as the lack of interdisciplinary meetings. As well as this, care staff members experienced problems with reporting the resident's behavior in a structured, objective and detailed manner. They were afraid to upset the relatives with the severity of the situation, as relatives have access to the (digital) resident files. This appears to be specific to Dutch NH organizations, who promote and facilitate this. Furthermore, setting personal boundaries towards, not only the resident, but also their relatives, was a challenge for care staff members. Striking a balance between delivery of personal care while maintaining boundaries has been found to be difficult for many nursing assistants.³⁵ Indeed, an optimal balance between personal intimacy and maintaining a professional attitude is lacking in the literature on person-centered care, although the nursing literature stresses the importance of boundaries and a good balance between distance and involvement.^{36,37} Too little attention on this balance could result in

person-centered care being misinterpreted by care staff members and may lead to a serving attitude and culture of over-acceptance of challenging behavior as 'part of the job',³⁸ ultimately compromising the wellbeing of nursing staff.^{37,39} Probably suboptimal professional behavior of NH staff is less relevant in cases with less severe challenging behavior and is especially required in residents with extreme challenging behavior. Namely, coping with extreme challenging behavior may engender a need for more personal leadership and insight into one's own behavior.^{40,41} It is not just about having the necessary knowledge and experience, but also about the way of dealing with tasks, oneself and others within the broader situation. Although in current Bachelor training programs for nurses in the Netherlands, professionalism is included as one of the required competences,⁴² in training programs for vocationally trained registered nurses, this is not the case. The newly developed ambassador trajectory for certified nurse assistants and the introduction of nurses with a Bachelors education in the NH may contribute to nursing leadership and empower members of the care team.⁴³

Our study also showed that treatment staff members did not recognize the knowledge and expertise of care staff, were unable to detect their needs or to support them properly. An earlier study suggested that acknowledgement of nurses' competencies by physicians is one of the keys to improving interdisciplinary collaboration.⁴⁴ Especially in the case of residents with extreme challenging behavior, treatment staff members should create an environment in which care staff members are sufficiently supported and their professionalism is appreciated.

Clinical implications

In sum, the findings of our study clarify that situations of extreme challenging behavior are experienced as an impasse by NH staff and relatives due to the resident's specific characteristics together with problems regarding mono- and interdisciplinary communication and collaboration of NH staff. As we now know these important contributing factors, we could develop interventions based on knowledge about mono- and interdisciplinary communication and collaboration to prevent these impasses in the future. We think that particularly in these complex cases, communicating and collaborating intensively is the key to managing these situations and finding the most optimal approach. Teaching NH

staff members solid communicative and reflective skills, tackling learned helplessness and developing self-awareness are important aspects to take into account.^{45,46}

Furthermore, having attention for each other and supporting each other in these complex cases, besides bearing the responsibility together, could be helpful for NH staff as it would make it a less heavy burden to bear. Sufficient time needs to be available for regular meetings in which there are opportunities and a safe atmosphere to share views, give feedback and inform each other about the interventions and treatment plans.

In addition, working uniformly and methodically seems to be very important and requires further attention, especially as it was found to be effective in reducing challenging behavior, but difficult to implement.^{47,48} This mainly concerns performing a good assessment and evaluation of treatment plans and medication. Also, the use of structured ways of communication, for instance a communicative framework based on the SBAR (Situation, Background, Assessment, and Recommendation) approach may be helpful.⁴⁹

Strengths and limitations

We performed a high quality, in-depth exploration of experiences with extreme challenging behavior involving all relevant stakeholders, using a combination of methods for data collection (data triangulation) and analytical techniques (analysis triangulation), having multiple researchers involved (investigator triangulation) and organized (consensus) meetings with each other and all authors. This approach enhanced the reliability and trustworthiness of the results.^{20,21}

Though, it is important to realize that our study focuses on extreme situations, all cases concerned impasses for which external expertise was requested. The issues uncovered in this study probably result in less severe problems when presented in less severe situations. In addition, only the experiences of NH staff and relatives were reported in this study. Therefore, inferences about extreme challenging behavior in general cannot be made. Furthermore, the characteristics and roles of the researchers could have influenced the analysis of the data.⁵⁰ Moreover, to ensure a safe environment, we did not share all the information obtained from the individual interviews in the focus group discussions and although we noticed in the individual interviews that interviewees had certain views about

each other, we did not investigate how these were related. Both of these factors could have provided additional insights. Finally, external validity of the results is unclear as these reflect the Dutch cultural, societal, and health care contexts.

Conclusion

Situations of extreme challenging behavior in NH residents with dementia can be experienced as an impasse by NH staff and relatives, especially due to the resident's characteristics together with suboptimal mono-and interdisciplinary communication and collaboration of NH staff. Although the conditions for high-quality care are present in the NH, namely the wide range of expertise and committed relatives, suboptimal collaboration and insufficient work processes still exist. The contributing factors found in this study provide important insights into the complexity and extent of these situations and offer caregivers targets to improve the provided care, treatment and interdisciplinary collaboration for NH residents with dementia and extreme challenging behavior. Situations of extreme challenging behavior require specific skills due to their complexity. Collaborating intensively, working methodically and achieving the right balance between personal intimacy and a professional attitude are key to dealing with those situations. Moreover, involving external expertise at an earlier point in time and finding the most optimal solution, which may be to transfer the resident to a specialized care unit, are important. To obtain further insight into situations of extreme challenging behavior, future research should investigate the added value of the use of assessment instruments to measure the frequency, severity and impact of the behavior, focus on the quality of (digital) reports and explore if a more structured, objective and detailed way of reporting could assist care staff members.

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Supplementary material table 1. Detailed applied methodology following the consolidated criteria for reporting qualitative studies (COREQ) 32-item checklist.¹

No. Item	Guiding questions/description	Application
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which authors conducted the interview?	AV ² conducted the individual interviews, AP and DG ² moderated the focus group discussions. AV ² asked additional questions, and observed body language and interactions between the interviewees.
2. Credentials	What were the researcher's credentials?	MD
3. Occupation	What was their occupation at the time of the study?	Elderly care physician in training and PhD student. ³
4. Gender	Was the researcher male or female?	Female
5. Experience and training	What experience or training did the researcher have?	AV ² : medicine, entry-level course in Atlas.ti, basic course qualitative health research. Research team: medical (SZ, MS, RK) ² , psychological (DG), ² nursing (science) (AP) ² and all are specialized in elderly care.
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	AV was not acquainted with interviewees before the interview.
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	A briefing letter about the purpose of the study and practical information about the interview was sent to the relatives of eligible candidates. This letter also mentioned that the interviewer was an elderly care physician in training (AV). ²
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. bias, assumptions, reasons and interests in the research topic	The occupation of the interviewer was given in the briefing letter.

Supplementary material table 1. (continued).

No. Item	Guiding questions/description	Application
Domain 2: Study design		
<i>Theoretical framework</i>		
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic analysis was used (both inductive and deductive), including conventional content analysis. ⁴⁻⁶
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	We used consecutive sampling to select cases. Cases were assessed for inclusion by two coordinators of the Centre for Consultation and Expertise (CCE) ⁷ and by AV ² and DG ² by verifying the inclusion criteria: a) the resident had dementia and extreme challenging behavior which affected their quality of life according to the professionals who reported the case to the CCE; b) there was no obvious easily treatable cause for the challenging behavior; c) the behavior was experienced as very difficult to cope with by the involved nursing home staff and they had been unable to treat the challenging behavior satisfactorily; d) the challenging behavior consisted of aggression and/or vocally disruptive behavior and/or agitation; e) the resident had no acute life-threatening diseases; and f) they had been staying in the nursing home for at least 4 weeks.

Supplementary material table 1. (continued).

No. Item	Guiding questions/description	Application
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	<p>The coordinator of the CCE telephoned the notifying party and asked them for the contact information of the elderly care physician of the resident.</p> <p>The coordinator telephoned the elderly care physician and asked if AV² was permitted to contact them.</p> <p>AV² contacted the elderly care physician within a week after notification and gave them information about the study. The elderly care physician was asked to talk with their manager regarding permission for participation in the study. Also, a briefing letter about the rationale and aim of the study was sent to them by post or by email.</p> <p>When the elderly care physician and supervisor agreed to participate in the study, they were asked to sign a consent form.</p> <p>The elderly care physician telephoned the relatives of the nursing home resident and asked if AV² was permitted to contact them.</p> <p>AV² contacted the relative within a week and gave them information about the study. A briefing letter and a consent form were sent to them by post or by email. The relative was given two weeks to think about the participation.</p> <p>The relative was contacted again by AV² within two weeks by telephone or email to ask for consent. After agreement to participate in the study, relatives were asked to sign the consent form and appointments were scheduled for the interviews.</p> <p>When a case was deemed appropriate for inclusion by the elderly care physician and the unit manager of the nursing home, intensively involved nursing staff members (as mentioned in Table 1) and the relative were asked for consent to participate in the study. For consent a written consent form was used.</p>

Supplementary material table 1. (continued).

No. Item	Guiding questions/description	Application
12. Sample size	How many participants were in the study?	Of the 19 applied cases, 9 were assessed as eligible according to the inclusion criteria. The other 10 cases were excluded, because a) they did not meet the inclusion criteria; b) they did not meet the inclusion criteria; c) the consultation question was too narrow; c) AV ² was absent due to an internship; or d) there was a sufficient number of cases at that time. Individual interviews: 42 interviewees. Focus group discussions: 52 interviewees.
13. Non-participation	How many people refused to participate or dropped out, and why?	In 2 cases, the elderly care physician/ nursing home refrained from participating in the study. These cases were therefore not included in the study.
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	The individual interviews with nursing home staff were held during April-December 2016 in the nursing home of the resident, while interviews with relatives took place during April-October 2016 at their own home (N=4) or in the nursing home (N=3). The focus group discussions with nursing home staff were held during April 2016-January 2017 in the nursing home of the resident.
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Interviewees had the opportunity to be interviewed together with a second representative of the same perspective. No non-participants were present during the interviews.
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	See Table 2.
<i>Data collection</i>		

Supplementary material table 1. (continued).

No. Item	Guiding questions/description	Application
17. Interview guide	Were questions, prompts, or guides provided by the authors? Were they pilot tested?	For each group of stakeholders and for the focus group discussions, AV used a semi-structured interview guide, in which the main questions and sub-questions were displayed. These interview guides were also used as an extra check to make sure all topics were discussed. The interview guides were not pilot tested. Planned, informal and floating prompts were used during the interviews. The topic list of the focus group discussions could change after each focus group discussion: debriefing took place between the moderator and observer to discuss the findings and to identify topics that could be explored further.
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	All interviews were audio-taped and transcribed verbatim by three medical students (LS, KE and LB) ² and a professional transcription office (6), eliminating any names or privacy-related information. The transcripts were read closely and cross-checked against the tapes for accuracy by AV. ²
20. Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were made by AV during and after each individual and focus group discussion.
21. Duration	What was the duration of the interviews?	The individual interviews lasted between 60 and 90 minutes. The focus group discussions lasted between 120 and 150 minutes.
22. Data saturation	Was data saturation discussed?	All authors discussed findings and data saturation after each case. We expected to include ten cases, but stopped inclusion after interviewing for seven as we had reached data saturation, determined by all authors. For the seventh case, no new codes were added to the coding tree. ⁸

Supplementary material table 1. (continued).

No. Item	Guiding questions/description	Application
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	A summary of each transcription was made (AV) ² and returned to the interviewees for checking. After a few adjustments based on comments from eleven interviewees, all agreed with the summaries.
Domain 3: Analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	5: AV, AP, EV, MW and KM. ² For the first case, 5 interviews were coded twice by two coders (AV and AP) ² and the coded transcripts were discussed in a consensus meeting. The other 2 interviews of the first case were coded by AV ² and checked by AP. After analysis of the first case, the coding tree was discussed in a meeting with AP, AV and DG, ² and also in a meeting with all authors. A modified version of this coding tree was used for the analysis of the other cases. For the other cases, except for the fourth case, one interview was coded twice by two coders. The coded transcript of the twice coded interviews were discussed between these two coders, and as a result, further changes were made in the coding tree. The other interviews were coded by one person, with all codes checked by AV. ² If necessary, changes were made. After analysis of the last case, the latest version of the coding tree was used for re-coding of the transcripts of the other six cases to improve analysis accuracy (MW). ²
25. Description of the coding tree	Did authors provide a description of the coding tree?	No, but this is available from the authors on request.

Supplementary material table 1. (continued).

No. Item	Guiding questions/description	Application
26. Derivation of themes	Were themes identified in advance or derived from the data?	For each case, consensus meetings took place with the two data coders involved (AV, AP, EV, MW, KM) ² and one of the authors (DG). ² In these meetings, the case was discussed, categories were refined into definitive themes and sub-themes and an overall theme was defined. Per case, mind maps were made for within-case analysis (EV, AV). ² The mind maps were discussed in meetings with all authors. For a cross-case analysis, one mind map was made consisting of all mind maps together (AV). ² A final graphic representation of the themes, sub-themes and their connections was made after several group discussions. Three main factors were derived from the data.
27. Software	What software, if applicable, was used to manage the data?	Analysis with Atlas.ti version 7.1.4. was conducted during data collection (Atlas.ti Scientific Software Development, Berlin, Germany).
28. Participant checking	Did participants provide feedback on the findings?	Eleven interviewees provided feedback on the summaries of their interview or focus group discussion. After a few adjustments, they agreed with the summaries.
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes, see Results section of the manuscript and Supplementary material table 4. Quotes were translated into English by translation agency Univertaal
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes, see Results section of the manuscript, Table 3 and Figure 1.
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

Notes:

¹ Tong A, Sainsburg P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007; 19(6), 349-57.

²AV: Annelies Veldwijk; SZ: Sytse Zuidema; MS: Martin Smalbrugge; RK: Raymond Koopmans; DG: Debby Gerritsen; AP: Anke Persoon; LS: Lex van Son; KE: Kyra Ekker; LB: Leonie Buijsse; EV: Erica de Vries; MW: Mandy Wijnen; KM: Kim Maassen.

³Koopmans RTCM, Pellegrom M, van der Geer ER. The Dutch Move Beyond the Concept of Nursing Home Physician Specialists. *J Am Med Dir Assoc*. 2017; 18(9):746-9.

⁴Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006; 3(2):77-101.

⁵Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2008; 62(1):107-15.

⁶Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005; 15(9):1277-88.

⁷Centre for Consultation and Expertise (CCE). Available from: <https://www.cce.nl/english>. (Accessed on September 2nd 2021).

⁸Evers JC, van Staa AL. Qualitative analysis in case study. In: Mills AJ, Eurepos G, Wiebe E, editors. *Encyclopedia of case study research Part 2*. 1st ed. Thousand Oaks: Sage Publications; 2010. p. 749-57.

Supplementary material table 2. Topic list for semi-structured in-depth interview with interviewees.

Topic	Interview questions	Additional sub-questions
Nature and course of challenging behavior	What does the extreme challenging behavior of the resident consist of?	<p>Can you provide examples?</p> <p>How was the extreme challenging behavior expressed over time?</p> <p>Was the resident's extreme behavior already present before nursing home admission, and if yes, how did that manifest? (asked to relatives)</p> <p>What are possible reasons for the behavior in your opinion?</p> <p>Which factors influenced the resident's extreme challenging behavior in your opinion?</p> <p>Which role do you think that the environment plays in the resident's extreme challenging behavior?</p> <p>Could there be a connection between the resident's extreme challenging behavior and prior events in the resident's life? (asked to relatives)</p>
Actions undertaken	<p>Asked to professionals: Which action(s) did you undertake to change the situation regarding the resident's extreme challenging behavior?</p> <p>Asked to relatives: Which action(s) were undertaken to change the situation regarding the resident's extreme challenging behavior? (asked to relatives)</p>	<p>For what reasons did you undertake these action(s)?</p> <p>What added value do you think that your actions had on the resident's extreme challenging behavior?</p> <p>What do you think about the actions undertaken by other professionals?</p> <p>In retrospect, what would you have done differently?</p> <p>What do you think about these actions?</p> <p>What role did you play in these actions?</p> <p>What added value do you think that your role had on the resident's extreme challenging behavior?</p> <p>In retrospect, what could have been done differently in your opinion?</p>

Supplementary material table 2. (continued).

Topic	Interview questions	Additional sub-questions
Factors contributing to an impasse	Do you think that a certain point of crisis was reached?	If yes, which factors contributed to this point of crisis? What difficulties did you experience when dealing with the resident's extreme challenging behavior? Why is the resident's extreme challenging behavior untreatable/unsolvable? Do you have any ideas on that? (asked to professionals) As a professional, do you think you have tried everything to solve the problem? (asked to professionals)

Supplementary material table 3. Topic list for focus group discussions with interviewees.

Topic	Interview questions
Introduction	What is it that makes this situation a problem for the people involved? What was the final point which made you all decide to involve the Centre for Consultation and Expertise (CCE)?
Treatment and care	What difficulties did you experience during treatment of the resident's extreme challenging behavior and in caring for the resident? Which interventions were successful in treating the resident's extreme challenging behavior and in caring for the resident? Which interventions had no improvement in treating the resident's extreme challenging behavior and in caring for the resident? Why is/was the resident's extreme challenging behavior untreatable/unsolvable? Do you have any idea about that?
Multidisciplinary collaboration	How was the multidisciplinary collaboration in addressing this problematic situation?
Dealing with the situation	What did you miss in the multidisciplinary collaboration in addressing this problematic situation? What difficulties did you experience in dealing with the resident's extreme challenging behavior? What do/did you need in this kind of situation?
Factors contributing to an impasse	Do you think that a certain point of crisis was reached? (asked to all focus group discussion participants individually) If yes, which factors contributed to this point of crisis? At which point would you mark the situation as being a crisis? What makes/made this situation different from other situations with residents with challenging behavior? What has changed by involving the CCE?
Impact of the resident's extreme challenging behavior	What was the impact of the resident's extreme challenging behavior on you up until now? Which emotions and feelings did the resident's extreme challenging behavior evoke within you?

Supplementary material table 4. Additional quotes for all described general, main and sub-factors of the six (groups of) stakeholders.

(GROUPS OF) STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
RESIDENT	CHARACTERISTICS		
	PERSON	Unlike other residents	Because he (<i>the resident</i>) has very good moments where... Of course, there will be a medical explanation for everything, but sometimes I really do feel and his wife says that too sometimes... Of course, the brain scan was not a full 100% because that was no longer possible because of his behavior. Yes, the other day she (<i>the relative</i>) said: "He (<i>the resident</i>) still remembers everything sometimes. He is not really demented then." (<i>Care staff member in focus group discussion</i>)
	BEHAVIOR	Nature of the behavior	But aggression I do find, I do find that difficult, yes. You must also protect the fellow residents, and sometimes that is not possible at all. You are in a balancing act. You want to, but you just can't. (<i>Care staff member in focus group discussion</i>)
		Course of the behavior	Interviewer: "Why exactly was the situation perceived as a problem for you?" I think the behavior is continuous. It's not intermittent but it is from the time when she (<i>the resident</i>) gets up to the time she goes to bed and wakes up again during the night, the behavior is continuous. (<i>Nurse in focus group discussion</i>)
		Severity of the behavior	Sure, there are more residents with agitation, there certainly are, but not in that extreme form that this lady (<i>the resident</i>) has that it really goes on all night. Every night. (<i>Unit manager in focus group discussion</i>)
		Unpredictability of the behavior	It (the behavior) comes all at once, it's unpredictable. I've had experiences with other residents that you can kind of sense that this aggression is coming on and with her (the resident), you can't. It (the behavior) comes all at once and it may happen that she (the resident) walks over to you and at once she relaxes and is very sweet and quiet. (<i>Care staff member in focus group discussion</i>)

Supplementary material table 4. (continued).

GROUPS OF STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
		Unclear triggers of the behavior	What I see is a number of behaviors that I cannot properly pinpoint, I do not know what is behind them, and so I do not know what I need to treat. <i>(Elderly care physician in individual interview)</i>
		Behavior considered as (partly) on purpose	She <i>(the resident)</i> did throw coffee all over someone once. Yeah, and then you'll think, of course, she's deliberately taking that cup and she's deliberately throwing the coffee over someone... But whether it's really conscious or just a scream for attention... Yes. Tricky. <i>(Certified primary nurse assistant in individual interview)</i>
		Behavior differs from personality before diagnosis of dementia	I also have the idea, at least from what I know of how she <i>(the resident)</i> is described by the family, that she is actually a very sweet gentle woman most of the time. So, the behavior she shows, which is also described here of suddenly being aggressive, to my mind it doesn't fit the person she is. <i>(Elderly care physician in focus group discussion)</i>
INTERACTION ISSUES WITH OTHER GROUPS OF STAKEHOLDERS WITH OTHER RESIDENTS		The resident's behavior causes inconveniences and danger for the other residents	But also for the situation with the other residents to whom she <i>(the resident)</i> responds aggressively. And the other residents, they cannot act, they just have to take it. They cannot walk away, some are in a wheelchair but are still being beaten or almost pulled from the wheelchair, that too is, and not so much for the lady <i>(the resident)</i> or for the care staff, but perhaps is worst for the other residents. <i>(Care staff member in focus group discussion)</i>
		Reactions of other residents negatively affect the resident's behavior	And there's a Turkish lady and she <i>(the resident)</i> absolutely doesn't get along with her, you can't leave those two alone. Because then things go wrong. <i>(Relative in individual interview)</i>

Supplementary material table 4. (continued).

GROUPS OF STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
WITH NURSING HOME STAFF	The resident not understanding verbal requests		I definitely think that understanding is a factor. That she (<i>the resident</i>) really doesn't know what... she can't follow a conversation anymore... she also doesn't know if you want to do something with her, help her, then she doesn't know what you want either, you can't explain that to her. (<i>Elderly care physician in individual interview</i>)
	The resident giving short answers/minimal reaction		When you ask things, he (<i>the resident</i>) says very little to nothing. It is only "yes" or "no". (<i>Certified primary nurse assistant in focus group discussion</i>)
	The resident not wishing to/not making any contact		We do try to have a chat but he (<i>the resident</i>) very often indicates that he just doesn't want to. Then he'll keep his eyes closed too. (<i>Care staff member in individual interview</i>)
	Inability of nursing home staff to read the resident's emotions		It is sometimes a blank look in the eyes. That she (<i>the resident</i>) can look at you in a way of, like, what would I do? Sort of. But whether it (<i>the behavior</i>) is really fear then, or the lack of understanding I can't, no... I find that a little difficult to say, what it is. (<i>Certified primary nurse assistant in individual interview</i>)
WITH CARE STAFF SPECIFICALLY	Nursing home staff not understanding the resident's behavior and having no control over the behavior		And if she (<i>the resident</i>) is in an angry mood, then you can't get her out of it either, you can try all sorts of things but then you can't get her to calm down, she'll stay in that mood. (<i>Certified primary nurse assistant in individual interview</i>)
	Not noticing signs of escalation of the resident's behavior in a timely manner		The last time he (<i>the resident</i>) grabbed me by my arm was when I wasn't focusing on him 100%, which meant I missed the signal. Yes, then I was too late in picking up the signal. (<i>Certified primary nurse assistant in individual interview</i>)

Supplementary material table 4. (continued).

(GROUPS OF) STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
		Positive moments with the resident are scarce	Yes, you know, then you really have to make the most of the good moments with the resident and if that is already very rare, then you don't get the positivity out of it anymore and then you remain very negative. Yes, and at one point, the whole care team, I understood that from the team meeting as well, the whole care team had actually just run out of steam. <i>(Certified primary nurse assistant in individual interview)</i>
		Paying attention to the resident takes a lot of time	You actually have to divide five hours and 45 minutes among seven people <i>(other residents)</i> . But when I think about that, I think, my goodness, I spent two and a half hours on her <i>(the resident)</i> . And yes, if you add it up, I went along to the bathroom ten times that night. To her room, get some chocolate, walked into the living room together, sat together for a while, had a chat. Just to calm her down so that the other residents don't get restless as well, so that the other residents can watch television in peace for a while. <i>(Care staff member in individual interview)</i>
		Undertaking pleasant activities with the resident is problematic	This man <i>(the resident)</i> , he was also cognitively deteriorating so it was increasingly difficult to go for a walk with him or to read together. Yes, that, that also decreased his quality of life. <i>(Unit manager in focus group discussion)</i>
		Applying compulsory treatment is difficult	Yes, and that compulsory treatment, that's something you'd rather not use. That is very unpleasant... It is very drastic for someone to do something to them against their will. <i>(Elderly care physician in training in individual interview)</i>
RELATIVE CHARACTERISTICS PERCEPTIONS		Having a different perception of the behavior, treatment and care	She <i>(the relative)</i> didn't want medication and she didn't think it was necessary, she had a very strong opinion about it... While it really wasn't possible at times. <i>(Unit manager in individual interview)</i>

Supplementary material table 4. (continued).

<p>(GROUPS OF) STAKEHOLDERS</p>	<p>GENERAL AND MAIN FACTORS</p>	<p>SUB-FACTORS</p>	<p>QUOTE</p>
		<p>Finding it hard to accept that usual care could not always be provided</p>	<p>Yes, his (<i>the resident's</i>) wife had a really hard time with it in the beginning when he was incontinent and still wearing dirty clothes. Or that he had smears on his clothing and didn't want a napkin. I think that we went along with that too much in the beginning. (<i>Care staff member in focus group discussion</i>)</p>
<p>PERCEPTIONS</p>		<p>Having a different perception of the behavior, treatment and care</p>	<p>She (<i>the relative</i>) didn't want medication and she didn't think it was necessary, she had a very strong opinion about it... While it really wasn't possible at times. (<i>Unit manager in individual interview</i>)</p>
<p>CHARACTERISTICS</p>			
<p>INTERACTION ISSUES WITH OTHER (GROUPS OF) STAKEHOLDERS</p>		<p>Nursing home staff insufficiently informs/involves relatives</p>	<p>It (<i>an intervention</i>) was not discussed with (<i>name relative</i>) or with another contact person, that is unfortunate... I think, to talk to the daughter sooner. I kind of missed that too. Kind of overlooked it myself. (<i>Certified primary nurse assistant in individual interview</i>)</p>
<p>WITH NURSING HOME STAFF</p>		<p>Relative has limited trust in (certain) care staff members</p>	<p>I've had a lot of conversations with her (<i>the relative</i>), and she just doesn't trust certain people. (<i>Certified primary nurse assistant in individual interview</i>)</p>
		<p>Relative criticizes actions of care staff</p>	<p>That we actually couldn't do well in her (<i>the relative</i>) eyes no matter what we did... so I think it may have been a bit of self-preservation that caused her to react that way. But especially not doing it right in her eyes, that was difficult. (<i>Care staff member in individual interview</i>)</p>
		<p>Relative crosses personal boundaries of care staff members</p>	<p>With a, a strong powerful wife who... Yes, who also crossed our (<i>care staff</i>) limits. (<i>Unit manager and nurse in focus group discussion</i>)</p>

Supplementary material table 4. (continued).

(GROUPS OF) STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
CARE STAFF	CHARACTERISTICS	PERSONALITY ISSUES	But I also find it very difficult to gauge them (<i>the relative and family</i>) in that respect, like, what they (<i>the relative and family</i>) really believe and what they really think. (<i>Certified primary nurse assistant in individual interview</i>)
		PERSONALITY ISSUES	She (<i>the resident</i>) has to deal with someone else every time, of course, who reacts differently to her. Of course, we are all different and everyone reacts differently. (<i>Nurse in focus group discussion</i>)
		SKILLS ISSUES	You don't learn these kinds of things (<i>About ways of dealing with the behavior</i>) in school. It gets mentioned once, people with problematic behavior, and you get a nice booklet. By the time it happens, you don't remember. (<i>Certified primary nurse assistant in individual interview</i>)
	ATTITUDE ISSUES		To put something about the behavior on paper... I find that a bit trickier myself and I think that is generally true... putting something clearly on paper is harder to convey than through a conversation. (<i>Care staff member on the nightshift in individual interview</i>)
			That reflection (<i>of care staff members</i>) is so minor, it almost doesn't happen. To express what it does to you exactly. (<i>Unit manager in individual interview</i>)
			Yes, because when you are indeed multidisciplinary, you still notice that the care staff is more of a follower. While I think, like, they are on it 24 hours a day. They are the ones that should lead. And it is us (<i>the care staff</i>) that should actually say, like, listen, we have had it up to here, we need help now. (<i>Unit manager and nurse in focus group discussion</i>)

Supplementary material table 4. (continued).

(GROUPS OF) STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
		<p>Not asking for help/asking for help too late</p> <p>Refraining from complying with the behavioral management approach that was agreed on</p> <p>Having a fatalistic attitude</p>	<p>Yes, we didn't show enough that we needed help. <i>(Care staff member in individual interview)</i></p> <p>Yes, then if <i>(name psychologist)</i> gets involved and he prescribes advice, then we have to do that or try it. And then if that is eventually not done, it stops. <i>(Certified primary nurse assistant in individual interview)</i></p> <p>Then I had to do Mr... <i>(name resident)</i> again after a very long time. And then I was quite clearly told: "Yes, you have to be careful. Don't stand on his right side. He hits and he does things". So I went in there already thinking: Okay. That made sense, that they would warn you about that <i>(the behavior)</i>, of course. But I might have preferred to go back in with an open mind. <i>(Care staff member in focus group discussion)</i></p>
		<p>Differences in views on the behavior, approaches in dealing with the resident's extreme challenging behavior and experiences of the behavior due to a difference in working shifts (day/night) and number of working hours</p> <p>Difference in opinions about appropriate care</p>	<p>Being able to better understand the signals from colleagues sooner, because that's what it is... I am sometimes too easy when it comes to that. I then assume that others know and can do the same. And that is not so. <i>(Certified primary nurse assistant in individual interview)</i></p> <p>That's what I found tricky too in terms of the approach, that you <i>(to a care staff member in the focus group discussion)</i> went and laid in her <i>(the resident's)</i> bed with her <i>(the resident)</i> because that calmed her down. I thought that was really nice when I heard that and that you <i>(to a care staff member in the focus group discussion)</i> rocked her <i>(the resident)</i> so that she fell asleep, but <i>(name of another care staff member)</i> asks the question, and for good reason: isn't that too intimate? You are a professional. <i>(Psychologist in focus group discussion)</i></p>

Supplementary material table 4. (continued).

(GROUPS OF) STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
		Difference in the extent to which the resident's behavior is accepted	Of course in one person the limit is here and in another the limit is there and I think that some persons kept providing care longer than they should have done, for their own sake. (<i>Care staff member in focus group discussion</i>)
	INTERACTION ISSUES WITHIN STAKEHOLDER GROUP		
	WITHIN CARE STAFF	Little opportunity for formal and informal exchange of information	It's difficult, because you don't have many team meetings, you rarely sit down with your whole team together... an actual moment to talk about a case like this, we haven't really planned it. (<i>Care staff member in focus group discussion</i>)
		Giving each other feedback is difficult	I find it difficult to confront a colleague with this. For I am afraid I'll have a discussion or get a nasty reaction. And I don't want that. I want to avoid that. (<i>Care staff member in focus group discussion</i>)
		New ideas from care staff members often receive a negative response from other care staff members	In any case, it is true that there is also someone in that team (<i>care staff</i>) with a special focus on people with problematic behavior and that someone has taken a special course for that. And they tried to explain a little bit about it, but it didn't go down well with the rest of the team, at least not with everyone in that team. So there's some, yes, I did sense some friction there... you think you know it all, but we actually know it too and we do it this way. (<i>Elderly care physician in individual interview</i>)
		Communication takes place indirectly	Look, one week I see (<i>name of a care staff member</i>) very often, and then, just like that, I don't see her for two, three weeks. Look, it also just depends on when someone works... And when I discuss things with her, they don't all know... (<i>Care staff member in focus group discussion</i>)

Supplementary material table 4. (continued).

GROUPS OF STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
TREATMENT STAFF	CHARACTERISTICS BEING AT BAY	<p>Missing the whole picture of the situation and the resident's behavior</p> <p>Only present during office hours</p>	<p>He (<i>the elderly care physician</i>) only sees part of her (<i>the resident</i>) sometimes. I find that situation very difficult. (<i>Certified primary nurse assistant in individual interview</i>)</p> <p>If you are in large-scale unit, then you are in your office in the middle of the department. Then you don't miss anything. In small-scale units, you really are not involved. And that takes some getting used to. They (<i>the care staff</i>) really have to make an effort to tell me something. (<i>Unit manager in individual interview</i>)</p>
	TREATMENT ISSUES	<p>Difficult to develop and implement a treatment plan</p> <p>Treatment plans have no effect/temporary effect</p>	<p>It's everything, the whole picture. It's not one thing and that's how you solve it. (<i>Certified primary nurse assistant in individual interview</i>)</p> <p>Well, we have done so much and tried so much and it has all either helped temporarily or not at all. (<i>Care staff member in focus group discussion</i>)</p>
		<p>The situation often needed to end as soon as possible</p>	<p>And then the medication is changed and then you hope that the behavior changes too... You have to give that another couple of weeks and then it still does not work adequately, leading to it being changed again. It then often takes another few weeks to give the medication a chance... of course you just don't want that behavior, you want it gone as soon as possible. But by giving the medication a chance you have to, yes, that just takes a long time. (<i>Certified primary nurse assistant in individual interview</i>)</p>
		<p>Difficulties with prescribing medication</p>	<p>It was particularly intense at first when she (<i>the resident</i>) had just been admitted, when Ms ... (<i>name of the resident</i>) would walk around the unit, banging on the windows that she wanted to go home. That, before, you were just putting out fires and then we would intervene with medication to de-escalate... it was actually intervening immediately to get things under control. (<i>Elderly care physician in focus group discussion</i>)</p>

Supplementary material table 4. (continued).

(GROUPS OF) STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
			The PIT team (<i>advisory team</i>) came up with the advice: yes, cut down that medication, because it doesn't do anything. So we cut it down and everything was derailed. (<i>Elderly care physician in individual interview</i>)
			I would personally feel very bad, that the man (<i>the resident</i>) is sitting in the chair completely dazed, that it doesn't do his wife any good. That it doesn't do him any good. And that should not be at the expense of all of us. So, that should actually balance out a little bit. But, well, there isn't a balance, really. (<i>Care staff member in focus group discussion</i>)
	SKILLS ISSUES		
		Having insufficient knowledge and experience	Lack of experience with extreme behavior. This also makes it difficult for me to treat... I don't have the knowledge and experience to deal with it (<i>the behavior</i>). (<i>Psychologist in individual interview</i>)
		Making treatment plans which are outdated/impractical/unachievable/not feasible	<i>Name of behavioral expert</i> is a behavioral expert, who has identified a lot of good things and made very nice diagrams of what you can do and what you cannot do and how should you do it. But well, that, you know in advance that it doesn't help. (<i>Certified primary nurse assistant in individual interview</i>)
		Unable to detect the needs of the care staff, meet their expectations or support them properly	I think we needed a little more guidance, in terms of the care staff. From her (<i>the psychologist</i>) there could have been a little more support, more meetings with us. (<i>Certified primary nurse assistant in individual interview</i>)

Supplementary material table 4. (continued).

GROUPS OF STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
		Involving external expertise too late	Well, some actions could have been faster, I can tell you that. Yes, that intervention team could have been involved a little sooner. That may have been delayed for too long, even by myself. And the Centre for Consultation and Expertise (CCE) could have been involved more quickly, too. Also the psychiatrist in consultation. It could all have been a bit faster. <i>(Psychologist in individual interview)</i>
ATTITUDE ISSUES		Being indecisive/taking little responsibility	She <i>(the psychologist)</i> didn't feel it was her responsibility to do anything about it. Yes, it was within her capabilities, but that was insufficient in this situation, there was just more to be done and that, she didn't feel that was her responsibility. <i>(Unit manager in individual interview)</i>
		Undertaking too few actions	If you look at it in terms of actual actions, very little has happened. <i>(Unit manager about elderly care physician in individual interview)</i>
		Not informing themselves properly about the (severity of) the behavior	Being a little more on top of things, that they <i>(the treatment staff)</i> come round more often... <i>(Care staff member in focus group discussion)</i>
		Unaware of the expertise of care staff	That I sometimes notice, that's not to be mean, but they <i>(the treatment staff)</i> then come to us to start such a plan, but then it actually has to come from us <i>(the care staff)</i> , sure we are the experiential experts. <i>(Certified primary nurse assistant in individual interview)</i>

Supplementary material table 4. (continued).

(GROUPS OF) STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
	INTERACTION ISSUES WITHIN STAKEHOLDER GROUP		
	WITHIN TREATMENT STAFF	Different perceptions as to everyone's responsibilities pertaining to the situation	They (<i>about the elderly care physicians in general</i>) say, yes, well, this is a solution and you are in charge of the organisation, so go and arrange it... I think that's a bit too easy... and maybe I'll favour it too, but then there has been a doctors meeting and then everything is discussed and then you get an email. <i>Unit manager's name</i> , do you want to take care of camera surveillance, do you want to take care of this... Sometimes they say: just arrange some staff for it. Well, and then it is put on my plate, like, well, you sort it out. Please, and then I think, yeah, right, how nice. (<i>Unit manager in individual interview</i>)
NURSING HOME STAFF	INTERACTION ISSUES WITHIN STAKEHOLDER GROUP	Not enough formal and informal exchange of information between the psychologist and elderly care physician	She (<i>unit manager</i>) works a lot with the elderly care physician, so with that transfer they (<i>elderly care physician and unit manager</i>) have pretty much ignored me for example, so to speak. (<i>Psychologist in individual interview</i>)
	QUALITY OF INTERDISCIPLINARY COMMUNICATION	Limited exchange of information due to few meetings	And perhaps you should also sit down together as a team sooner, as a kind of multidisciplinary team meeting, and ask, how do we deal with this. (<i>Care staff member in focus group discussion</i>)

Supplementary material table 4. (continued).

GROUPS OF STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
		No room for reflection	I do think that we need to have a little more consultation with each other, like when do you get stuck and how do we get stuck? What are your issues, I don't think we have always expressed that properly to each other. <i>(Elderly care physician in focus group discussion)</i>
		No room for giving each other feedback	Giving feedback or anything together, that's difficult anyway, let alone to someone who... is in another discipline who is a little better educated. <i>(Care staff member in focus group discussion)</i>
		No room for an extensive analysis of the behavior	Then, I think, you do have to look at everything much more broadly, much earlier... I think that not everyone was aware of the resident's history, his life and pathology, what this entails and what kind of behavior comes along with it. <i>(Certified primary nurse assistant in individual interview)</i>
		Care staff members not communicating their needs, wishes and actions taken with the treatment staff	They <i>(about the care staff)</i> are really good at a lot of things, but even then saying, like, we are working on that, is a problem, though. <i>(Unit manager in focus group discussion)</i>
		Care staff members share incomplete and unclear information	Interviewer: "Are you saying that the care team did not clearly present the problem to the elderly care physician? Or that the elderly care physician didn't see the seriousness of the situation. Why is that, do you think?" For a small part, that has to do with the clarity of communication of the team. <i>(Unit manager in individual interview)</i>
		Treatment staff members insufficiently involving care staff in their plans	Maybe we should have coordinated a little more with, with the care team. <i>(Psychologist in focus group discussion)</i>

Supplementary material table 4. (continued).

GROUPS OF STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
		Care and treatment staff not taking each other seriously or not listening to each other's ideas/rationalizations for approaching the problem	Then I noticed that there were annoyances there and the care staff said, we don't feel heard, while <i>(elderly care physician's name)</i> said, you don't agree with my decision and that's what makes you react like that. So that was the end of the moral deliberation, especially that they would listen to each other more and why do you do it this way with Ms <i>(resident's name)</i> and what is the underlying thought, there was no listening to that at all by the team. <i>(Unit manager in individual interview)</i>
INEFFICIENT WORK PROCESSES		Indirect communication between care and treatment staff	If you have an issue now and you run into something, say... a notebook, and I respond to it and I look at it and I turn the notebook back in and done. I think you need to start making much more use of each other's disciplines. Like, what is your disciplinary input and what exactly do you run into? It's not a matter of questions and answers and done. That is not how it works. <i>(Elderly care physician in focus group discussion)</i>
		Inefficient communication due to a missing working agreement	They <i>(about care team on night shifts)</i> are also part of another team so they have their work meetings there, that goes via other routes... that soon makes the consultation indirect. That goes, for example, for <i>the unit manager's name</i> , it goes for a number of people, but also for some of her colleagues, so it's often indirect. <i>(Elderly care physician in individual interview)</i> Then, for example, I have to visit a resident where I discuss the misunderstood behavior with a care staff member and right after my visit there's an appointment with the psychologist where that same misunderstood behavior is discussed and I think that twice over is a bit much. <i>(Elderly care physician in individual interview)</i>

Supplementary material table 4. (continued).

GROUPS OF STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
			<p>We actually have very little contact, especially as care staff members, we have very little contact with the psychologist. That all actually runs via the certified primary nurse assistant ... so that you are hardly in the know as a team. (<i>Care staff member in focus group discussion</i>)</p>
			<p>But what happens <i>name of care staff member</i> can stand this behavior well, <i>name of another care staff member</i> cannot stand this behavior, but when <i>name of care staff member</i> has a visit of the elderly care physician, then according to <i>name of another care staff member</i> the behavior comes across differently. (<i>Unit manager in individual interview</i>)</p>
			<p>And then if something is needed to be discussed, the psychologist would discuss it with the intern. Well, I think that is wrong and then I confront them about it. I am the care provider, at that time I am ultimately responsible for the care of my residents and that you don't consult with an intern. (<i>Care staff member in individual interview</i>)</p>
ORGANIZATION	CHARACTERISTICS	Short staffing and staff-turnover	<p>Very soon after I started in February, March, I very quickly got the question why do we have so few staff, we really have a shortage of staff, we have a resident in our group who demands a lot of attention and as a result we can no longer provide the other residents with quality care. (<i>Unit manager in individual interview</i>)</p>
	STAFFING ISSUES	Excessive workload	<p>There are some staff changes. Of course, it's a unit with a great number of staff anyway ... so he (<i>the resident</i>) does see a lot of different people. (<i>Unit manager in individual interview</i>)</p> <p>Yes, then you have to run sometimes, because you have seven people in the group. You actually have to divide five</p>

Supplementary material table 4. (continued).

(GROUPS OF) STAKEHOLDERS	GENERAL AND MAIN FACTORS	SUB-FACTORS	QUOTE
UNIT	Size of the unit	hours and 45 minutes among seven people. But when I think about that, I think, my goodness, I spent two and a half hours on her. (<i>Care staff member in individual interview</i>)	The environment doesn't work in my favour, because it continues to be busy in the unit, I can't make it quieter there. There are really far too many people living here in too small an area. (<i>Unit manager in individual interview</i>)
ORGANIZATIONAL NORMS	Acceptance of the behavior by considering it as part of the dementia or the resident's personality	If you yourself don't think the behavior is actually normal, you don't dare say it. Another says you work with this target group for a reason, that (<i>behavior</i>) is normal, and I then say that is not normal... I think it is the culture... the culture in the team makes it so that no-one dares to be so open, like, where is my limit? (<i>Unit manager in individual interview</i>)	What I have missed in the whole story is that <i>the name of the institution</i> would put some money into Ms's (<i>the resident's name</i>)... room. Other curtains to add depth, stick a front door on her door, an alarm with snooze, a little more... Yes, just name everything you can think of and I miss it. (<i>Certified primary nurse assistant in individual interview</i>)
ROLE OF MANAGEMENT	Management staff insufficiently investing in solutions to improve the situation for the resident	Management staff making decisions interfering with the clinical situation	It has also saddened me as a person and especially because the management team interfered with the content... I really did have very unpleasant weekends because of that... what they do closes the door to my relationship with the relatives. (<i>Unit manager in individual interview</i>)

“Het zoeken naar de echte weg de juiste weg, die staat er niet altijd bij natuurlijk. Hoe ver kan je nou gaan om een man met zo’n opvallend heftig gedrag te behandelen? Dat is ook ingewikkeld of je dat nog behandelen mag noemen. Je bent in een soort strijd met iemand die oorlog voert tegen zichzelf en tegen de wereld en dat vond ik lastig.”

Specialist ouderengeneeskunde in individueel interview



5

Continuous palliative sedation in nursing home residents with dementia and refractory neuropsychiatric symptoms

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Annelies E. Veldwijk-Rouwenhorst

Martin Smalbrugge

Sytse U. Zuidema

Suzan A.J. Hanssen

Raymond T.C.M. Koopmans

Debby L. Gerritsen

Abstract

Objectives: Extreme neuropsychiatric symptoms can be a heavy burden for nursing home (NH) residents, relatives, and caregivers. Sometimes, when extreme neuropsychiatric symptoms are considered refractory, continuous palliative sedation is administered. The aim of this study was to explore the trajectory leading to continuous palliative sedation and its administration in NH residents with dementia and refractory neuropsychiatric symptoms.

Design: A qualitative interview and explorative study was performed.

Setting and Participants: Relatives, elderly care physicians, and other staff members involved with 3 NH residents with dementia and extreme refractory neuropsychiatric symptoms who received continuous palliative sedation were interviewed. These NH residents lived on dementia special care units of 3 NHs in the Netherlands.

Methods: Consecutive sampling was used to select participants. Medical files were studied. Semi-structured interviews were conducted. Transcriptions were analyzed with thematic analysis, including directed content analysis.

Results: Nine in-depth interviews with 13 participants were held. Analysis resulted in 6 main themes, with several subthemes reflecting phases of the continuous palliative sedation trajectory: (1) run-up, describing an unbearable struggle of the resident; (2) turning point, at which hope was lost; (3) considering continuous palliative sedation and administration of intermittent sedation; (4) decision to start continuous palliative sedation based on 1 decisive trigger; (5) administration of continuous palliative sedation with stakeholders experiencing relief; and (6) evaluation.

Conclusions and Implications: The trajectory leading up to continuous palliative sedation in NH residents with dementia and extreme refractory neuropsychiatric symptoms was complex and burdensome, but the initiation led to relief and contentment for all those involved. This study highlights that continuous palliative sedation can be a valuable treatment option among these residents. A recommendation is to include external

consultation in the decision process and to administer intermittent sedation as a preceding step when continuous palliative sedation is considered.

Key Words: Continuous palliative sedation, neuropsychiatric symptoms, dementia, nursing home

Introduction

Palliative sedation is a way to reduce unbearable suffering in patients with dementia. According to the Dutch practice guideline, palliative sedation is defined as “the deliberate lowering of a person’s level of consciousness in the last stages of life”.¹ Palliative sedation encompasses 2 distinct types of interventions: brief or intermittent sedation and continuous palliative sedation. The Dutch guideline states that continuous palliative sedation can only be administered if the patient’s life expectancy is less than 2 weeks and if 1 or more refractory symptoms cause unbearable suffering.¹ A symptom is refractory if “none of the conventional treatments are effective or fast-acting enough and/or if these treatments are accompanied by unacceptable side-effects”.¹⁻³ In the Netherlands, 21% of nursing home (NH) residents with dementia received continuous palliative sedation on their day of dying. The most common reasons for starting continuous palliative sedation were physical symptoms, that is, pain, exhaustion, or dyspnea.⁴

Neuropsychiatric symptoms, such as anxiety, aggression, or agitation, occur in 82% of NH residents with dementia.⁵ At times, these symptoms become extreme and even refractory. Guidelines on palliative sedation do not specify neuropsychiatric symptoms as potential refractory symptoms.^{1,6,7} However, from clinical practice we know that in exceptional cases, continuous palliative sedation is sometimes administered in NH residents with dementia and refractory neuropsychiatric symptoms,⁸ but exact numbers are missing. Little is known about this exceptional practice; more specifically, there is a lack of clarity surrounding the process of decision making that leads to continuous palliative sedation. Therefore, the aim of this study was to explore this process of decision making, the trajectory of continuous palliative sedation, and the experiences of those involved.

Methods

Study aim, design, setting and participants

This qualitative explorative study is part of the WAALBED (WAAL-Behavior-in-Dementia)-III study that focuses on NH residents with dementia and extreme neuropsychiatric symptoms.⁹ The aim of the current qualitative study was to explore the process of decision

making, the trajectory of continuous palliative sedation, and the experiences of those involved. We conducted and reported this study according to the Consolidated criteria for Reporting Qualitative studies (COREQ) checklist (see Supplementary material table 1).¹⁰

For this explorative study, we intended to include 3 cases of deceased NH residents with dementia and extreme refractory neuropsychiatric symptoms in whom continuous palliative sedation had been administered. Our sample size was determined using the model of information power of Malterud et al.¹¹ Following this model, (1) a narrow study aim and a specific combination of participants was applied; (2) a longitudinal in-depth exploration of narratives was performed; and (3) the interviewer had relevant background knowledge because she was an elderly care physician in training.¹¹

To recruit cases, we used consecutive sampling (see Supplementary material table 1), where the participants were selected in order of sign-up according to their appropriateness for inclusion.¹² Cases were assessed by AV and RK based on whether (a) they occurred recently, preferably less than 3 months ago; (b) continuous palliative sedation was administered because of extreme neuropsychiatric symptoms; (c) the NH resident had no acute life-threatening disease; and (d) they had been staying in the NH for at least 4 weeks.

Three interviews per case were performed to explore the perspective of different stakeholders: 1 with the involved elderly care physician, 1 with an involved staff member, and 1 with a relative. Participants were not involved in the setting up of the study. The study was assessed by the local Medical Ethics Review Committee (CMO Regio Arnhem-Nijmegen [number 2015-1723]), which stated that the study did not require medical ethical approval under the legislation in medical trials. In accordance with the Declaration of Helsinki and the applicable Dutch legislation,¹³ all participants provided written informed consent for participation and audio recording of the interviews. Before starting the interview, participants were assured that the transcripts would be anonymized and that only the researchers would have access to the original interviews.

Data collection

Resident's characteristics, reason for admission, medical history, drug prescriptions, and course of neuropsychiatric symptoms were extracted from their medical files. A topic list for the interviews was prepared by AV and discussed with the coauthors (see Supplementary material table 2). A separate topic list was developed for the interviews with the relatives (see Supplementary material table 3). Topics were as follows: course of and interventions for reducing the neuropsychiatric symptoms, process of decision making leading to continuous palliative sedation and its administration, and the impact on those involved. Face-to-face, semi-structured, in-depth interviews were conducted and audio-taped. During the analysis process, an additional telephone interview was held with each elderly care physician to obtain more information.

Data analysis

All interviews were transcribed verbatim, eliminating any private information. Thematic analysis was used including directed content analysis.¹⁴⁻¹⁶ This concerned an iterative process involving several steps. Based on the aims of our study and topic list, deductive coding was used, with the identification of potential categories and sub-categories as codes (SH, AV, DG).¹⁴ Inductive coding (deriving codes from the data, modifying them throughout the coding process, and moving to an explanation of the data) was also applied.¹⁴ New codes were grouped into categories and combined with existing codes and categories into a coding tree (SH). In weekly consensus meetings (SH, DG, AV), codes, categories, and the coding tree were discussed. All authors performed individual critical appraisals of the coding tree and of 1 or more coded interviews, which were discussed as a group. Relevant elements of the additional telephone interviews were highlighted in the transcripts of these interviews and added to the results of the other analyses. Categories were refined into definitive themes and subthemes during consensus meetings (SH, DG, AV).

For within-case analysis, mind maps were made per case, which are "visual, non-linear representations of themes and sub-themes and their relationships".^{17,18} These 3 mind maps covered the range of themes, subthemes, and their connections. Group discussions about the mind maps were held with all authors. The mind maps were combined into 1 mind map for a cross-case analysis (SH). After having analyzed the interview fragments that pertained

to the codes that were included in the mind map and having had several group discussions, a final graphic representation of the themes, subthemes, and connections was made.

Results

Three cases from dementia special care units of 3 NHs in the Netherlands were included. We conducted 9 interviews with a total of 13 participants. Participants were 3 elderly care physicians (1 per case), an elderly care physician in training (case 1), 2 nurses (case 1 and 2), a vocational nurse specifically assigned to the resident (case 3), 1 psychologist (case 3), and 5 relatives (two each in case 1 and 2, and one in case 3, respectively). Four of the interviews had 2 interviewees.

The background information of each case is described in Table 1. The neuropsychiatric symptoms were unpredictable and extreme in all 3 cases. Also, 2 residents had a history of psychiatric disorders. Furthermore, several interventions had been applied since the beginning of the neuropsychiatric symptoms, such as psychosocial interventions (e.g. playing music and guidance from the psychologist on how to cope with the behaviors), prescription of several psychotropic drugs, and an external consultation by a (geriatric) psychiatrist (see Table 1). All of these interventions failed in reducing the neuropsychiatric symptoms.

Analysis of the interview data resulted in the identification of 6 main themes. Retrospectively, these can be described according to phases (see Figure 1). To improve readability, the results are mainly formulated from the perspective of the elderly care physician, as they lead the process of decision making and the administration of continuous palliative sedation. The themes are summarized below, illustrated by a selection of quotes that were translated into English. We display additional quotes for all described themes in Supplementary material table 4.

Phase 1: Run-up

In the run-up to continuous palliative sedation, relatives and members of staff mentioned that the neuropsychiatric symptoms were detrimental to the quality of life of the NH

resident. They described it as an unbearable suffering and dubbed the experience of the NH resident as an inner struggle.

"Hanging in the chair like a battered human, yes that was just horrible. And to that effect, it was clear enough to me: this is unbearable suffering." (Elderly care physician, case 1)

Elderly care physicians termed suffering of the NH resident as unbearable based on (non) verbal expressions (having a disconcerted appearance and body posture or constant screamed wishes to sleep and to have rest). However, they stated that they found this very difficult to determine, because of the subjective character of this judgment. Furthermore, hope played an important role for all participants. This included hope in reducing the neuropsychiatric symptoms and the unbearable suffering of the NH resident, as well as for creating a manageable situation for all of those involved, particularly the nursing staff.

"Still you hope that you will find something which turns it (the suffering) around and that someone feels better... every change of medication, every new approach you keep hoping that you invented Columbus' egg." (Nurse, case 2)

Phase 2: Turning Point

At a certain moment, the elderly care physicians and other staff members lost hope and became convinced that they had tried all possible treatment options. They were convinced that no further improvement of the neuropsychiatric symptoms could be expected and that these were considered refractory.

"In my view we had tried everything, we had a lot of patience and we used several interventions, which just didn't help... Crudely stated, this (continuous palliative sedation) was the last intervention which we could apply." (Nurse, case 1)

Elderly care physicians and the other staff experienced feelings of powerlessness and failure, especially as they could not relieve the suffering of the NH resident.

"Drugs which you could try, had all failed and that makes it powerless again. We became more powerless by the look of that man. And by the intense grief of the wife and especially the kids." (Elderly care physician, case 1)

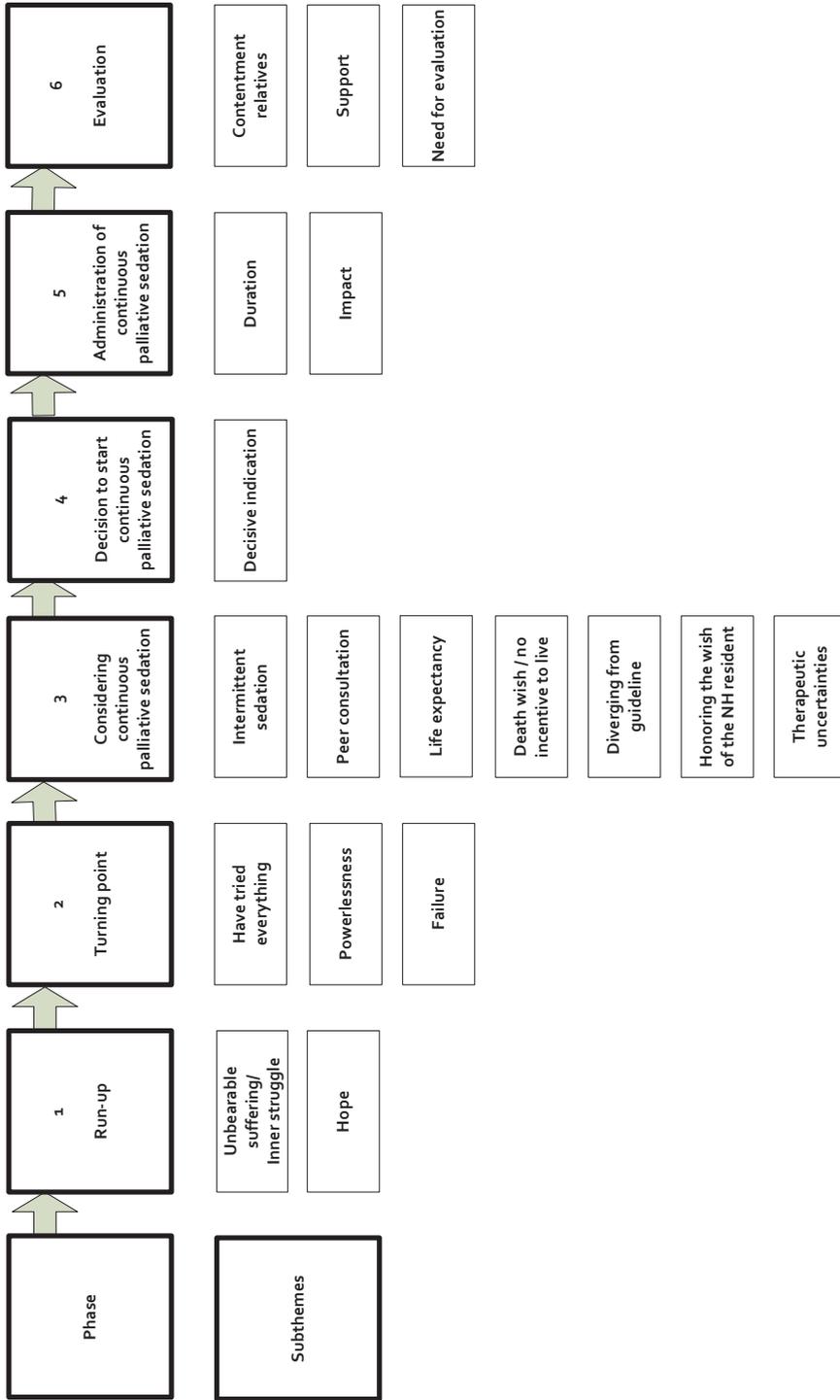
Table 1. Background information of each case.

	Case 1	Case 2	Case 3
Gender, age	Man, 82 years old	Woman, 80 years old	Woman, 78 years old
Duration of institutionalization	4 months	30 months	18 months
Department	Psychogeriatric unit	Psychogeriatric unit	Psychogeriatric unit, specialized in neuropsychiatric symptoms
Medical problems	Alzheimer's disease Hypertension Cataract Osteoarthritis hip	Dementia Bipolar disorder Depressive disorder Hereditary spastic paraparesis	Alzheimer's disease Alcohol abuse, Osteoarthritis knee Suspicion of borderline personality disorder
Interventions	Visits from family with dog Behavior management Advice to cope with behavior (psychologist) External consultation psychiatrist	Family conversations Playing music Looking at photo albums Advice to cope with behavior (psychologist) Crisis intervention plan (psychologist) External consultation geriatric psychiatrist, psychiatric nurse	Dimming the lights Warm and indulging care Advice to cope with behavior (psychologist) External consultation psychiatrist
Medication applied (less than 3 months before continuous palliative sedation)	Haloperidol, midazolam, temazepam, quetiapine, oxazepam, clozapine, lorazepam, valproic acid	Analgesics, oxazepam, lithium, nortriptyline, cypramil, haloperidol, lorazepam, clozapine, midazolam, levopromazine	Trazodone, haloperidol, zuclopenthixol, midazolam, valproic acid, quetiapine, lorazepam

	Case 1	Case 2	Case 3
Medications applied during continuous palliative sedation	Midazolam (60 mg/day, sc) Morphine (60 mg/day, sc)	Midazolam (240 mg/day, sc) Levopromazine (150 mg/day, sc) Fentanyl (600 mcg/day, transdermal)	Midazolam (up to 165 mg/day, infusion pump) Midazolam (30 mg before care) Midazolam (prn, max 180mg/day, sc) Morphine (up to 60mg/day, infusion pump) Morphine (15 mg before care) Morphine (prn, max 60mg/day, sc) Haloperidol (up to 2.5mg/day, infusion pump) Levopromazine (up to 25 mg/day, infusion pump) Levopromazine (prn, max 100 mg/day, sc)

Notes: prn: pro re nata; sc: subcutaneously.

Figure 1. Phases in the trajectory continuous palliative sedation with corresponding subthemes



Notes: NH: nursing home.

Phase 3: Considering Continuous Palliative Sedation

Several considerations played a role in phase 3. During this phase, elderly care physicians involved relatives and staff intensively. First, all 3 elderly care physicians applied intermittent sedation to relieve symptoms such as sleeping problems, agitation, and anxiety. Thereby, they hoped to achieve comfort for the resident and to create a period of ease. To receive additional support, 2 elderly care physicians employed peer consultation (a colleague in case 3, and a geriatric psychiatrist and psychiatric nurse in case 2). Because intermittent sedation had only a temporary and limited effect, and because the unbearable suffering of the NH resident persisted, the option of continuous palliative sedation was considered. Several factors influenced this consideration. A first influencing factor was life expectancy. All elderly care physicians estimated the life expectancy of the NH residents as less than 2 weeks, but estimating the life expectancy was difficult for them. For example, the elderly care physician of case 3 questioned whether the criterion of a life expectancy of less than 2 weeks is appropriate in an NH resident with extreme neuropsychiatric symptoms.

"Well, in my opinion those 2 weeks are not a real critical boundary; it can be something more and something less, but it's the idea of the approaching death anyway, so that plays a role."
(Elderly care physician, case 3)

A second influencing factor was whether there had been a death wish of the NH resident. In all cases, relatives mentioned that the NH resident had expressed a wish to die before admission and/or during the stay in the NH. Before admission to the NH, the NH resident case 1 had asked his relatives for a rope to commit suicide, and during his stay in the NH he expressed several times that he did not want to live anymore. The NH resident case 2 repeatedly asked people to kill her during her stay in the NH, saying that this was no life for her. The NH resident case 3 had repeatedly expressed a wish to die in the last 15 years, including during the stay in the NH. The elderly care physicians of cases 2 and 3 included these expressions in their considerations for continuous palliative sedation but did not regard this as a main issue. In case 1, the elderly care physicians did not include the resident's expressed wish to die in his consideration for continuous palliative sedation, as he had never heard this wish from the NH resident himself. A third influencing factor in the consideration for continuous palliative sedation were thoughts about diverging from the

Dutch practice guideline regarding palliative sedation.¹ Although they could rationalize their actions, elderly care physicians regarded administering continuous palliative sedation to NH residents with dementia and extreme neuropsychiatric symptoms as “acting on the edge.” Relatives understood the struggle of the elderly care physicians and wished that the criteria for administering continuous palliative sedation could be more flexible for exceptional cases.

“It’s good that there are laws and rules but sometimes it (continuous palliative sedation) is good for the exceptional cases. And then it is always the question when is it an exception and when may you ease that rule, true or not? That’s difficult and I think this remains a very difficult thing.” (Relative, case 1)

A fourth influencing factor concerned honoring the wish of the NH resident. For example, the relative of case 1 wondered how long the suffering of the NH resident should continue, because being in the current situation would have been unacceptable for the NH resident himself. Furthermore, the decision for continuous palliative sedation was experienced as a great responsibility for the elderly care physician. The final influencing factor in considering continuous palliative sedation were therapeutic uncertainties. Namely, elderly care physicians mentioned that it was difficult to determine the moment at which they could decide to start continuous palliative sedation. Moreover, they wondered if they had followed “the right way” in managing the neuropsychiatric symptoms.

Phase 4: Decision to Start Continuous Palliative Sedation

The initiation of continuous palliative sedation was regarded as a medical decision by the elderly care physicians. All relatives consented with the decision. Influencing factors for this decision were the accumulation of refractory neuropsychiatric symptoms, a short estimated life expectancy, and unbearable suffering. However, in each case, 1 specific aspect was considered as being the decisive trigger for the ultimate decision to initiate continuous palliative sedation. These were a complete loss of dignity (case 1), severe anxiety (case 2), and severe agitation in combination with a repeatedly expressed wish to die that already existed before the onset of dementia (case 3).

"The huge anxiety, I think that prevailed ... and that hallucinations, all those bad events, I think that prevailed together with the fact that she just had a death wish. So, fears, that was really the reason why we actually just wanted her to sleep continuously." (Elderly care physician in training, case 2)

Phase 5: Administration of Continuous Palliative Sedation

Finally, continuous palliative sedation was administered with the administered drugs displayed in Table 1. As a result of continuous palliative sedation, in all cases the NH resident became more relaxed and comfortable and his or her consciousness was lowered until death. The duration of continuous palliative sedation was 77 hours in case 1, 7 hours in case 2, and 92 hours in case 3. Staff and relatives previously had expected that this trajectory would take longer. Feelings of relief, gratefulness, relaxation, and contentment after the start of continuous palliative sedation were expressed by all those involved.

"Especially rest and gratefulness that the fighting was finally over, because he was fighting and the others were victim, but actually he of course was the biggest victim." (Elderly care physician, case 1)

Phase 6: Evaluation

After the residents died, relatives were content and felt to have been properly involved in the decision trajectory leading to continuous palliative sedation and its administration.

"I was really okay with it, I had a lot of good conversations in advance. Everything was explained very clearly to me, what, and how it could go.. No, I really liked it, before and during the sedation. Questions, treatment staff who were very thoughtful, came to me and asked if I would like to know something or were also caring to my mother No, I don't know if I wished it had happened differently." (Relative, case 1)

Different opinions were expressed among the participants about the support received. Relatives had experienced enough support from the elderly care physician and their own social network. However, the elderly care physician of case 3 said that she had not received enough emotional support from colleagues, partly because she had not expressed her

needs clearly. In case 2, the elderly care physician considered the assistance and support of the consulted mental health care organizations as unsatisfactory.

"I feel myself standing lonely at the top sometimes.. That you support the care staff very much as a doctor and always answer the questions, but you wouldn't be so quick to say like well, this is how it affects me, that's difficult to me." (Elderly care physician, case 3)

Two elderly care physicians (case 2 and 3) indicated having a need for evaluation after the resident's death, both regarding the process and the impact of continuous palliative sedation on all those involved. The elderly care physician in training of case 2 suggested learning by reflecting on personal experiences with colleagues as a point for improvement.

Discussion

As far as we know, this is a first exploration of administering continuous palliative sedation to NH residents with extreme refractory neuropsychiatric symptoms. In all 3 cases, the neuropsychiatric symptoms were described as unpredictable and difficult to manage. Analysis showed that the unbearable suffering of the NH resident and the hope for improvement were important key points in the run-up to continuous palliative sedation. Participants were convinced they had tried everything and experienced feelings of powerlessness and failure. Several considerations played a role before continuous palliative sedation was initiated (which was based on 1 decisive indicator). In retrospect, relatives were content and felt to have been properly involved.

These important insights in the process and evaluation of continuous palliative sedation in NH residents with dementia and neuropsychiatric symptoms give rise to several reflections. To begin with, this study shows that the behavior of the NH resident and the trajectory up to and the initiation of continuous palliative sedation had a great impact on care and treatment staff. These findings are in line with a Dutch study by Zwijsen et al, which demonstrates that the presence of neuropsychiatric symptoms is a strong predictor of distress of care staff.¹⁹ The study emphasizes the importance of supporting care staff in coping with neuropsychiatric symptoms in NH residents with dementia.¹⁹ Therefore, we

think it might be helpful if elderly care physicians and psychologists take the time to share emotions and experiences with care staff and other stakeholders and evaluate the steps taken in the decision-making process and the trajectory of continuous palliative sedation in NH residents with dementia and refractory neuropsychiatric symptoms. Future research should investigate how this can be provided optimally.

A second reflection concerns estimating the life expectancy of the NH resident. According to the Dutch guideline, continuous palliative sedation can only be administered if the patient's life expectancy is less than 2 weeks.¹ Although the elderly care physicians in this study estimated the life expectancy of the 3 NH residents as less than 2 weeks, they found determining life expectancy difficult in these residents, which is supported by previous research in terminally ill patients with and without dementia.²⁰⁻²² Estimating imminent death or the terminal status is more difficult in these residents, and the terminal status may last longer than exactly 2 weeks, raising doubts about the applicability of the 2-week life expectancy criterion for use of continuous palliative sedation. It may be conceivable to apply the criterion of a life expectancy of less than 2 weeks less strict in NH residents with dementia and extreme refractory neuropsychiatric symptoms.

Unbearable suffering is a third point to discuss. All participants in our study mentioned that the NH residents were suffering unbearably. They based their judgment on (non)verbal expressions and aggravation of the neuropsychiatric symptoms. Especially in NH residents with dementia, it is difficult to judge and assess the degree and bearableness of suffering. These residents are not able to describe and reflect on their own situation, thus requiring the judgment of an elderly care physician in agreement with a relative. The Dutch guideline for palliative sedation states that "in practice, it is frequently a nonlinear combination of diverse dimensions of one or more symptoms that leads to a situation that constitutes unbearable suffering for the patient."^{1,3} In line with our study, Dees et al²³ state that medical and social elements may cause suffering, but that especially when accompanied by psychoemotional and existential problems suffering will become unbearable. Because it is not yet known how to determine and how to diagnose unbearable suffering in NH residents with extreme refractory neuropsychiatric symptoms and a terminal status, this should be a subject for further investigation, for example, with a Delphi study among clinical experts. The possibility of mandatory external consultation (e.g. by a geriatric psychiatrist) to

overcome the subjectivity of determining unbearable suffering of the NH resident could also be examined in further studies.

Fourth, the refractoriness of the neuropsychiatric symptoms gives reason for discussion. Although in our study refractoriness of neuropsychiatric symptoms were the most important reason for starting continuous palliative sedation, guidelines on palliative sedation do not include these symptoms as potentially refractory.^{4,6,7} Nevertheless, a previous study among patients who had recently received continuous palliative sedation (including NH residents) showed that administering this sedation tends to follow from a situation in which not only physical, but also psychological, symptoms together produce a “refractory state.”³ Not being able to relieve the state of the patient establishes the need for continuous palliative sedation.³ In our opinion, refractoriness of neuropsychiatric symptoms should be taken into account when guidelines on palliative sedation are revised or developed.

A final reflection includes the recurrent death wish of the NH resident with dementia and refractory neuropsychiatric symptoms before and during admission. In our study, this death wish was considered relevant by the involved elderly care physicians in the decision-making process. However, it is difficult to determine if these uttered wishes are manifestations of an underlying depressive disorder or of the unbearable suffering as a result of the refractory neuropsychiatric symptoms. An accurate diagnostic process with analysis of depression could be of added value in these cases.

The results of this study were incorporated into a recently published Dutch practice guideline from the occupational group of elderly care physicians (Verenso) about palliative sedation among people with dementia and refractory neuropsychiatric symptoms.²⁴ It provides elderly care physicians with tools in the administration of intermittent sedation and continuous palliative sedation for refractory neuropsychiatric symptoms in NH residents with dementia. The guideline describes that continuous palliative sedation can be a final treatment option in NH residents with dementia and refractory neuropsychiatric symptoms when intermittent palliative sedation has not resulted in an acceptable situation. It states that thorough multidisciplinary analysis, decision-making process, and

treatment must have taken place beforehand as well as external consultation by, for example, a geriatric psychiatrist.

Strengths and limitations

The qualitative design of our study allowed for an in-depth description of this niche area enabling participants to express in their own words how they experienced the process of decision-making leading to continuous palliative sedation and its trajectory. Moreover, with the inclusion of several participants, additional telephone interviews (data source triangulation), and the combination of analytical techniques (analysis triangulation), we increased the internal validity of our study. Furthermore, by involving multiple researchers (investigator triangulation), we enhanced the reliability.²⁵

However, this study also has some possible limitations. To start with, 4 interview sessions concerned interviews with 2 participants. Participants may have influenced each other, leading to different answers than in individual interviews. Furthermore, our results reflect the Dutch cultural, societal, and health care context, which might hamper the generalizability of the findings to other countries. Namely, the Dutch national legislation has a law on euthanasia, and in the Netherlands, a national Guideline for Palliative Sedation exists.¹ Furthermore, Dutch geriatric care has a long history of conducting advance care planning conversations with residents in which the quality of life of a resident is taken into account and elderly care physicians have experience with administering continuous palliative sedation. Administering continuous palliative sedation in NH residents with dementia is not uncommon for them and has become a part of practice. Moreover, the perception of suffering and the choice to administer continuous palliative sedation could be influenced by the Dutch culture, in which autonomy, including autonomy regarding the end of one's life, are held in high regard by many people. Finally, the study was not guided by the principle of saturation, which may imply that our understanding of continuous palliative sedation in the case of refractory neuropsychiatric symptoms is not yet exhaustive.

Conclusions and implications

This study offers important insights into the trajectory leading up to continuous palliative sedation, its administration, and evaluation of this trajectory in NH residents with dementia and extreme refractory neuropsychiatric symptoms. It highlights that continuous palliative sedation can be a valuable treatment option among these residents.

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Supplementary material table 1. Detailed applied methodology following the consolidated criteria for reporting qualitative studies (COREQ) 32-item checklist.

No. Item	Guide questions/description	In our research:
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which authors conducted the interview?	SH: ¹ She was instructed and coached by an experienced interviewer (AV). ¹
2. Credentials	What were the researcher's credentials?	SH: MD, AV: MD ¹
3. Occupation	What was their occupation at the time of the study?	SH ¹ : academic trainee and elderly care physician in training (in the last months of her education). ² AV ² : elderly care physician in training and PhD-student
4. Gender	Was the researcher male or female?	Female
5. Experience and training	What experience or training did the researcher have?	SH ¹ : medicine, AV ² : medicine, entry-level course in Atlas.ti, basic course qualitative health research Research team: Medical (SZ,MS,RK) ¹ and psychological (DG) ¹ and are all specialized in elderly care.
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	SH ¹ was not acquainted with study participants before the interview.
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	An information letter about the purpose of the study and practical information about the interview was sent to the participants of the eligible cases. This letter also mentioned that the interviewer was an elderly care physician in training (SH). ¹
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	The occupation of the interviewer was written in the information letter.
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic analysis was used (both inductive and deductive), including directed content analysis. ³⁻⁵

Supplementary material table 1. (continued).

No. Item	Guide questions/description	In our research:
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	We used consecutive sampling to select participants. Cases were assessed for inclusion by AV ¹ and RK ¹ based on whether a) these occurred recently, preferably less than 3 months ago; b) continuous palliative sedation was administered because of extreme neuropsychiatric symptoms; c) the NH-resident had no acute life-threatening disease; and d) had been staying in the NH for at least 4 weeks. We explored the perspectives of different stakeholders. To recruit cases, an advertisement was placed (January 2017) in the online newsletters of the Dutch association of elderly care physicians (Verenso), ⁶ the university network of elderly care Nijmegen (UKON) ⁷ and the Centre for Consultation and Expertise (CCE). ⁸
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	AV ¹ telephoned the notifying party and the relatives of the NH-resident within a week and sent them an information letter by post or by email. They were contacted again by AV within two weeks by telephone or email to ask for consent. After agreement with participation in the study, appointments were scheduled for the interviews.
12. Sample size	How many participants were in the study?	13 Of the 6 applied cases, 3 were assessed as eligible according to the inclusion criteria. The other 3 cases were excluded, because a) the resident had died more than 3 months ago; b) intermittent sedation but not continuous palliative sedation was applied; c) continuous palliative sedation was considered but not applied yet.
13. Non-participation	How many people refused to participate or dropped out? Reasons?	None of the approached people refused to participate.
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	The interviews with professionals were held in March 2017 in the NH of the NH-resident, those with relatives at their own home (N=1), the NH (N=1) or in a quiet public place (preference of the participant, N=1)

Supplementary material table 1. (continued).

No. Item	Guide questions/description	In our research:
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Interviewees had the opportunity to be interviewed together with a second representative of the same perspective. No non-participants were present during the interviews.
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	See Table 1
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	For each group of stakeholders, SH ¹ used a semi-structured interview guide, in which the main questions and sub-questions were displayed. This interview guide was also used as an extra check to make sure all topics were discussed. The interview guide was not pilot tested. Planned, informal and floating prompts were used during the interviews.
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	All interviews were audio-taped and transcribed ad verbatim by two medical students (KE and LB), ¹ eliminating any names or privacy-related information. The transcripts were read closely and cross-checked against the tapes for accuracy by SH. ¹
20. Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were made by SH ¹ during and after each interview.
21. Duration	What was the duration of the interviews?	The interviews lasted between 60 and 90 minutes.
22. Data saturation	Was data saturation discussed?	All authors discussed the findings and data saturation. We did not include more cases in order to obtain saturation, to keep the analyses manageable. However, during the analysis process, an additional telephone interview was held by SH ¹ with each elderly care physician to obtain more detailed information and to answer remaining questions.

Supplementary material table 1. (continued).

No. Item	Guide questions/description	In our research:
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	A summary of each transcription was made (SH) ¹ and returned to the participants as a membercheck. After a few adjustments in some cases, all participants agreed with the summaries.
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	2, SH ¹ and AV ¹
25. Description of the coding tree	Did authors provide a description of the coding tree?	No, available from the authors on request .
26. Derivation of themes	Were themes identified in advance or derived from the data?	Six themes were derived from the data.
27. Software	What software, if applicable, was used to manage the data?	Analysis with Atlas.ti version 7.1.4. was conducted during data collection (SH) (Atlas.ti Scientific Software Development, Berlin, Germany).
28. Participant checking	Did participants provide feedback on the findings?	Two participants provided feedback on the summaries of their interview. After a few adjustments they agreed with the summaries.
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes, see results section of the manuscript and Appendix 4. Quotes were translated into English by AV ¹ and crosschecked by, MG ¹ a teacher of English.
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes, see results section of the manuscript and Appendix 4.
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

Notes:

¹SH: Suzan Hanssen; AV: Annelies Veldwijk; SZ: Sytse Zuidema; MS: Martin Smalbrugge; RK: Raymond Koopmans; DG: Debby Gerritsen; NH: nursing home; KE: Kyra Ekker; LB: Leonie Buijsse; MG, Martijn de Groot.

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Supplementary material table 2. Topic list for semi-structured in-depth interview with participants.

Topic	Interview questions	Additional sub-questions
Course of neuropsychiatric symptoms	What does the extreme neuropsychiatric symptoms of the resident consist of?	Can you give examples of that? What was the expression of the extreme neuropsychiatric symptoms during the past three months? Which factors influenced the extreme neuropsychiatric symptoms the past three months?
Applied interventions	Which interventions were applied for the extreme neuropsychiatric symptoms during the past three months?	
Process of continuous palliative sedation	How did the process of continuous palliative sedation take place?	Were you present when the continuous palliative sedation started and how did it go? Did you have to increase the dosage in between? (asked to elderly care physicians (in training)) Would you describe the suffering of this resident as unbearable? If yes, why? How long did it last from the start of the continuous palliative sedation until death? What kind of difficulties did you all experience during this process? Do you experience that starting continuous palliative sedation for extreme neuropsychiatric symptoms as an indicator is different from starting continuous palliative sedation for a physical indicator? If yes, could you explain that?

Supplementary material table 2. (continued).

Topic	Interview questions	Additional sub-questions
Impact of continuous palliative sedation	What was the impact of starting continuous palliative sedation on those involved?	<p>Which role did other disciplines play in this process? (like social worker, spiritual carer, previous general practitioner)</p> <p>Is there any routine or standing appointment in your nursing home about continuous palliative sedation in neuropsychiatric symptoms?</p> <p>What was your opinion about starting continuous palliative sedation in this resident?</p> <p>What feelings arose with this?</p> <p>To what extent did you discuss this case with your colleagues?</p> <p>Did you feel supported enough by your colleagues?</p> <p>How did the relatives feel about this process?</p> <p>(asked to elderly care physicians (in training), other staff members)</p> <p>How did the communication with the relatives take place?</p> <p>(asked to elderly care physicians (in training), other staff members)</p> <p>What did you notice in the others involved?</p> <p>Is this process evaluated afterwards and by whom?</p>

Supplementary material table 3. Topic list for semi-structured in-depth interview with relatives.

Topic	Interview questions	Additional sub-questions
Course of neuropsychiatric symptoms	What does the extreme neuropsychiatric symptoms of the resident consist of?	<p>Can you give examples of that?</p> <p>What was the expression of the extreme neuropsychiatric symptoms during the past three months?</p> <p>Which factors influenced the extreme neuropsychiatric symptoms the past three months?</p>
Decision to start with continuous palliative sedation	Finally it was decided to start with palliative sedation, can you tell me how this went?	<p>How did you experience this?</p> <p>To what extent did you play a role in this decision?</p> <p>Did you experience this decision as difficult? If yes, why?</p> <p>Who was involved in the decision-making and how?</p> <p>How did the communication with the elderly care physician and the vocational nurse specifically assigned to the resident take place?</p> <p>How did the communication with the nursing staff take place?</p> <p>How did the communication with others involved take place?</p> <p>In what way was the decision for continuous palliative sedation discussed with the relatives?</p>
Impact of continuous palliative sedation	What was the impact of the neuropsychiatric symptoms and the process of palliative sedation on the resident and his/her environment?	<p>What impact has this situation and process had on you so far?</p> <p>Which feelings did you experience with starting palliative sedation?</p> <p>Did you feel supported?</p> <p>If yes, by whom?</p> <p>If no, from whom did you miss support?</p> <p>What were the consequences of this process for the residents him/herself?</p> <p>What were the results of starting palliative sedation for the residents and his/her environment?</p> <p>If you look back on this process, are there things which could have been done differently? If yes, which things?</p>

Supplementary material table 4. Additional citations for all described themes with subthemes.

Theme	Additional quote
Phase 1: Run-up	
Unbearable suffering/ inner struggle	"The sight of that man who, did his absolute best to fight against this current reality, which he did from admittance, but the real fighting started a month later and became worse, by way of physical aggression, in the price he paid, crashing down, hanging knocked out on the ropes like a damaged boxer, sometimes with wounds of falling or he was stubbed and he only kept on going until he couldn't anymore, that was such a sad image to see that man getting lost in such a way." (<i>Elderly care physician, case 1</i>)
Hope	"Well yes, indeed you hope that maybe someone still has the miracle drug." (<i>Elderly care physician in training, case 2</i>)
Phase 2: Turning point	
Have tried everything	"And totally no other way left. I mean no way to change the behavior, but in fact we had just tried everything. Everything was applied and we didn't have the feeling that we could influence her more in some way that she, how should I say this, would be living in a pleasant way." (<i>Psychologist, case 2</i>)
Powerlessness	"In my opinion, unbearable is when just not a single moment is left when you think that you could get someone out or when you think you could still mean something for someone, you can make the suffering more soft, or something like that. There was just nothing left actually which we could do....the last week also the meeting was about the powerlessness everyone felt, like how far should we go with this and to what extent? what do you do to her and what do you do to everyone, to the environment? and is this not possible in a different way? so to speak." (<i>Psychologist, case 2</i>)
Failure	"Well I think that every physician sort of feels that at that time, if you don't succeed in something, that you think that you failed. And it was just very miserable that you could not help her." (<i>Elderly care physician in training, case 2</i>)
Phase 3: Considering continuous palliative sedation	
Peer consultation	"I think it is decent to just let someone else take a look at her [NH-resident] as well, that we will not all enter some tunnel vision while there may be other options left and while it is maybe actually ethically not as pure as you think yourself... So that is actually the reason to ask her [a colleague]." (<i>Elderly care physician, case 3</i>)
Life expectancy	"She just did not eat or drink and that was already less for weeks... that few sugar cubes she had, and that, and the renal function which was not very well and which was deteriorating already...then she would not have made it for two weeks that way, I think." (<i>Elderly care physician in training, case 2</i>)
Wish to die	"I think that she gave up all courage in the last phase and also really had something like, I am done, I don't want to live anymore like this...she also mentioned it very often, this is an inhumane existence, she also said that very often, she could describe that very well and I think for her this was..." (<i>Nurse, case 2</i>)

Supplementary material table 4. (continued).

Theme	Additional quote
Diverging from guideline	<p>"It was definitely cycling on a line but it was truly right." (<i>Nurse, case 1</i>)</p> <p>"What do you mean with cycling on a line?" (<i>Interviewer</i>)</p> <p>"It [continuous palliative sedation] isn't something you just apply, there were really a lot of meetings about this and people discussed a lot about this, like is this the best solution." (<i>Nurse, case 1</i>)</p>
Honoring the wish of the NH resident	"Because how long do you need to let someone suffer while you know he doesn't want to?" (<i>Relative, case 1</i>)
Therapeutic uncertainties	"Searching for the real way, that's not always there of course, how far can you just go to treat a man with such a remarkable and extreme behavior... I was waiting for it like when can I do more and when that point is reached?" (<i>Elderly care physician, case 1</i>)
Phase 4: Decision to start continuous palliative sedation	
Decisive indication	"The most dominant thing was that she was totally done with it and that you had the feeling that there was a high distress in which on the one hand she indeed constantly really wanted to sleep but on the other hand her legs and her arms and the agitation then again gave a lot of restlessness." (<i>Elderly care physician, case 3</i>)
Phase 5: Administration of continuous palliative sedation	
Duration	"We expected that it would take much longer. So that went also pretty fast and with her it was just that her candle shed a light and maybe she did hear us and thought like, fine, now they are gone and now I can sneak out nice and quiet." (<i>Relative, case 2</i>)
Impact	"As it started to help for him, that he really received that rest, then I thought like yes it's a relief anyway, not only for us and the other residents, but really especially for him." (<i>Nurse, case 1</i>)
Phase 5: Evaluation Contentment relatives	
	"And if you look back to the trajectory of the sedation, could things be done differently?" (<i>Interviewer</i>)
	"No nothing." (<i>Relative, case 3</i>)
	"That was" (<i>Interviewer</i>)
	"Perfectly, really." (<i>Relative, case 3</i>)
Support	"My trainer also said to me [name nurse case 1] if you want to talk or something like that, it's an intense situation, it has an impact on you, my door is always open, so just come around and you can just talk about it with me, she also asked what you asked me, if I receive support at home." (<i>Nurse, case 1</i>)
Need for evaluation	"You can never turn back time, of course you can learn something about it if something went wrong, but yes that's in principle not the aim. I think is just also a bit to vent and look, for other people maybe like, what's the plan? As a learning experience." (<i>Elderly care physician in training, case 2</i>)

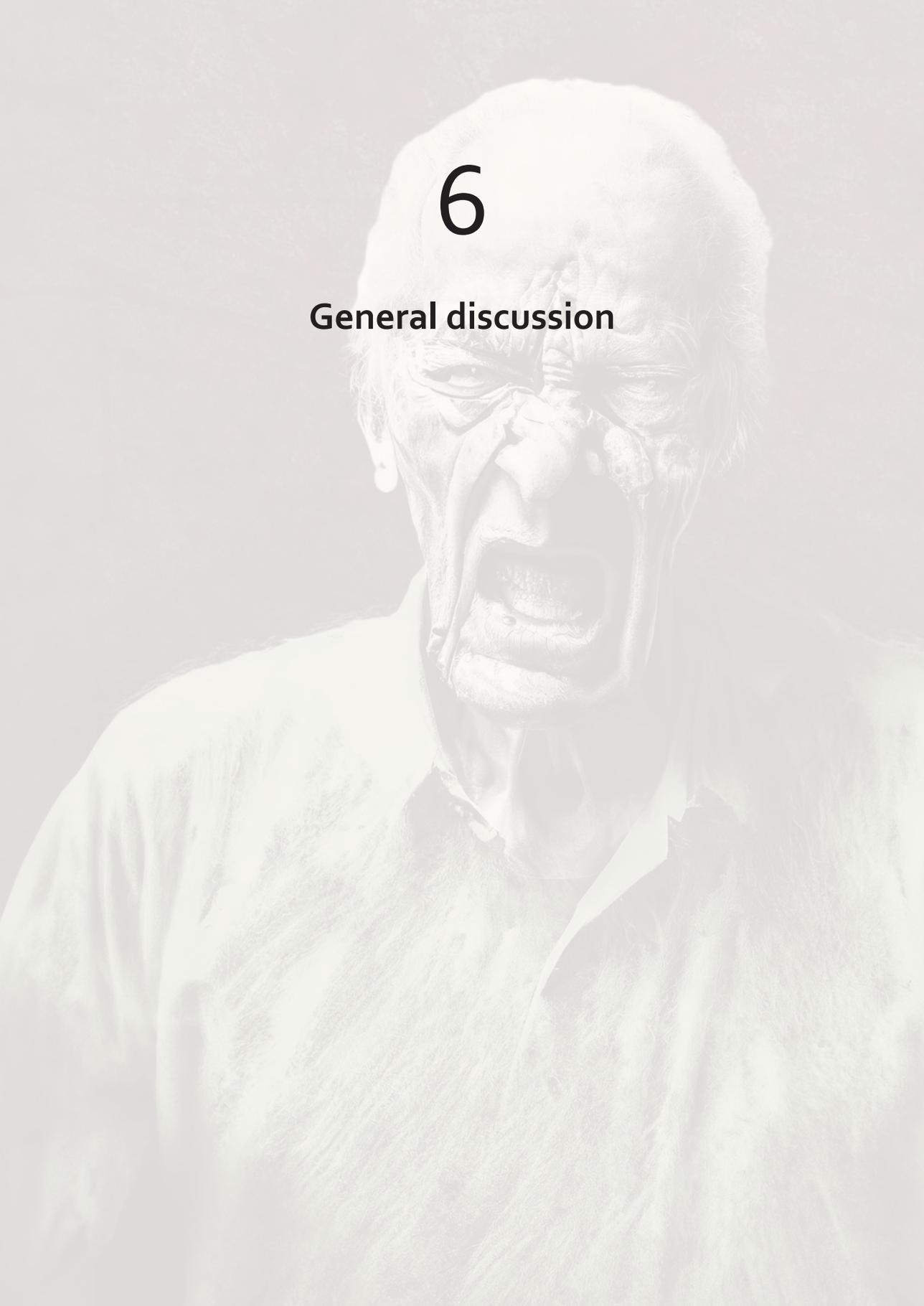
Notes: NH: nursing home.

“Als je komt, dan praat je met de ene uit de zorg en de volgende keer praat je weer met iemand anders uit de zorg en die heeft net weer een iets andere mening of een andere beleving of een ander gevoel... want je gaat er dan vanuit dat zo'n zorgteam met één stem spreekt, dat is best lastig.”

Specialist ouderengeneeskunde in focusgroep interview

6

General discussion



This thesis focuses on nursing home (NH) residents with dementia and very severe or extreme challenging behavior. The overarching goal was to gain further knowledge of and insight into this group of NH residents. The first part of this thesis described the investigation into the characteristics of NH residents with dementia and very severe or extreme challenging behavior, including associative factors for the behavior (**Chapter 2 and 3**). In the second part, experiences of NH staff with situations of very severe or extreme challenging behavior in residents with dementia were studied, including identification of the contributing factors in experiencing these situations as an impasse (**Chapter 4**). The third part explored the decision-making process and the trajectory of continuous palliative sedation (CPS) in NH residents with dementia and refractory challenging behavior (**Chapter 5**).

This chapter provides an overview of the main findings and compares the findings with existing literature. Furthermore, methodological considerations are outlined, followed by implications and recommendations for practice, health care policy, education and future research.

Main findings in the light of existing literature

NH residents with dementia and very frequent challenging behavior: a particular group

In the cross-sectional sub-study, results on the prevalence of NH residents with dementia and very frequent challenging behavior were presented, as well as associative factors for this behavior. Two-week prevalence rates of 7.4% for very frequent agitation, 2.2% for very frequent physical aggression and 11.5% for very frequent vocalizations were found (**Chapters 2 and 3**).^{1,2} Similar prevalences are described in the existing literature,³⁻⁵ with one study reporting a higher prevalence rate for vocalizations.⁶

Overlapping associative factors that were found for very frequent agitation and vocalizations in the cross-sectional sub-study were age, dementia severity and euphoria.^{1,2} These findings are comparable with other international studies into less severe forms of these behaviors.^{3,7-9} The association of delusions and anxiety for very frequent agitation is

also evidenced in other studies on severe and less severe behaviors.^{3, 10-13} However, other associations are mentioned in the literature which were not identified in the cross-sectional sub-study, such as older age, being male and dementia severity for physical aggression;⁴ depression, anxiety and irritability for vocalizations¹⁴⁻¹⁹ and apathy, night-time behaviors, being male and motor disturbances for very frequent agitation.³

A possible explanation for the disparity in findings is the difference in the applied definitions for the behaviors and the use of various measurements in these studies.²⁰ A new finding of the cross-sectional sub-study concerned the association of antipsychotic and antiepileptic drug use for very frequent vocalizations. Unfortunately, this association is less relevant in the identification of NH residents with very severe or extreme challenging behavior, as it is most likely that these drugs are prescribed because of the vocalizations, rather than causing vocalizations themselves.

A wide variety of factors contributing to the experience of an impasse

Chapter 4 takes the resident's context into account and describes a variety of factors that contribute to experiencing a situation of extreme challenging behavior as an impasse.²¹ Three main factors could be identified: the characteristics and attitudes of stakeholders involved (NH resident, relatives, care staff, treatment staff, NH staff, and the NH organization), issues within a stakeholder group and interaction issues among (groups of) stakeholders.²¹ The greatest difficulties experienced were the resident's characteristics, together with suboptimal mono- and interdisciplinary communication and collaboration. For example, interviewees mentioned that the resident was unlike the other residents and considered the resident's behavior as highly complex and challenging because of its unpredictability. In addition, interviewees said that care staff members found it difficult to ask for help, rarely reflected on their own actions and feelings and that treatment staff members did not adequately support care staff members.

The findings of this qualitative multiple case study are partly in line with other studies. Previous work has also described difficulties with: the characteristics of the NH resident and the resident's behavior; with developing a clear treatment plan and prescribing medication; with organizing enough time for multidisciplinary meetings; the need for

more knowledge and the disparity in views and attitudes of NH staff about the resident's behavior.²²⁻²⁷

New findings are specifically related to the context and concern the difficulties regarding interactions (e.g. NH resident with other residents and NH staff; NH staff with relatives), NH staff's and relatives' characteristics and the NH organization. Moreover, a new and remarkable finding concerned the suboptimal interdisciplinary collaboration and communication among NH staff, which is supported by another recent Dutch qualitative study about collaboration among elderly care physicians (ECPs) and care staff regarding challenging behavior in general.²⁷

CPS in refractory challenging behavior: a burdensome but rewarding trajectory

The trajectory leading to CPS and its administration in NH residents with dementia and refractory challenging behavior was explored in a qualitative explorative study (**Chapter 5**).²⁸ Six main themes with several subthemes were identified from the interview data, reflecting phases of the CPS trajectory. Although the trajectory was reported as complex and burdensome for those involved (relatives, ECPs, and other staff members), the administration of CPS itself led to relief and contentment.

It is very difficult to compare the findings of this study with other studies as it seems to be the first exploration of the trajectory of CPS in NH residents with dementia and refractory challenging behavior. There are only two published studies which mention the administration of intermittent or CPS for very severe or extreme challenging behavior in people with dementia as a treatment option,^{29,30} and there are a small number of studies about CPS that concern people with dementia in general.³⁰⁻³⁶ These studies highlight that challenging behavior is commonly present prior to the administration of CPS and that a quarter of international experts on palliative care believe that performing CPS is a good treatment option in these cases.³⁰⁻³⁶ However, the studies do not describe whether the challenging behavior and/or its refractoriness are the reasons for starting with CPS.

Methodological considerations

Design of the study

One of the strengths of the WAALBED-III study concerns its design. The applied mixed methods approach, in which an extensive set of quantitative and qualitative data was collected, resulted in an in-depth understanding of very severe or refractory challenging behavior in NH residents with dementia in its context. The combination of data from four existing studies in the cross-sectional sub-study (**Chapter 4**) resulted in a large dataset with sufficient statistical power to investigate the characteristics of NH residents with dementia and very severe or extreme challenging behavior and the associative factors for this behavior. Despite the valuable information acquired, it should be noted that no statements could be made about possible causal relationships.

Nosologic uncertainties

Internationally, NH residents with very severe or extreme challenging behavior do not yet comprise a well-defined group and a generally accepted definition of this group of NH residents is still missing. With the WAALBED-III study, a first attempt has been made to operationally define very frequent agitation, vocalizations and physical aggression. A previous German study operationally defined severe agitation in a similar manner.³ However, these definitions are not yet comprehensive. The operational definitions in the cross-sectional sub-study were solely based on the behavior's frequency, and not on its severity. In addition, these definitions were based on epidemiological data and not on clinical data. Elements such as burden, contextual factors and an inability for NH staff to act were not incorporated in these definitions. Developing a definition for very severe or extreme challenging behavior appears difficult due to differing views about what this behavior comprises and issues with determining to what extent this definition has to be about the behavioral characteristics of the NH residents, their personal characteristics, and/or their context.²⁰

Generalizability and trustworthiness

First, given the extensive dataset in which a large number of NHs from across the Netherlands were included, it can be assumed that the results of the cross-sectional sub-study (**Chapters 2 and 3**) are representative of the total Dutch population of NH

residents with dementia and very frequent challenging behavior. Moreover, the results of the qualitative sub-studies (**Chapters 4 and 5**) are assumed to be representative, as a very heterogeneous group of interview participants was included.

Second, the trustworthiness of the results of the qualitative sub-studies is high due to the application of data and analysis triangulation. For data collection, a combination of methods was applied including individual interviews and focus group discussions, with several relevant stakeholders being interviewed by ECPs in training that are familiar with the NH setting. The interviewers did not have a professional relationship with the interviewees and therefore can be seen as fully independent. Furthermore, multiple researchers were involved in the data analysis, whereby several techniques were combined with fine-tuning during the analytical process, including letting the interviewees check an extensive summary of their interview (member check). This enhanced the credibility of the results.³⁷⁻³⁹

Third, the transferability, dependability and confirmability of the results of the qualitative sub-studies are sufficient, as a detailed description of the setting, sample, inclusion and exclusion criteria, interview procedure and topics was provided and the analyses were described in a transparent way.³⁷ The trustworthiness of the qualitative results can be affected by the limited geographical distribution of the participating NHs (participating NHs were located in four (**Chapter 3**) and two (**Chapter 4**) of the twelve provinces in the Netherlands) and the inclusion of small study populations in the qualitative sub-study on CPS (**Chapter 4**). However, data saturation was reached and the analyses revealed no findings that appeared to be specific to the location of the NHs.

Measurements

All four datasets included in the cross-sectional sub-study contained the Dutch versions of the CMAI and the NPI-NH, which are both validated assessment instruments frequently used for measuring behavior in NH residents with dementia.^{40,41} Despite this, some remarks can be made about their use.

First, the CMAI score is only based on the frequency of behavior and not on its intensity or severity. This restricted the operational definition of very severe or extreme agitation, vocalizations and physical aggression.

Second, both measurement instruments were completed by one of the care staff members involved with the NH resident. As it is known that the experience and education of care staff members influences their resilience and capacity, it is possible that they also influence how measurement instruments are completed.⁴² For example, when a care staff member experiences a lot of distress in relation to a NH resident's behavior, he/she may report a higher severity score. Therefore, the scores have a certain subjective character, which could have influenced the results of the cross-sectional sub-study.

Third, by assessing challenging behavior with the NPI-NH, challenging behavior was operationalized as symptoms, which may lead to interpreting behavior as a direct consequence of brain damage, without having meaning in itself.^{20,43,44} Yet, the challenging behavior of a person with dementia is often a response to internal or external stimuli and provides information about their needs. Viewing challenging behavior as a signal and interpreting that it has a function might therefore be more beneficial.²⁰ Finally, as the measurement instruments in the four datasets were limited, inclusion of other potentially interesting variables in the analyses, such as pain, was not possible.

Implications and recommendations for practice

Dutch long-term care is constantly being subjected to improvement. A publication from the Dutch Health and Youth Care Inspectorate in 2020 demonstrated three themes for improvement regarding very severe challenging behavior: 1) a better implementation of the Dutch guideline titled "Challenging behavior in people with dementia" from the occupational groups of ECPs and geropsychologists (Verenso/NIP),⁴⁵ 2) professional development and the involvement of other experts and 3) strengthening of regional collaboration and organizations for mental health. It also mentions the importance of knowing the signs of and adequately reporting the resident's behavior, having knowledge about dementia, being capable of responding to challenging behavior in an adequate way,

and performing a multidisciplinary functional analysis.⁴⁶ Unfortunately, the WAALBED-III study showed that these elements have not yet been met for NH residents with dementia and very severe or extreme challenging behavior. In the following paragraphs, the implications of the study for practice are described.

Description of and views on behavior

In order to know and analyze the resident's behavior and its signs and causes, a systematic description and assessment of the behavior is necessary. First, it would be desirable that all NH organizations apply the same definition for very severe or extreme challenging behavior to demarcate this group of NH residents and develop or tailor interventions for this group of NH residents specifically. However, formulating a comprehensive definition is a major challenge and perhaps even unfeasible²⁰ as very severe or extreme challenging behavior can have different causes. It may be the direct result of internal causes, such as brain damage, but may also result from contextual, external factors. Therefore, in describing very severe or extreme challenging behavior, approaching it as a unidimensional concept is too simplistic.^{43,44} Thus, focusing on both internal and external causes in this description is recommended.⁴⁷ Recently, a Dutch mixed-methods study tried to include several elements (e.g. the nature, characteristics and consequences of behavior) into a definition for severe challenging behavior,⁴⁸ and brings us another step forward in the identification of a clearly defined study population. This definition can be used as a starting point to facilitate interdisciplinary communication.

Second, to be able to describe the nature of the behavior and monitor its course over time, the use of assessment instruments and thorough observations by care staff members can be beneficial. In addition, repeated observations by a psychologist are important. By observing the situation with a certain distance, a psychologist can study the interactions between a NH resident, care staff and other residents and possibly identify certain warning signs before the behavior occurs as a way to ascertain if the resident's behavior is truly unexplainable and/or unpredictable.

Third, in order to describe the behavior properly, it is important to report it objectively. One of the qualitative sub-studies in this thesis (**Chapter 4**) showed that care staff members often did not report challenging behavior or that reports were of an insufficient quality.

The reasons for this were time issues, a difficulty in expressing the severity of the behavior in words and not wanting to upset the relatives as they had access to the resident's reports. Having enough time to consistently report challenging behavior and to describe its severity in a detailed, structured and objective way is important to obtain a reliable picture of the situation.

In addition to a detailed description of the behavior, it is important to explore the views and attitudes of involved stakeholders as they may influence the NH resident's behavior and provide starting points for dealing with the situation. It should be noted that identifying these views and attitudes is often complex as they might be influenced by a variety of factors, such as the characteristics of NH staff members, their medical knowledge and previous experience with challenging behavior, their coping abilities and emotions and their relationship with the resident. For example, having NH staff with fewer years of formal education is related to more severe challenging behavior in residents.²⁶ So, in conclusion, to follow the Dutch guideline "challenging behavior in people with dementia" properly and increase the quality of reporting, the abovementioned views and attitudes of stakeholders need to be addressed.

Identification of causes and consequences

Next to the description of and views on the behavior, it is important to develop an understanding of the function or meaning behind the residents' behavior. In doing this properly, the Dutch guideline "Challenging behavior in people with dementia" recommends performing a functional analysis.^{45,49} With this analysis, challenging behavior is specified, possible causes (physical/psychopathological/contextual) and preceding/maintaining factors are identified and consequences are described.⁴⁹

As one of the qualitative sub-studies (**Chapter 5**) showed the existence of a death wish in NH residents with very severe or extreme behavior, it may be useful to find out whether the NH resident has an actual death wish and if there are treatable underlying causes. An accurate diagnostic process with analysis of possible depression is thus important.

Furthermore, in these cases it may be valuable if the functional analysis specifically focuses on the role of environmental stimuli and sensory integration.⁵⁰ Next to having impairments

in perception, interpretation and response control,⁴⁷ NH residents with very severe or extreme challenging behavior are very sensitive to environmental stimuli due to neurological deficits.⁴⁸

Finally, although performing a solid functional analysis is recommended in NH residents with very severe or extreme challenging behavior, the process may be difficult. It can be a great challenge to perform additional diagnostics or a physical examination in NH residents with very severe or extreme challenging behavior because they often refuse to cooperate, leading to a high risk of injury for the ECP or care staff member. For example, it is difficult to determine if a death wish in a NH resident with very severe challenging behavior is a manifestation of an underlying depressive disorder or of the unbearable suffering as a result of the refractory neuropsychiatric symptoms. In these cases, an ECP can be necessarily forced to diverge from the guideline and therefore possibly miss physical causes for the behavior.

Interventions

From the WAALBED-III study, it seems that NH residents with dementia and very severe or extreme challenging behavior need a specific care approach and tailor-made interventions based on their individual needs. Clinical practice shows that in these residents, a single intervention is often not sufficient and a combination of interventions is needed. Therefore, it would be beneficial that NH staff members involved with these residents are inventive and able to think “outside the box”.

External consultation by, for example a (geriatric) psychiatrist, an ECP with special expertise on psychogeriatrics or by the Center for Consultation and Expertise (CCE), at an early stage may also help in applying specific intervention(s) and may also prevent feelings of powerlessness and failure for the professionals involved.

In developing interventions, it is advisable to determine in a multidisciplinary meeting with a functional analysis to what extent the search for interventions for the extreme behavior should be continued and to what extent the behavior has to be accepted.⁴⁹ This is to prevent expectations regarding interventions diverging among the people involved.

When the NH resident's challenging behavior seems to be unresolvable or as a result of severe depression, the application of electroconvulsive therapy (ECT) may be considered,⁵¹⁻⁵⁴ which is currently hardly applied in the Netherlands. An earlier study showed promising results of ECT in decreasing severe agitation in patients with dementia⁵¹ and another Dutch study (not published yet) also reported a reasonably good response to ECT for patients with dementia and (severe) challenging behavior.⁵² Further, the administration of intermittent sedation or CPS can be a valuable final treatment option in the case of refractory challenging behavior. After completing the WAALBED-III study, Verenso developed a practice guideline about this subject in which the findings were incorporated.⁵⁵ This guideline provides the ECP with tools regarding the administration of intermittent sedation and continuous palliative sedation for refractory neuropsychiatric symptoms in NH residents with dementia.

Interdisciplinary communication and collaboration

Although the Dutch guidelines by Verenso/NIP and van Voorden et al. state that working in a structured, methodical and multidisciplinary manner is necessary regarding challenging behavior⁴⁵ and an essential element in the successful treatment of severe challenging behavior,⁵⁶ one of the qualitative sub-studies (**Chapter 4**) showed that in situations of very severe or extreme challenging behavior, this is not actually realized.²¹ In these complex cases with significant impact on those involved, it seems to be especially important to prevent working out of sync, to keep each other informed on a frequent basis and to evaluate interventions on a regular basis in order to monitor the whole decision-making process.

Existing studies highlight several important conditions for optimal interdisciplinary communication and collaboration.^{27,57} First, care staff and treatment staff benefit from fully informing each other and having trust in and respect for each other. Second, it is recommended that treatment staff involve care staff in the decision-making process, support them sufficiently and value their knowledge and expertise. In addition, treatment staff should be in contact with and visible to care staff members. This may be facilitated if a treatment staff member is part of the NH organization, rather than outsourced from another organization, as the latter can increase the distance and hinder insight to the situation even further. Third, an important condition for interdisciplinary communication

and collaboration is having consideration for each other's feelings, emotions, views and ideas regarding the situation, reflecting about someone's own influence when interacting with the resident, and supporting each other in bearing the responsibility and burden of the complex situation. This creates more awareness and is helpful in coping with the situation and in experiencing it less as an impasse. In particular, care staff members can experience a heavy burden, because they are in the closest and most frequent contact with the resident and therefore have to deal with the behavior most often. As such, it may be helpful if treatment staff pay attention to the well-being of care staff by acknowledging their feelings and emotions and taking time to discuss these. In order to meet the abovementioned conditions, it is necessary to schedule extra time for multidisciplinary meetings in which sufficient time is reserved to reflect, share views, and give each other feedback in a safe atmosphere. In those meetings, attendance of the CCE can be of added value in helping to improve communication and collaboration. Other types of meetings, such as intervision sessions and moral case deliberations, may also contribute to making an inventory of the ethical dilemma's encountered in these complex situations.^{58,59} Regarding communication, the use of structured ways of communication,⁶⁰ as well as direct communication between care and treatment staff without the involvement of intermediaries, is recommended. Finally, it is important that NH staff raise difficulties to NH management in a timely manner. In this way, dealing with very severe or extreme challenging behavior becomes a mission for the entire NH organisation. ^{see also 46}

A supportive environment

Chapter 4 showed that the majority of NH residents with very severe or extreme challenging behavior lived on small-scale units. Although the higher engagement on small-scale units is mentioned as having a positive effect on NH resident's behavior,⁶¹ it can be questioned whether these units provide the appropriate environment for NH residents with very severe to extreme challenging behavior. As on these units generally only one care staff member is present during each shift, it is likely that these residents do not receive the full attention they need because of the complexity and severity of their behavior. Moreover, care on small-scale units may complicate interdisciplinary communication and collaboration due to fewer mono-and interdisciplinary meetings on these units. However, regular large-scale units may also not be appropriate for NH residents with very severe or extreme behavior due to the variety of environmental stimuli on these units.

Therefore, specialized units with a supportive environment, equipped for the complexity and severity of the behavior are expected to be more appropriate for these residents. In the Netherlands, several long-term care organizations have already established such specialized units. Hopefully, these units can offer the most important care services identified in the WAALBED-III study, such as a higher care staff-resident ratio, care staff members with a higher level of knowledge and competencies regarding very severe or extreme challenging behavior and the expertise of professionals. Furthermore, a peaceful atmosphere, in which sufficient attention is paid to the amount of audio and visual stimuli is important. Namely, poor soundscapes have been associated with challenging behavior, a soundscape awareness intervention can help in reducing this behavior.^{62,63} Finally, to specify which residents benefit from such specialized units, a clear definition of very severe or extreme challenging behavior is necessary.

Implications and recommendations for health care policy

The severity of the behavior and, especially, its consequences for the residents and their social environment is reflected in that NH residents with dementia and very severe or extreme challenging behavior increasingly receive attention in the Netherlands. In 2021, they were designated by the Dutch Ministry of Health, Welfare and Sports as one of eight distinct patient groups in long-term care with low prevalence rates, but high complexity.⁶⁴ For these resident groups, so-called centers of expertise are in development. This is on both a national and regional scale with the aim to improve care, research, implementation and collaboration, while striving to share knowledge, competences and skills among professionals working with these residents.^{64,65} In line with this, a specialized care program was developed for people with dementia and very severe challenging behavior.⁶⁶

In order to further optimize care and treatment for this specific group of residents, the following recommendations can be made. A first step should be incorporation of the findings from the WAALBED-III study and the latest insights and knowledge obtained by the national and regional centers of expertise into this care program. Furthermore, it is important that NH organizations and organizations for mental health work together and use each other's expertise. Structural deployment of mental health care professionals,

such as a geriatric psychiatrist, as a member of the NH staff or as a fixed contact person can be of great added value. Moreover, as also stated by the Dutch Health and Youth Care Inspectorate of the Ministry of Health, Welfare and Sports, NH management should acknowledge the difficulties in dealing with very severe or extreme challenging behavior and invest in necessary interventions.⁴⁶ NH management and policy makers can do this by facilitating the provision of appropriate resources and tools to optimize the care for NH residents with very severe or extreme challenging behavior and the communication and teamwork among NH staff, for example by providing educational resources for all team members, which is further specified in the next section.

Implications and recommendations for education

NH staff members will be increasingly confronted with very severe or extreme behavior. To influence the behavior itself, and NH staffs' attitudes and experienced stress regarding the behavior, it is important to increase their knowledge, skills and competencies.

Having a skilled team is seen as one of the essential elements for the successful treatment of severe challenging behavior.⁵⁶ An inventory of knowledge questions among care staff members in Dutch NHs showed that challenging behavior was mentioned as the most important topic on which care staff members indicated a need for training.⁶⁷ This is understandable, because care staff members hardly come into contact with challenging behavior during their initial training and must increase their knowledge and skills through learning in the workplace. Therefore, educational programs on challenging behavior in general as well as on specific aspects, such as reporting behavior, sensory integration, resilience and effective communication may contribute to enhancing the NH staff's knowledge, competencies and skills.

In addition, an environment emphasizing learning and reflection in the NH may improve this further. For example, care staff members of a unit can exchange specific knowledge that is not necessarily known to their colleagues which may help in diminishing the NH resident's behavior. Also, embedding reflection as a fixed part of this learning environment can be rewarding. Furthermore, NH staff should consult the NH resident's relatives to

obtain more information about the resident's life and habits in order to understand their behavior.

In addition to an environment conducive to learning, interprofessional training and education is of added value, whereby professionals from different disciplines, such as ECPs, geriatric psychiatrists, psychologists and specialized nurses, can learn from each other.⁶⁸ This may also strengthen and ease the collaboration with other health care organizations. Moreover, sharing the knowledge and expertise from the CCE and the national and regional centers of expertise with NHs in the area may be beneficial. This means that when a NH asks for consultation, the NH resident can stay on the unit where he/she lives and is visited by a consultation team, which also provides coaching on-the-job. A transfer to another NH is therefore prevented. This is important as literature shows that relocation of a person with dementia can cause a decline in physical, mental, behavioral and functional well-being.⁶⁹

Implications and recommendations for future research

To improve the care, treatment and quality of life of NH residents with dementia and very severe or extreme challenging behavior, further research across several domains is necessary.

First, as the operational definitions in the cross-sectional sub-study were not comprehensive, it would be helpful if future studies focus on developing a comprehensive definition of very severe or extreme challenging behavior. Suggested elements of this definition based on the results of WAALBED-III are the severity of the behavior, the distress and unbearable suffering of the NH resident, distress of NH staff and other residents and the NH staff's experienced inability to act. In addition, as situations of extreme challenging behavior in NH residents with dementia were experienced as an impasse by NH staff and relatives, defining the concept 'impasse' and relating it to 'crisis'^{70,71} might help in preventing these situations. For both definitions, an international Delphi study among clinical experts can be an appropriate research design.

Second, it would be of added value if future research would investigate which assessment instruments are suitable for measuring very severe or extreme challenging behavior. As definitions in the cross-sectional sub-study were solely based on the behavior's frequency, and not on its severity, an assessment instrument containing multiple elements derived from a comprehensive definition of very severe to extreme challenging behavior is preferable.

Third, more insight into possible physical, psychopathological and contextual causes for very severe or extreme challenging behavior is necessary. Regarding physical and psychopathological causes, interesting factors to examine are an underlying death wish as found in this thesis, pain, depressive symptoms, delirium, the process of sensory integration and the role of underlying biological mechanisms. The latter seems to be understudied at this moment.⁴⁷ By studying which specific brain areas are damaged, the observed behavior itself, the associations and simultaneous occurrence of several kinds of behaviors and some of the associative factors found in the WAALBED-III study could possibly be explained. The executive functioning syndrome especially deserves attention in this, as it is known that damage in the three brain circuits involved can lead to the co-occurrence of apathy and aggression.^{72,73} Regarding contextual factors, it would be interesting to study NH residents with very severe or extreme challenging behavior living on specialized units and to explore the influence of such settings on the NH resident's behavior and quality of life. In the ongoing WAALBED-IV study, the characteristics and course of challenging behavior from residents on these units are being studied.⁵⁶ Furthermore, it can be useful to create a profile of these specialized units in terms of the presence/absence of stimuli and to compare this profile with general units. Collaboration in research with clinical experts, such as the CCE which also studies behavior in context, would support the relevance of this research.

Fourth, it would be interesting to explore the longitudinal effect of specific interventions which are sometimes applied in daily practice, such as ECT or a canopy-enclosed bed.⁷⁴ In addition, research should focus on the development of specific psychosocial interventions for very severe or extreme challenging behavior due to a lack of effect of existing psychosocial interventions in this particular group of NH residents. For example, as one of the qualitative studies in this thesis showed that paying attention to a NH resident with

very severe or extreme challenging behavior is difficult and positive moments are scarce. As such, interventions which invest in the quality of interaction with the NH resident could be the subject of further research. In experimenting with these specific interventions, it is important to take the NH resident's resilience into account and to connect this with daily practice.

Fifth, one of the qualitative sub-studies showed that unbearable suffering was an important subtheme in the trajectory of CPS. However, it is still unclear how to diagnose unbearable suffering and a terminal state in NH residents with dementia and refractory challenging behavior, and therefore more research is needed in this field. Namely, a clear understanding of unbearable suffering and a terminal state may facilitate the quality and content of care at the end of life for these residents. In this, the effect of and experiences with external consultation to reduce the subjectivity of determining what is classed as unbearable suffering should also be studied further, as one of the qualitative sub-studies showed that two elderly care physicians employed peer consultation in the trajectory of CPS.

Finally, in this thesis, not all data collected in the WAALBED-III study has been analyzed. An analysis of the collected resident's medical files would be of added value, as well as insight into the quality of life of these residents and the impact of the behavior on (in)formal caregivers.

Conclusion

The WAALBED-III study is probably the first study which explored NH residents with dementia and very severe or extreme challenging behavior from different perspectives. This thesis shows that NH residents with dementia and very severe or extreme challenging behavior form a particular group because of their own characteristics, specific associative factors for their behavior and various difficulties experienced by those involved. Alongside a supportive environment, these NH residents need a higher level of expertise, skills and competencies from NH staff than that offered on current regular dementia special care units. NH staff working with residents with very severe or extreme challenging behavior should acquire more specific knowledge about this behavior, communicate and collaborate

more intensively together, have frequent contact with relatives and cooperate extensively with experts from outside the NH organization. The findings of this thesis offer starting points for developing tools to manage (a situation of) very severe or extreme behavior in a NH resident with dementia and can enrich the existing specialized care program for these residents.⁶⁶ Moreover, this thesis provides starting points for further research into the care for these residents as well as the training and education of NH staff working with them. Hopefully, this will optimize their care, treatment, and quality of life.

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"Een poos geleden was er ook rondom de heer iets, ik had die dag dienst maar ik werd niet gevraagd om mee te denken. Dan gaan hier voor mijn gevoel dan de arts, de psycholoog, m'n leidinggevende en de kwaliteitsverpleegkundige zitten en dan wordt het voor ons beslist."

Verzorgende in individueel interview

7

Samenvatting (summary in Dutch)

Datamanagement

Dankwoord (acknowledgements in Dutch)

Curriculum Vitae (in Dutch)

**Publications, presentations,
training and teaching activities**

Samenvatting (summary in Dutch)

Inleiding

In **hoofdstuk 1** van dit proefschrift wordt de achtergrond van dit onderzoek beschreven. Meer dan 80% van de verpleeghuisbewoners met dementie vertoont op enig moment in het dementieproces probleemgedrag. Hieronder wordt al het gedrag verstaan dat door de bewoner zelf of de omgeving als moeilijk hanteerbaar wordt ervaren. Er bestaan verschillende soorten probleemgedrag waaronder agitatie, agressie en roepgedrag. Verpleeghuisbewoners met dementie kunnen één of meerdere soorten probleemgedrag vertonen. In de loop van de tijd kan het verschillen hoe vaak het gedrag voorkomt en hoe ernstig het is. Probleemgedrag vermindert de kwaliteit van leven van de bewoner en kan geestelijke achteruitgang bij de bewoner versnellen. Daarnaast heeft dit gedrag een negatieve invloed op medebewoners, zorgmedewerkers, behandelaren en naasten. Zo kan het ernstige probleemgedrag van een bewoner een verminderde kwaliteit van leven bij medebewoners veroorzaken en kunnen zorgmedewerkers, behandelaren en naasten het gevoel hebben dat ze te kort schieten in de zorg voor de bewoner. Anderzijds kunnen deze betrokkenen ook een negatieve invloed op het probleemgedrag van de bewoner hebben door het bijvoorbeeld in stand te houden of te versterken door hun eigen gedrag.

Bij een kleine groep verpleeghuisbewoners met dementie neemt het probleemgedrag zeer ernstige vormen aan, soms met lichamelijk letsel van de bewoner zelf of betrokkenen tot gevolg. Er is nog weinig bekend over de groep verpleeghuisbewoners met dementie en zeer ernstig probleemgedrag. Wel is vanuit de praktijk bekend dat deze bewoners vaak verschillende soorten medicijnen krijgen voor hun ernstige gedrag, zoals kalmeringsmiddelen en medicijnen tegen een depressie of psychotische symptomen (het anders beleven van de wereld of het horen, zien of denken van dingen die anderen niet horen zien of denken). Bij bewoners met zeer ernstig probleemgedrag hebben deze medicijnen nauwelijks effect. Ook andere oplossingen voor het gedrag ontbreken, waardoor betrokkenen een grote machteloosheid ervaren en niet weten wat ze moeten doen. In uitzonderlijke situaties is het probleemgedrag onbehandelbaar en is er zelfs geen andere oplossing mogelijk dan het toepassen van continue palliatieve sedatie. Hiervoor kan worden gekozen als de arts verwacht dat het overlijden van de bewoner binnen één tot twee weken zal plaatsvinden. Palliatieve sedatie is geen actieve beëindiging van het leven,

maar houdt in dat er een medicijn wordt toegediend waardoor de bewoner gaat slapen, geen last meer heeft van klachten en niet meer lijdt.

Om meer te weten te komen over verpleeghuisbewoners met dementie en zeer ernstig probleemgedrag, onderzocht de WAAL Behavior in Dementia (WAALBED)-III studie: 1) hoe vaak zeer ernstig probleemgedrag voorkomt bij bewoners met een dementie in de Nederlandse verpleeghuizen; 2) wat de kenmerken zijn van bewoners met zeer ernstig probleemgedrag; 3) met welke factoren dit ernstige gedrag samenhangt; 4) welke factoren maken dat een situatie rondom een verpleeghuisbewoner met dementie en zeer ernstig probleemgedrag als moeilijk wordt ervaren door betrokkenen en; 5) hoe het traject van continue palliatieve sedatie bij verpleeghuisbewoners met dementie en zeer ernstig probleemgedrag verloopt.

Samenvatting van de bevindingen

In **hoofdstuk 2 en 3** worden de kenmerken beschreven van bewoners met zeer ernstige agitatie, roepgedrag en fysieke agressie en de factoren waar hun gedrag mee samenhangt. Hiervoor werd gebruik gemaakt van bestaande gegevens uit vier verschillende studies (WAALBED-I en WAALBED-II studie, de Dementia Care Mapping Studie en de GRIP op probleemgedrag studie) wat resulteerde in een totale groep van 2074 verpleeghuisbewoners. Voor het maken van definities voor zeer vaak voorkomende agitatie, roepgedrag en fysieke agressie werd de Cohen Mansfield Agitation Inventory (CMAI) vragenlijst gebruikt. Dit is een vragenlijst waarin 29 verschillende soorten gedragingen worden omschreven en waarbij de zorgmedewerker moet aangeven in welke mate deze gedragingen bij de bewoner voorkwamen in de afgelopen twee weken. Daarbij kan de zorgmedewerker kiezen tussen een score van 1 (het gedrag kwam nooit voor) tot 6 (het gedrag kwam meerdere keren per dag voor) en zelfs 7 (het gedrag kwam meerdere keren per uur voor). Voor de definities voor zeer vaak voorkomende agitatie, roepgedrag en fysieke agressie moest er op bepaalde gedragingen door de zorgmedewerkers een 6 of 7 zijn ingevuld. In de totale groep van 2074 bewoners werd vervolgens gekeken bij hoeveel bewoners deze definities van toepassing waren.

We vonden dat 7.4% van de bewoners (174 bewoners) zeer vaak voorkomende agitatie, 11.5% van de bewoners (239 bewoners) zeer vaak voorkomend roepgedrag en 2.2% van de

bewoners (54 bewoners) zeer vaak voorkomende fysieke agressie vertoonden. Zeer vaak voorkomende agitatie en zeer vaak voorkomend roepgedrag hingen samen met het hebben van een oudere leeftijd, een ernstiger dementie en een onnatuurlijk vrolijke stemming. Zeer vaak voorkomende agitatie hing ook samen met het hebben van wanen (verkeerde denkbeelden over een situatie), angst en prikkelbaarheid. Een opmerkelijke nieuwe bevinding was dat zeer vaak voorkomend roepgedrag samenhang met het gebruik van medicijnen tegen psychotische symptomen en tegen epilepsie. Een gebrek aan interesse en initiatief hing als enige samen met zeer vaak voorkomende fysieke agressie.

Concluderend heeft de WAALBED-III studie verschillende samenhangende factoren gevonden met zeer vaak voorkomende agitatie, roepgedrag en fysieke agressie die betrekking hebben op zaken rondom de bewoner zelf, maar deze kunnen lang niet al het gedrag verklaren. Daarom is het belangrijk om ook te kijken naar samenhangende factoren buiten de bewoner zelf.

Hoofdstuk 4 beschrijft de resultaten van een deelonderzoek waarin zeven vastgelopen situaties bij verpleeghuisbewoners met dementie en zeer ernstig probleemgedrag diepgaand in kaart gebracht zijn. Deze bewoners waren via het Centrum voor Consultatie en Expertise (CCE) aangemeld. Het CCE is een uitgebreid netwerk van deskundigen met specifieke kennis en ervaring, onder andere op het gebied van probleemgedrag.

Er werden interviews en groepsbijeenkomsten gehouden met diverse betrokkenen: de arts/specialist ouderengeneeskunde, psycholoog, teamleider, eerst verantwoordelijk verzorgende, een andere zorgmedewerker en een naaste van de bewoner. In deze interviews werd de betrokkenen gevraagd naar de ervaren moeilijkheden rondom een situatie van de bewoner met zeer ernstig probleemgedrag.

Uit de analyses van de interviews kwamen veel verschillende thema's naar voren, die te maken hebben met moeilijkheden rondom verschillende betrokkenen bij de situatie. (Figuur 1). Ten eerste ervoeren de geïnterviewden moeilijkheden die te maken hadden met de kenmerken, de houding en ervaring van verschillende groepen betrokkenen. De geïnterviewden gaven bijvoorbeeld aan dat de situatie door hen als moeilijk werd ervaren omdat de bewoner werd gezien als anders in vergelijking met medebewoners, het gedrag

van de bewoner onvoorspelbaar was en zorgmedewerkers en behandelaren over onvoldoende kennis beschikten. Andere voorbeelden betroffen de té afwachtende houding, het niet tijdig om hulp vragen en het niet goed kunnen terugblikken op je eigen handelen en ervaringen van zorgmedewerkers. Daarnaast werd aangegeven dat behandelaren onvoldoende verantwoordelijkheid namen, zich onvoldoende lieten informeren over de situatie en te veel op afstand waren waardoor ze geen volledig beeld kregen. Ten tweede werden er door betrokkenen moeilijkheden ervaren die betrekking hadden op het contact binnen een zorgteam of behandelteam. Zo werd aangegeven dat het voor zorgmedewerkers lastig was om elkaar feedback te geven over elkaars handelen en behandelaren onvoldoende gelegenheid namen om onderling informatie over de situatie uit te wisselen. Ten derde werd het contact tussen groepen betrokkenen als problematisch ervaren. Een voorbeeld was dat zorgmedewerkers en behandelaren het moeilijk vonden om contact met de bewoner te maken omdat emoties van de bewoner niet goed te lezen waren. Een ander voorbeeld was het suboptimale contact van behandelaren en zorgmedewerkers met naasten om verschillende redenen, zoals het anders tegen de situatie aankijken door naasten. De communicatie en samenwerking tussen zorgmedewerkers en behandelaren was ook moeizaam omdat men elkaar niet serieus nam, men onvoldoende tijd en ruimte had om de situatie met elkaar te analyseren, zorgmedewerkers behandelaren niet om hulp durfden te vragen en behandelaren zorgmedewerkers onvoldoende ondersteunden en informeerden.

Om inzicht te krijgen in het traject van continue palliatieve sedatie bij verpleeghuisbewoners met dementie en onbehandelbaar zeer ernstig probleemgedrag, beschrijft **hoofdstuk 5** hoe verschillende betrokkenen tegen dit traject aankijken. Er werden interviews gehouden met naasten, specialisten ouderengeneeskunde, andere behandelaren en zorgmedewerkers die betrokken waren bij drie bewoners met extreem probleemgedrag waarbij uiteindelijk continue palliatieve sedatie is toegepast.

Uit de analyse van de interviews kwamen zes thema's naar voren die te beschouwen zijn als de verschillende fases van het traject van continue palliatieve sedatie (Figuur 2). De eerste fase van dit traject betrof de aanloopfase waarin de ondraaglijke worsteling van de bewoner werd beschreven, betrokkenen de hoop hadden om het lijden van de bewoner te verlichten en een hanteerbare situatie wilden bereiken. De tweede fase betrof een

omslagpunt, waarin betrokkenen het gevoel hadden alles geprobeerd te hebben en hun hoop verloren. Betrokkenen ervoeren gevoelens van falen en machteloosheid. In de derde fase werd het starten van continue palliatieve sedatie overwogen door de specialist ouderengeneeskunde. In alle drie de gevallen werd eerst kortdurende sedatie toegepast en in twee van de drie gevallen werden experts zoals een ouderenpsychiater geconsulteerd. Verschillende overwegingen speelden een rol, zoals de geschatte levensverwachting van de bewoner, de geuite doodswens van de bewoner en in hoeverre er afgeweken werd van de richtlijn palliatieve sedatie. In de vierde fase werd besloten om continue palliatieve sedatie toe te passen, wat werd gebaseerd op één doorslaggevend punt naast de beperkte levensverwachting, het onbehandelbare probleemgedrag en het ondraaglijk lijden van de bewoner. Een voorbeeld van zo'n doorslaggevend punt betrof het verlies van waardigheid van de bewoner. In de vijfde fase werd continue palliatieve sedatie daadwerkelijk toegepast, wat als een opluchting werd ervaren door alle betrokkenen. De zesde fase betrof de evaluatiefase. Er werd door de betrokkenen aangegeven dat het na het doorlopen van een dergelijk traject belangrijk is om met elkaar te evalueren hoe dit proces verlopen is en wat de invloed op eenieder is geweest en welke emoties dit bij iedereen oproept. Concluderend is het traject van continue palliatieve sedatie bij een bewoner met dementie en onbehandelbaar probleemgedrag complex en belastend voor betrokkenen, maar het leidt wel tot tevredenheid.

Hoofdstuk 6 beschrijft de belangrijkste bevindingen uit dit proefschrift. Er zijn bijna geen onderzoeken waarmee deze bevindingen zijn te vergelijken, maar de studies die er zijn vertonen deels vergelijkbare resultaten. Opmerkelijke nieuwe bevindingen van dit proefschrift waren de samenhang van zeer ernstig roepgedrag met het gebruik van medicijnen tegen psychotische symptomen en epilepsie, de ervaren moeilijkheden van betrokkenen die betrekking hadden op de communicatie en samenwerking tussen zorgmedewerkers en behandelaren en het feit dat continue palliatieve sedatie een behandeloptie kan zijn bij verpleeghuisbewoners met dementie en zeer ernstig probleemgedrag.

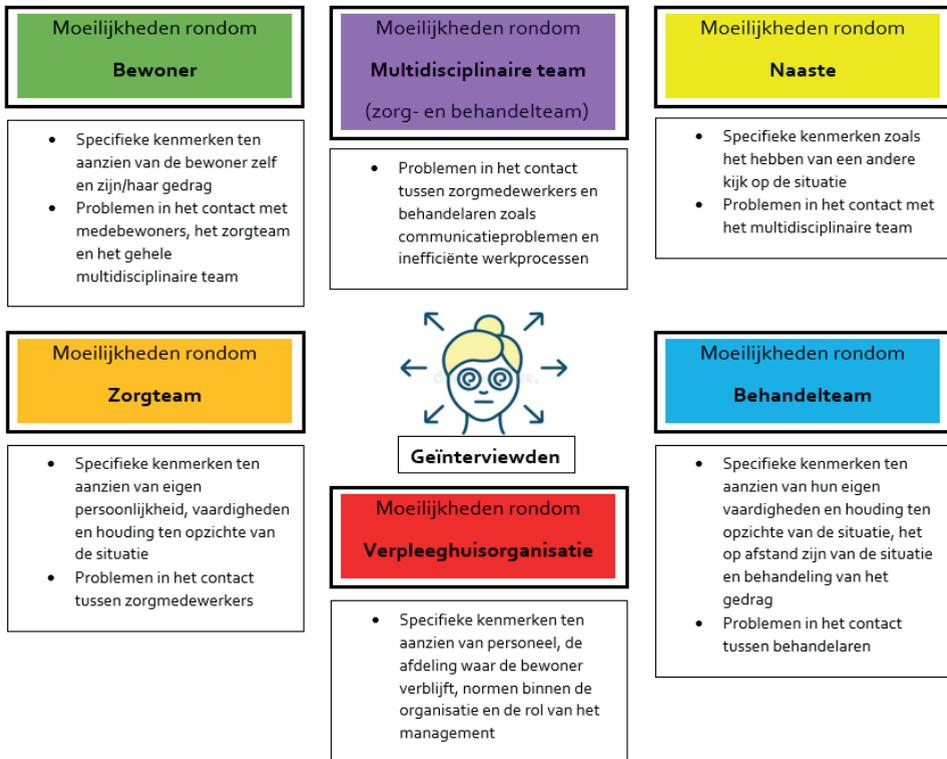
De resultaten van dit proefschrift benadrukken dat het bij bewoners met zeer ernstig probleemgedrag extra belangrijk is dat zorgmedewerkers en behandelaren goed met elkaar communiceren en samenwerken. De communicatie en samenwerking zouden

kunnen verbeteren als er een duidelijke beschrijving komt van wat het zeer ernstige probleemgedrag precies inhoudt, dit gedrag ook op een gestructureerde wijze wordt geanalyseerd en er zorgvuldig wordt gerapporteerd in het dossier. Daarnaast is het belangrijk dat zorgmedewerkers en behandelaren naasten betrekken bij hun ideeën. Verder is het van belang dat teams laagdrempelig hulp van experts van andere instanties kunnen inroepen, zoals een ouderenpsychiater. Verder is scholing van zorgmedewerkers en behandelaren nodig om hun kennis, vaardigheden en competenties op het gebied van zeer ernstig probleemgedrag te vergroten. Het is bij toekomstig onderzoek essentieel om een grondige doelgroepomschrijving te formuleren en het effect van mogelijke interventies op het gedrag te verkennen. Daarnaast zou het goed zijn als onderzoek zich verder richt op oorzaken van het gedrag, waarbij zowel gekeken moet worden naar oorzaken die betrekking hebben op de bewoner zelf als op diens omgeving.

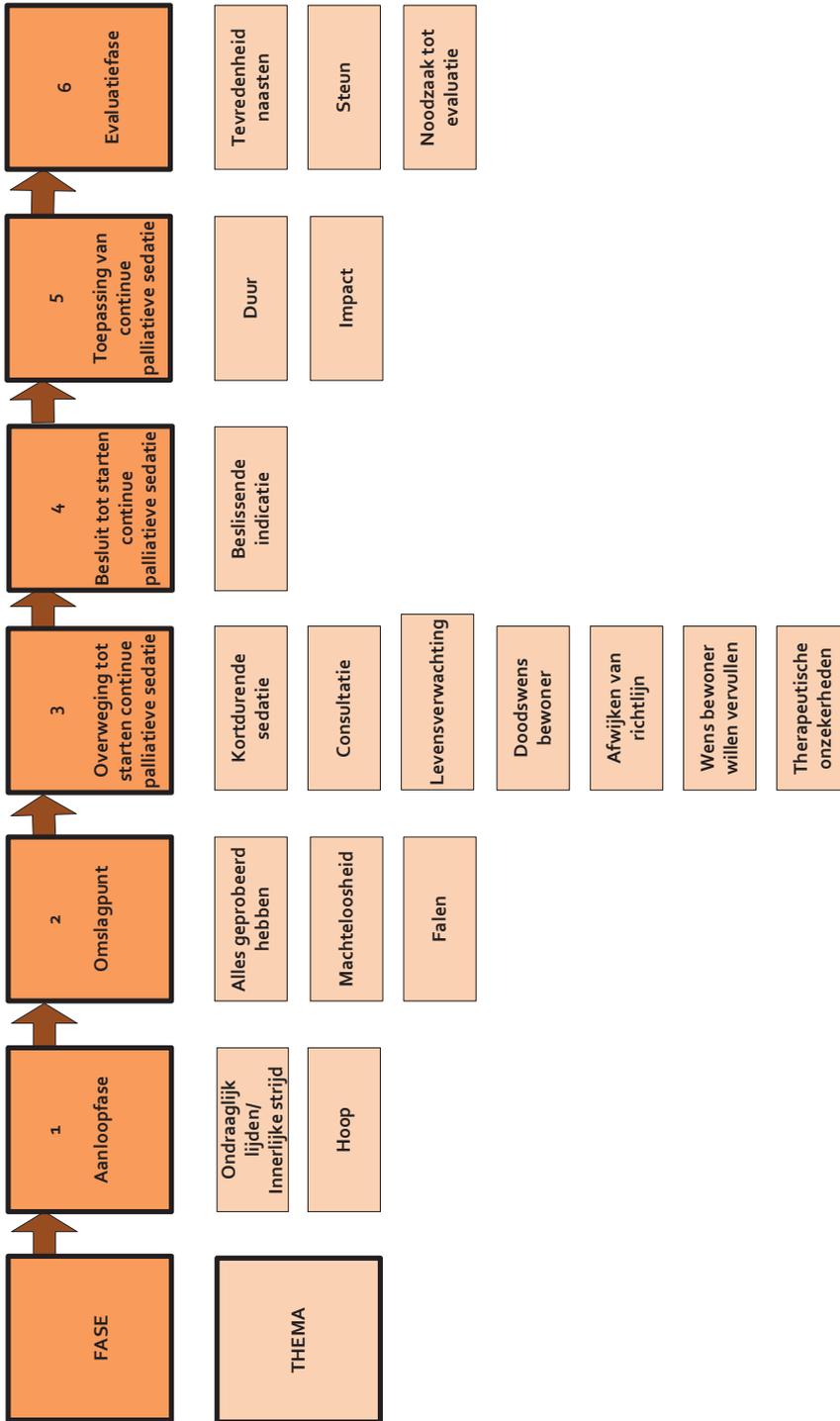
Conclusie

Dit proefschrift laat zien dat situaties rondom verpleeghuisbewoners met dementie die zeer ernstig probleemgedrag vertonen complex zijn. Deze bewoners hebben specifieke kenmerken en er zijn verschillende factoren waarmee hun ernstige gedrag samenhangt. Betrokkenen bij dergelijke situaties ervaren allerlei moeilijkheden. Een traject waarin continue palliatieve sedatie wordt toegepast kan een waardevolle behandeloptie zijn. Vanwege de complexiteit van deze situaties vragen deze bewoners om een hoger niveau van kennis, vaardigheden en competenties van zorgmedewerkers en behandelaren. Verder vragen dergelijke situaties om een intensieve communicatie en samenwerking tussen zorgmedewerkers en behandelaren, met naasten en experts van andere instanties. Dit proefschrift biedt aanknopingspunten om de zorg, behandeling en kwaliteit van leven van verpleeghuisbewoners met dementie en zeer ernstig probleemgedrag te verbeteren.

Figuur 1: Ervaren moeilijkheden rondom situaties van verpleeghuisbewoners met dementie en zeer ernstig probleemgedrag



Figuur 2: Thema's die betrekking hebben op de verschillende fases van het traject van continue palliatieve sedatie



Datamanagement

Ethics and privacy

This thesis is based on the results of medical-scientific research with human participants. The WAALBED-III study was conducted in accordance with Dutch Law and the Declaration of Helsinki (World Medical Association)¹ and the “Code of Conduct for Health Research”². The regional medical ethical review board Committee on Research Involving Human Subjects assessed this study and stated that the study did not require medical ethical approval under the legislation in medical trials. This thesis contains quantitative and qualitative data of nursing home residents with dementia, including residents with very severe or extreme challenging behavior. For the quantitative part of the study, data were combined from four studies. In all four studies, informed consent was obtained from the primary legal representative or legal guardian of the NH resident. For the qualitative part of the study, a separate informed consent was obtained for participation in the individual and focus group interviews. To safeguard the availability, integrity and confidentiality of the data, pseudonymization, access authorization and secure data storage were applied. For the quantitative part of the study, the four separate datasets were provided without names of the participants but with their dates of birth to check whether residents could have been part of more than one dataset. The dates of birth were deleted and replaced with year of birth in the study data and keys to the subject codes were stored separately from the study data. The privacy of the participants in the qualitative study is warranted by use of encrypted and unique individual subject codes.

Data collection

These data were disposed in SPSS and saved as .sav files. In addition, this thesis is based on qualitative data of relatives and nursing home staff. Individual interviews and focus group discussions were tape-recorded and transcribed verbatim in Microsoft Word. In these transcripts names of participants were replaced with unique individual subject codes and privacy-related information was eliminated. Transcripts were entered into Atlas.ti version 7.1.4 for data analysis (Atlas.ti Scientific Software Development, Berlin, Germany).

Data storage

Data storage was guided by the Findable, Accessible, Interoperable and Reusable (FAIR) principles.³ Informed consents on paper and interview guides are stored at the locked archive of the department of Primary and Community care of the Radboud University Medical Center (room number m245.-2.0053). All digital data is stored at the H-station of the department of Primary and Community care in the folder H:\OZ-Ouderen-Langdurige-Zorg\OLZ-WAALBED-III. During the project, back-ups were made automatically by the Radboud University Medical Center and Annelies Veldwijk made weekly and monthly back-ups of the data on two separate USB keys and stored them in a locked cabinet on the Department of Primary and Community care Radboudumc. The data will be archived for 15 years after termination of the study. The project leader of the WAALBED-III study (Prof. dr. Raymond Koopmans) will decide after expiry of this period, if the data can be destroyed or has to be stored for a longer period of time. In the latter case, the period of data storage will be determined again. Data are only accessible to the project leader and to employees responsible for archiving.

Availability of data

Reusing the qualitative data for future research other than the WAALBED-III study is only possible after a renewed permission by the participants. The anonymous quantitative datasets that were used for analysis are available from the project leader upon reasonable request. Before providing the data, the project leader will first discuss with Annelies Veldwijk if this is possible.

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Dankwoord (acknowledgements in Dutch)

Het is zo ver! Mijn proefschrift is af! Wat voelt dat onwerkelijk en vreemd. De afgelopen 9 jaar heb ik samen met mijn projectgroep gewerkt aan de WAALBED-III studie en nu is het einde opeens daar. Op zolder nog een uurtje werken als het buiten toch regent, tijdens slaapjes van de kinderen nog wat aanpassingen doen aan dat ene artikel en mijzelf voor de laatste loodjes en puntjes op de i opsluiten in een hotel. Ondanks de inspanningen en lange adem die het soms vergde had ik het niet willen missen, het was het dubbel en dwars waard! Ik ben trots op wat ik bereikt heb en dit had ik niet gekund zonder vele fijne en lieve mensen om mij heen, waarvoor ik nu mijn dank wil uitspreken.

Ten eerste wil ik de verpleeghuisorganisaties, verzorgenden, behandelaren, managers en de families van de patiënten die hebben meegedaan aan de WAALBED-III studie bedanken. Hun inzet heeft geleid tot de huidige resultaten van dit proefschrift. Het CCE heeft bijgedragen aan de inclusie van patiënten, waarvoor veel dank. Verder wil ik de onderzoekers van de WAALBED-I studie, WAALBED-II studie, DCM studie en GRIP studie bedanken voor het beschikbaar stellen van de onderzoeksdata voor het eerste deel van dit onderzoek.

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Curriculum Vitae (in Dutch)

Annelies Veldwijk-Rouwenhorst werd geboren op 24 maart 1986 in Apeldoorn. Zij groeide op in de bossen van Ugchelen en behaalde in 2004 haar Gymnasium diploma aan het Veluws College Walterbosch in Apeldoorn.

Daarna is zij geneeskunde gaan studeren aan de Vrije Universiteit in Amsterdam. Gedurende haar studie deed zij een keuze coschap radiologie in het St. Lucas Andreas Ziekenhuis in Amsterdam en reisde zij af naar Tanzania voor het coschap tropengeneeskunde in het Sokoine Regional Hospital in Lindi. Hier deed zij onder andere ervaring en kennis op op de afdelingen interne geneeskunde, dermatologie en gynaecologie en obstetrie. Tijdens haar studietijd werkte Annelies als thuiszorg-medewerker bij Cordaan in Amsterdam, waarmee haar interesse voor de oudere patiënt werd gewekt. Hierop besloot ze een keuze coschap geriatrie te doen aan het Slotervaartziekenhuis te Amsterdam. Ook haar wetenschappelijke stage had betrekking op de oudere patiënt. Zij deed onderzoek naar de inter-beoordelaarsbetrouwbaarheid van de Nederlandse versie van de CORE; een studie bij opgenomen ouderen met een depressie op de afdeling Ouderen van de Valeriuskliniek te Amsterdam. Haar oudste coschap deed zij bij de interne geneeskunde het Medisch Centrum Alkmaar.

In 2011 behaalde Annelies haar artsdiploma en ging zij als arts-assistent psychiatrie aan de slag bij een herstelafdeling en een Assertive Community Treatment team van het psychiatrisch instituut Mentrum in Amsterdam. Hier was zij verantwoordelijk voor de medische zorg van ongeveer 15 patiënten met verslavingsproblemen op twee herstelafdelingen en leverde zij in een team van onder andere een psychiater, maatschappelijk werker en psychiatrisch verpleegkundigen bemoeizorg en ondersteuning thuis aan patiënten met psychiatrische problemen en een verslaving. In 2012 werkte zij als arts-assistent geriatrie, wederom in het Slotervaart ziekenhuis in Amsterdam.

Omdat de ziekenhuiswereld haar niet trok en zij de oudere patiënt graag langer wilde volgen in de tijd, besloot zij in september 2012 aan de slag te gaan als arts-assistent ouderengeneeskunde bij Me-doc in Utrecht en werd zij gedetacheerd bij verpleeghuisorganisatie Atlant. Al kort na haar start in het verpleeghuis voelde zij zich als een vis in

het water en zag zij een toekomst voor zich in de ouderengeneeskunde. In 2014 startte zij daarom met de opleiding tot specialist ouderengeneeskunde bij de VOSON van het Radboudumc in Nijmegen, die zij combineerde met een promotietraject op de WAAL Behavior in Dementia (WAALBED)- III studie bij de afdeling Eerstelijngeneeskunde van het Radboudumc. Deze studie heeft geresulteerd in dit proefschrift. In 2021 won zij de Jan Stoopprijs en in 2022 de Myrra Vernooij Dassen prijs, beide betrekking hebbend op de artikelen in dit proefschrift.

Sinds maart 2021 werkt Annelies als specialist ouderengeneeskunde bij haar eerdere werkplek Atlant en heeft zij van Atlant de mogelijkheid gekregen om haar promotieonderzoek af te ronden. In september 2023 is Annelies gestart als postdoc onderzoeker op het onderzoeksprogramma dementie op oudere leeftijd bij de eerstelijngeneeskunde aan het Radboudumc. Ook zal zij aan de slag gaan als consulent bij het Centrum voor Consultatie en Expertise (CCE).

Annelies is getrouwd met Robbie Veldwijk, samen hebben zij een zoon Bram (2017) en twee dochters Lisa (2019) en Nina (2021).

Publications, presentations, training and teaching activities

Publications other than outlined in this thesis

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Interviews

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- Website of Dutch elderly care physicians in training (VASON). – Interview Aioto Annelies Veldwijk. Available from: <https://www.vason.nl/werkgroepen-en-commissies/aioto-commissie/interview-aioto-annelies-veldwijk>

Presentations

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| April 2023 | Virtual presentation at the 4 th Dementia Conference, Krems (Austria): Veldwijk-Rouwenhorst, AE. - Very severe or extreme challenging behavior in nursing home residents with dementia. The WAALBED-III study. |
| March 2023 | Presentation for PhD-students Atlant Zorggroep, Beekbergen (the Netherlands): Veldwijk-Rouwenhorst AE. - |

- Nov 2022 Presentation at the Verenso regiocongres Zeeland/West Brabant, Renesse (the Netherlands): Veldwijk-Rouwenhorst AE. - Extreem probleemgedrag bij verpleeghuisbewoners met dementie. De WAALBED-III studie.
- June 2022 Presentation at the trainers day of Gerion, Soesterberg (the Netherlands): Veldwijk-Rouwenhorst AE. - Extreem probleemgedrag bij verpleeghuisbewoners met dementie. De WAALBED-III studie.
- April 2022 Presentation for elderly care physicians Atlant Zorggroep, Beekbergen (the Netherlands): Veldwijk-Rouwenhorst AE. - Extreem probleemgedrag bij verpleeghuisbewoners met dementie. De WAALBED-III studie.
- March 2022 Virtual presentation at the Leidse Ouderengeneeskundedagen, Leiden (the Netherlands): Veldwijk-Rouwenhorst AE. – Continue palliatieve sedatie bij verpleeghuisbewoners met dementie en extreem probleemgedrag. De WAALBED-III studie.
- Sept 2021 Virtual presentation for Universitair Netwerk Ouderenzorg (UNO), Amsterdam (the Netherlands): Veldwijk-Rouwenhorst AE. – Extreem probleemgedrag bij verpleeghuisbewoners met dementie. De WAALBED-III studie.
- Sept 2020 Presentation at the IPA virtual Congress: Veldwijk-Rouwenhorst AE, Koopmans RTCM, Zuidema SU, Gerritsen DL, Smalbrugge M. - Continuous palliative sedation in nursing home residents with dementia and refractory neuropsychiatric symptoms.
- Sept 2019 Poster presentation at the IPA Congress Santiago de Compostela (Spain): Bielderman A, Veldwijk-Rouwenhorst AE, Pelgrims B, Smalbrugge M, Zuidema SU, Koopmans RTCM, Gerritsen DL. - Quality

of life in nursing home residents with dementia and very frequent agitation, vocalizations or physical aggression.

Sept 2018 Presentation at the NHR Congress Rome (Italy): Veldwijk-Rouwenhorst AE, Koopmans RTCM, Zuidema SU, Gerritsen DL, Smalbrugge M. - Defining crisis concerning nursing home residents with dementia and challenging behavior in the perspective of stakeholders.

Presentation at the NHR Congress Rome (Italy): Veldwijk-Rouwenhorst AE, Koopmans RTCM, Zuidema SU, Gerritsen DL, Smalbrugge M. - Continuous palliative Sedation in NH residents with dementia suffering from extreme refractory neuropsychiatric symptoms; lessons from three cases.

Poster presentation at the NHR Congress Rome (Italy): Veldwijk-Rouwenhorst AE, Herbst C, van Heerbeek N, Zuidema SU, Smalbrugge M, Koopmans RTCM, Gerritsen DL. - Defining crisis concerning nursing home residents with dementia and challenging behavior in the perspective of stakeholders.

Poster Presentation at the NHR Congress Rome (Italy): Koopmans RTCM, Veldwijk-Rouwenhorst AE, Gerritsen DL, Hanssen SAJ, Smalbrugge M, Bor H, Zuidema SU. - Administering continuous palliative sedation to patients with dementia and extreme neuropsychiatric symptoms.

June 2018 Presentation at the Gerion Symposium Amsterdam (the Netherlands): Veldwijk-Rouwenhorst AE, Smalbrugge M. - Continue palliatieve sedatie bij extreem probleemgedrag bij verpleeghuisbewoners met dementie.

May 2018 Presenting workshop at the Congresparade StudieArena Lunteren (the

Netherlands): Veldwijk-Rouwenhorst AE. – Complex gedrag en samenwerking in teams.

- Sept 2017 Poster Presentation at the EUGMS Congress Nice (France): P-011: Koopmans RTCM, Veldwijk-Rouwenhorst AE, Gerritsen DL, Hanssen SAJ, Smalbrugge, Bor H, Zuidema SU. - Administering continuous palliative sedation to patients with dementia and extreme neuropsychiatric symptoms.
- Nov 2016 Presentation at the NHR Congress Barcelona (Spain): Veldwijk-Rouwenhorst, AE. – Symposium 6: Towards specialized long-term care for people with mental-physical multimorbidity, young onset dementia or severe challenging behavior. Challenging behaviour in nursing home residents with dementia; prevalence, characteristics and correlated factors of extreme aggression and vocally disruptive behavior.
- Oct 2016 Poster Presentation at the EUGMS Congress Lisbon (Portugal): P-137:Veldwijk-Rouwenhorst AE, Gerritsen DL, Smalbrugge M, Wetzels RB, Bor H, Zuidema SU, Koopmans RTCM. - Extreme agitation in nursing home residents with dementia; prevalence, characteristics and correlates.
- Sept 2016 Presentation at the IPA Congress San Francisco (United States of America): FC2: Treatment and BPSD. Veldwijk-Rouwenhorst AE, Koopmans RTCM, Zuidema SU, Smalbrugge M, Wetzels RB, Bor H. – Extreme aggression in nursing home residents with dementia: a part of the WAALBED III study.
- April 2016 Presentation at My-Doc symposium Utrecht (the Netherlands): Rouwenhorst AE. - From passion to power- waarom netwerken zo leuk is.

- Presentation at a meeting of the Radboud Alzheimer Centre Nijmegen (the Netherlands): Rouwenhorst AE.- Extreme agressie bij verpleeghuisbewoners met dementie: de karakteristieken in beeld.
- March 2016 Presentation at a meeting of the Centre for Consultation and Expertise Zwolle (the Netherlands): Rouwenhorst AE. - Extreem probleemgedrag bij verpleeghuispatienten met dementie. De WAALBED-III studie.
- Dec 2015 Presentation at the reference meeting of the department of primary and community care, Radboudumc Nijmegen (the Netherlands).
- Nov 2015 Presentation at the Verenso najaarscongres Den Bosch (the Netherlands): Rouwenhorst AE. – Extreem probleemgedrag bij dementie. De WAALBED-III studie.
- Oct 2015 Poster Presentation at the IPA Congress Berlin (Germany): PS01.76: Rouwenhorst A, Gerritsen DL, Smalbrugge M, Wetzels RB, Bor H, Zuidema SU, Koopmans RTCM. - Characteristics of nursing home residents with extreme agitation : the WAALBED III Study
- Sept 2015 Poster Presentation at the EUGMS Congress Oslo (Norway): P-081: Rouwenhorst AE, Gerritsen DL, Smalbrugge M, Wetzels RB, Bor H, Zuidema SU, Koopmans RTCM. - Characteristics of nursing home residents with extreme vocally disruptive behavior: a part of the WAALBED III study.
- April 2009 Presentation of a workshop on the spring congress of psychiatry Groningen (the Netherlands).

Dit proefschrift beschrijft hoe vaak zeer ernstig probleemgedrag voorkomt bij bewoners met dementie in de Nederlandse verpleeghuizen, wat hun kenmerken zijn en met welke factoren dit ernstige gedrag samenhangt. Daarnaast staat in dit proefschrift beschreven welke factoren maken dat situaties rondom verpleeghuisbewoners met dementie en zeer ernstig probleemgedrag als moeilijk worden ervaren door betrokkenen. Tenslotte is het traject van continue palliatieve sedatie bij deze groep verpleeghuisbewoners bestudeerd.

Uit de resultaten komt naar voren dat situaties rondom verpleeghuisbewoners met dementie die zeer ernstig probleemgedrag vertonen complex zijn. Deze bewoners hebben specifieke kenmerken en er zijn verschillende factoren waarmee hun ernstige gedrag samenhangt. Betrokkenen bij dergelijke situaties ervaren allerlei moeilijkheden. Een traject waarin continue palliatieve sedatie wordt toegepast kan een waardevolle behandeloptie zijn. De complexiteit van dergelijke situaties vraagt om een hoger niveau van kennis, vaardigheden en competenties van zorgmedewerkers en behandelaren en om een intensieve communicatie en samenwerking.



Annelies Veldwijk-Rouwenhorst is specialist ouderengeneeskunde bij Atlant in Beekbergen. Het onderzoek dat ten grondslag ligt aan dit proefschrift is gefinancierd door ZonMw en uitgevoerd vanuit het Universitair Kennisnetwerk Ouderenzorg Nijmegen (UKON) van het Radboudumc (Nijmegen) in samenwerking met het UMCG, Amsterdam UMC en het Centrum voor Consultatie en Expertise (CCE). Dit onderzoek is mede mogelijk gemaakt door de Stichting Beroepsopleiding Huisartsen (SBOH) en Atlant.