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

Gerrie van Voorden, Raymond T.C.M. Koopmans, Martin Smalbrugge, Sytse U. Zuidema, Anne M.A. van den Brink, Anke Persoon, Richard C. Oude Voshaar & Debby L. Gerritsen

Routledge
Taylor & Francis Group

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

Gerrie van Voorden[a] , Raymond T.C.M. Koopmans[a,b], Martin Smalbrugge[c] , Sytse U. Zuidema[d] , Anne M.A. van den Brink[a] , Anke Persoon[a] , Richard C. Oude Voshaar[e] and Debby L. Gerritsen[a]

[a]Department of primary and community care, Radboud university medical center, Nijmegen, The Netherlands; [b]Joachim en Anna, Center for Specialized Geriatric Care, De Waalboog, Nijmegen, The Netherlands; [c]Department of medicine for older people, Amsterdam UMC, Amsterdam, The Netherlands; [d]Department of General Practice and Elderly Care Medicine, Alzheimer Center Groningen, University of Groningen, University Medical Center Groningen, Groningen, The Netherlands; [e]University Center of Psychiatry, University of Groningen, University Medical Center Groningen, Groningen, The Netherlands

ABSTRACT

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

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

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

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

Introduction

Challenging behavior in persons with dementia—also known as neuropsychiatric symptoms or behavioral and psychological symptoms in dementia (BPSD) (Gerritsen et al., 2019)—is common in nursing homes, with a prevalence rate of more than 80% (Selbaek et al., 2013). Challenging behavior includes a broad range of behaviors such as agitation, physical or verbal aggression, vocalizations, disinhibition, irritability or nighttime disturbances. Challenging behavior is associated with lower quality of life for persons with dementia living in long-term care institutions (Henskens et al., 2019; Klapwijk et al., 2016; Livingston et al., 2017; Winzelberg et al., 2005) and increased caregiver distress (Brites et al., 2020). Although an exact definition of severe challenging behavior is lacking, Brodaty et al. propose a seven-tiered model for managing BPSD, where the prevalence rates of severe, very severe, and extreme BPSD are estimated at 10%, <1%, and rare, respectively, each requiring a different level of management (Brodaty et al., 2003). In a minority of residents challenging behavior can be very frequent, severe and/or persistent, with reported prevalence rates of 6.3% for severe agitation and 7.4% for very frequent agitation (Palm et al., 2018; Veldwijk-Rouwenhorst et al., 2017). Severe challenging behavior—especially agitation and aggression—may even lead to admissions to other settings such as

psychiatric inpatient settings and specialist care units (Backhouse et al., 2018) with more diagnostic facilities, more facilities to prevent harm from physical aggression as well as more highly trained staff members. Although a large number of non-pharmacological and pharmacological interventions have been investigated, the majority of studies vary in their methods applied, including different primary outcome measures, and moderate sample sizes hindering univocal insights into the effectiveness of interventions (Abraha et al., 2017; Dyer et al., 2018). The rationale for the different choice in treatment outcomes is often unclear or arbitrary, and a more standardized approach is needed (Koch et al., 2022). Outcomes used to date with different instruments include behavior, mood, and—less often—quality of life and caregiver distress (Abraha et al., 2017; Dyer et al., 2018; Feast et al., 2016). Some of these outcome measurements were used in a ten-year review of a highly specialized unit for the treatment of severe and persistent BPSD in Australia, although the authors only described discharge to regular long-term care services and reduction of psychotropic drugs as treatment success (Gresham et al., 2021), implying that treatment success is based on more than changes in behavior. This plethora of outcome measures reflects the need for a conceptual framework of treatment success in the context of severe challenging behavior, which may help to improve

care and treatment as well as the planning and evaluation of this particular group. To the best of our knowledge, no literature is available describing a conceptual framework for treatment of this specific group of people with dementia and severe challenging behavior. Therefore, we decided to consult experienced professionals in this treatment, formulating the following research question: 'How do experienced professionals conceptualize successful treatment in severe challenging behavior in dementia?' This conceptualization will address two aims: (1) improving the understanding of what successful treatment contains in persons with severe challenging behavior in dementia; and (2) evaluation of treatment.

Methods

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

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

Participants

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

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

Data collection and analysis

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

Preparation for phase 1

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

Phase 1: Brainstorm

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

Preparation for phase 2

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

Phase 2: Sorting and rating

In phase 2, participants individually sorted the statements into categories according to their own perception of similarity. Participants were also asked to provide a name for their categories according to their content. In the rating procedure, participants rated the individual statements according to their importance for the concept of successful treatment on a five-point Likert scale (Kane & Trochim, 2007).

Data analysis

Data approval, i.e. checking whether participants finished sorting according to instruction, and analysis were also conducted

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

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

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

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

Ethics statement

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

Results

Participants

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

Data collection and analysis

The brainstorm resulted in 187 statements, which we reduced to 93 statements. The *two-dimensional nonmetric multidimensional scaling* of the sorting data resulted in a *point map* (see Figure S1 attached as Supplementary material 1 in the Supplemental online material), with a stress value was 0.21. In the *hierarchal cluster analysis*, we agreed upon a set of three main clusters and ten sub-clusters optimal representing successful treatment.

Cluster map clarification

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

Table 2. Participant demographics (*n* = 82).

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

*without *n* = 3 that did not complete age
**often have more than one vocational training, ranging from nurse, physiotherapist, occupational therapist, physician assistant, psychologist, elderly care physician, psychiatrist and (team) manager.

shown. In Table S1, all bridging values and average rating values per statement are shown (see Supplementary material 2).

Cluster 1: Well-being

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

Cluster 2: Multidisciplinary analysis and treatment

The second cluster comprised four sub-clusters. The sub-cluster of *process conditions* provided a set of criteria that can be used to plan and evaluate the conditions needed for multidisciplinary analysis and treatment. Statement 35 '.*the organization supports, guides and facilitates the professionals involved in the appropriate manner to carry out the desired interventions'* had the second highest bridging value (0.96) and scored second highest of all statements (4.55) (see Supplementary material 2). This indicates that organizational facilitation was conceptually related to many statements and considered a very important factor of successful treatment. We consider this statement a precondition for a successful treatment process and outcome. The other statements in this sub-cluster were also related to more distant statements (cluster bridging value 0.6), probably because these statements were formulated as a relatively concrete criterium despite being related to the other topics.

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

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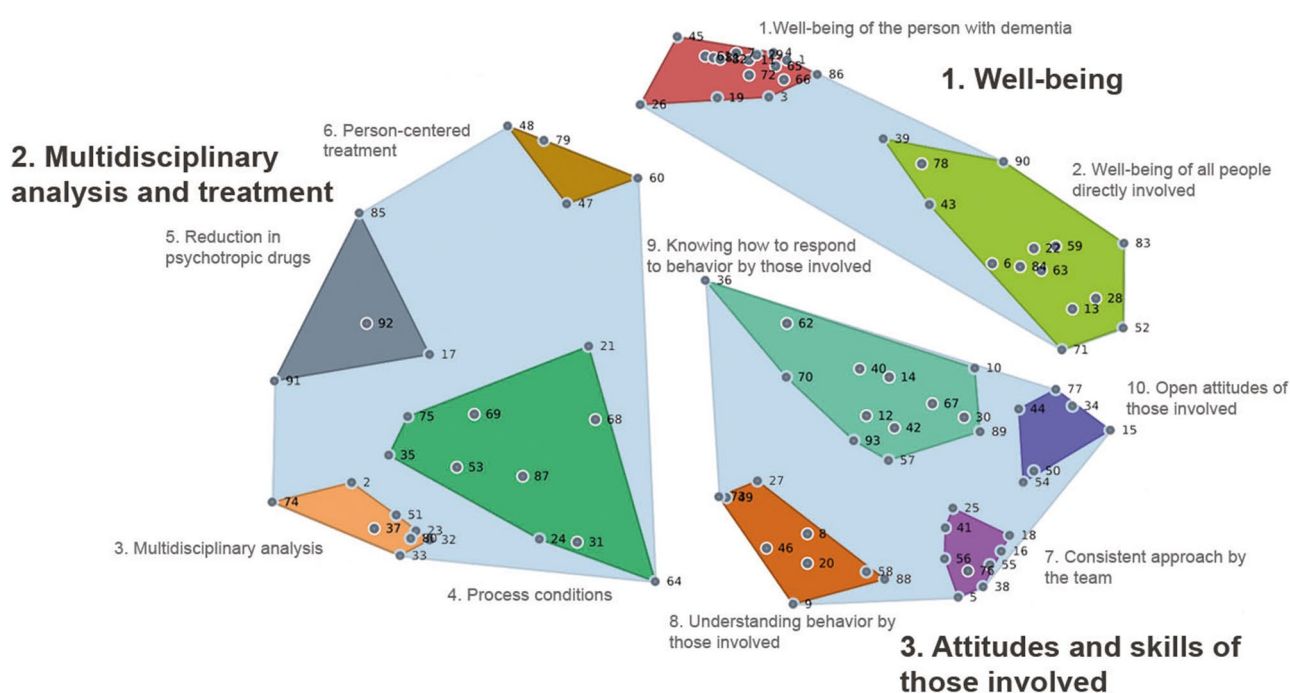

Figure 1. Final concept map: representations of how 93 statements (dots with numbers in grey) relate to the clusters.

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

Clusters and sub-clusters (number of statements)	Descriptions	B*	I**
1) Well-being (30 statements)	**Improvement of the well-being of the person with dementia and the people directly around the person with dementia.**		
1) Well-being of the person with dementia (16 statements)	Improvement of the well-being of the person with dementia. Aspects also mentioned here are stable behavior, recognizing the person behind the disease, being allowed to be oneself, experiencing positive contact with other people on a daily basis, feeling understood, being able to enjoy life, having meaningful daytime activities, appearing to be more relaxed, more peace and comfort for the person with dementia, dignity of existence, no longer being distressed by the behavior or the reason for the behavior, less suffering, and being able to be transferred to a regular long-stay ward.	0.08	3.98
2) Well-being of all people directly involved (14 statements)	Improvement of the well-being of the people around the person with dementia, including other patients. Aspects also mentioned here are manageability of the behavior, improvement of the tolerability of the behavior, less despair, being able to accept the behavior, feeling understood, experiencing better contact with the person with dementia, having a sense of control over the behavior, no longer being affected by the behavior, and no more unsafe situations arising.	0.38	3.89
2) Multidisciplinary analysis and treatment (26 statements)	**The behavior of the person with dementia is analyzed and treated from different perspectives. The roles of the persons involved in this are clear, and the treatment does justice to the person behind the disease.**		
3) Multidisciplinary analysis (8 statements)	The behavior is analyzed from different perspectives and disciplines and evaluated by a multidisciplinary team and relatives.	0.48	4.17
4) Process conditions (10 statements)	Conditions for a proper treatment process. These include aspects such as the organization's support and facilitation of professionals, clear problem definitions, agreements and roles, having a picture of the background of the behavior of the person with dementia, adhering to the guideline, involving relatives, and seeing the behavior as dynamic.	0.6	4.17
5) Reduction in psychotropic drugs (4 statements)	Reduction of psychotropic drugs, if possible.	0.86	3.67
6) Person-centered treatment (4 statements)	The treatment takes into account the individuality of the person with dementia. Aspects mentioned here are meeting the needs of the person with dementia, and doing justice to the dignity of the person with dementia and their need for control.	0.52	4.49
3) Attitudes and skills of those involved (37 statements)	**The people around the person with dementia understand their behavior and approach them consistently, and have adequate knowledge and skills to do so.**		
7) Consistent approach by the team (9 statements)	The team can consistently apply their knowledge of the behavior while adequately adapting their approach if necessary.	0.27	4.3
8) Understanding behavior by those involved*** (9 statements)	The team and relatives understand the background of the behavior. Aspects mentioned here are joint efforts by the team and relatives, better gauging and preventing the behavior's escalation, the allocation of meaning to the behavior and own actions by the person involved, and exploration of their personal values in relation to the behavior of the person with dementia.	0.32	4.17
9) Knowing how to respond to behavior by those involved*** (13 statements)	Those involved know which approach the person with dementia requires and can apply it. Aspects also mentioned here are reacting towards the person with dementia with more sensitivity, tailoring sensory stimuli, focusing on whatever goes well, and professionals developing self-confidence.	0.29	4.06
10) Open attitudes of those involved*** (6 statements)	Those involved have the skills to tailor their (re)actions to the person with dementia. Aspects also mentioned here are being able to look at the behavior with an open mind, not judging strong emotions, and seeing the behavior as a way of communicating about well-being.	0.36	4.22

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

sub-cluster of *person-centered treatment* was close to the well-being cluster, which implies that it is closely related to well-being of the person with dementia.

Cluster 3: Attitudes and skills of those involved
The third cluster comprised four sub-clusters: *7) consistent approach by the team, 8) understanding behavior by those involved not including other patients, 9) knowing how to respond to behavior by the those involved not including other patients,* and *10) open attitudes of those involved not including other patients.* The sub-cluster of *consistent approach by the team* was about the treatment by the nursing staff, while sub-clusters 8–10 were also important to others involved.

Discussion

To our knowledge, this is the first study to conceptualize domains of successful treatment of people with dementia and severe challenging behavior as perceived by experienced professionals. Three domains were identified: (1) *well-being* of the person with dementia and all people directly involved, including other patients; (2) *multidisciplinary analysis and treatment*; and (3) *attitudes and skills of those involved*. The first domain considers the treatment outcome, whereas the other two also

consider the treatment process. The clusters concerning treatment process can be considered prerequisites to ensure the well-being of people with dementia and people directly involved such as relatives and nursing staff. Below, we will discuss the domains and their interrelatedness in the light of what is already known from previous research.

Well-being of all involved

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

Treatment process

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

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

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

Strengths and limitations

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

This study has three main limitations. First, the online brainstorm has the disadvantage of less interactivity among participants than in a live group setting, which might have led to a lack of detail or specificity of some statements, especially clarifying the statements about psychotropic drugs and precising 'those involved', i.e. sometimes it was unclear whether the statement included the professional only or also the informal caregiver. Another disadvantage described for online brainstorming is a lower response rate (Kane & Trochim, 2007). However, our response rates for the data collection phases were comparable to other concept mapping studies, including live, online or hybrid data collections (Donnelly, 2017). We chose an online brainstorm based on its advantages such as involving no travel time, the ability to brainstorm with a larger group, the possibility to complete the brainstorm at participants' convenience during a given timeframe, and formulating this ideas in an environment surrounded by participants' own resources, thus increasing the depth of these contributions (Kane & Trochim, 2007). Given the advantages and disadvantages of an online brainstorm, a hybrid approach would probably be most optimal. Nevertheless, we think that our online method did not influence the results in its essence, due to the large and diverse group of participants, and because the results were highly interpretable despite incongruences in a few statements. Second, we asked participation of experienced professionals according to our research question. Using this approach, we did not include the perspective of less experienced staff, people with dementia themselves, their relatives or other informal caregivers. We did not choose this for we wanted to focus on the perspective of experts as a first step in exploring the concept of successful treatment of severe challenging behavior, but we think including the perspective of other stakeholders might nuance our findings and even show what experts may overlook. Third, a relatively large group of participants did not start sorting or did not complete sorting according to instruction. One reason for this might be that sorting is a time-consuming and complex task, asking the participants to sort many statements according to their own ideas. Indeed, in concept mapping studies, the sorting task is often not completed (Hanzen et al., 2017; Iris et al., 2012).

Conclusion and implications

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

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

Acknowledgements

Disclosure statement

Funding

ORCID

Gerrie van Voorden http://orcid.org/0000-0002-9677-0880
Martin Smalbrugge http://orcid.org/0000-0003-0538-4843
Sytse U. Zuidema http://orcid.org/0000-0002-4991-9507
Anne M.A. van den Brink http://orcid.org/0000-0003-2941-0882
Anke Persoon http://orcid.org/0000-0003-4581-4748
Richard C. Oude Voshaar http://orcid.org/0000-0003-1501-4774
Debby L. Gerritsen http://orcid.org/0000-0002-3356-0237

References

Abraha, I., Rimland, J. M., Trotta, F. M., Dell'Aquila, G., Cruz-Jentoft, A., Petrovic, M., Gudmundsson, A., Soiza, R., O'Mahony, D., Guaita, A., & Cherubini, A. (2017). Systematic review of systematic reviews of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia. The SENATOR-OnTop series. *BMJ Open*, *7*(3), e012759. https://doi.org/10.1136/bmjopen-2016-012759

Azermai, M., Petrovic, M., Elseviers, M. M., Bourgeois, J., Van Bortel, L. M., & Vander Stichele, R. H. (2012). Systematic appraisal of dementia guidelines for the management of behavioural and psychological symptoms. *Ageing research Reviews*, *11*(1), 78–86. https://doi.org/10.1016/j.arr.2011.07.002

Backhouse, T., Camino, J., & Mioshi, E. (2018). What do we know about behavioral crises in dementia? A systematic review. *Journal of Alzheimer's Disease*, *62*(1), 99–113. https://doi.org/10.3233/jad-170679

Berg, A., Hallberg, I. r., & Norberg, A. (1998). Nurses reflections about dementia care, the patients, the care and themselves in their daily caregiving. *International Journal of Nursing Studies*, *35*(5), 271–282. https://doi.org/10.1016/S0020-7489(98)00040-6

Bressan, V., Visintini, C., & Palese, A. (2020). What do family caregivers of people with dementia need? A mixed-method systematic review. *Health & Social Care in the Community*, *28*(6), 1942–1960. https://doi.org/10.1111/hsc.13048

Brites, R., Brandao, T., Moniz Pereira, F., Hipolito, J., & Nunes, O. (2020). Effects of supporting patients with dementia: A study with dyads. *Perspectives in Psychiatric Care*, *56*(3), 614-620. https://doi.org/10.1111/ppc.12476

Brodaty, H., Draper, B. M., & Low, L. (2003). Behavioural and psychological symptoms of dementia: A seven-tiered model of service delivery. *The Medical Journal of Australia*, *178*(5), 231–234. https://doi.org/10.5694/j.1326-5377.2003.tb05169.x

CCE. (2021). *About CCE*. Retrieved 17-12-2021 from https://cce.nl/about-ccev

The Concept System® groupwisdom™ [Web-based Platform] (2019). (Build 2019.24.01). Ithaca, NY. Available from https://www.groupwisdom.tech

de Boer, M. E., Depla, M., Frederiks, B. J. M., Negenman, A. A., Habraken, J. M., van Randeraad-van der Zee, C. H., Embregts, P., & Hertogh, C. (2018). Involuntary care—Capturing the experience of people with dementia in nursing homes. A concept mapping study. *Aging & Mental Health*, *23*(4), 498–506. https://doi.org/10.1080/13607863.2018.1428934

Donnelly, J. P. (2017). A systematic review of concept mapping dissertations. *Evaluation and Program Planning*, *60*, 186–193. https://doi.org/10.1016/j.evalprogplan.2016.08.010

Dyer, S. M., Harrison, S. L., Laver, K., Whitehead, C., & Crotty, M. (2018). An overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioral and psychological symptoms of dementia. *International psychogeriatrics*, *30*(3), 295–309. https://doi.org/10.1017/s1041610217002344

Feast, A., Moniz-Cook, E., Stoner, C., Charlesworth, G., & Orrell, M. (2016). A systematic review of the relationship between behavioral and psychological symptoms (BPSD) and caregiver well-being. *International psychogeriatrics*, *28*(11), 1761–1774. https://doi.org/10.1017/s1041610216000922

Gerritsen, D. L. (2021). Well-being in long-term care: An ode to vulnerability. *Aging & Mental Health*, *27*(2), 230–235. https://doi.org/10.1080/13607863.2021.2008869

Gerritsen, D. L., Smalbrugge, M., Veldwijk-Rouwenhorst, A. E., Wetzels, R., Zuidema, S. U., & Koopmans, R. (2019). The difficulty with studying challenging behavior. *Journal of the American Medical Directors Association*, *20*(7), 879–881. https://doi.org/10.1016/j.jamda.2019.01.148

Gresham, M., Morris, T., Min Chao, S., Lorang, C., & Cunningham, C. (2021). Specialist residential dementia care for people with severe and persistent behaviours: A ten-year retrospective review. *Australasian Journal on Ageing, 40*(3), 309–316. https://doi.org/10.1111/ajag.12964

Hanzen, G., van Nispen, R. M., van der Putten, A. A., & Waninge, A. (2017). Participation of adults with visual and severe or profound intellectual disabilities: Definition and operationalization. *Research in Developmental Disabilities*, *61*, 95–107. https://doi.org/10.1016/j.ridd.2016.12.017

Henskens, M., Nauta, I. M., Vrijkotte, S., Drost, K. T., Milders, M. V., & Scherder, E. J. A. (2019). Mood and behavioral problems are important predictors of quality of life of nursing home residents with moderate to severe dementia: A cross-sectional study. *PLoS One. 14*(12), e0223704. https://doi.org/10.1371/journal.pone.0223704

Iris, M., DeBacker, N. A., Benner, R., Hammerman, J., & Ridings, J. (2012). Creating a quality of life assessment measure for residents in long term care. *Journal of the American Medical Directors Association*, *13*(5), 438–447. https://doi.org/10.1016/j.jamda.2011.08.011

Kane, M., & Trochim, W. M. K. (2007). *Concept mapping for planning and evaluation*. Thousand Oaks: Sage Publications. http://site.ebrary.com/id/10333447

Keenan, J., Poland, F., Manthorpe, J., Hart, C., & Moniz-Cook, E. (2020). Implementing e-learning and e-tools for care home staff supporting residents with dementia and challenging behaviour: A process evaluation of the ResCare study using normalisation process theory. *Dementia (London, England)*, *19*(5), 1604–1620. https://doi.org/10.1177/1471301218803195

Klapwijk, M. S., Caljouw, M. A. A., Pieper, M. J. C., van der Steen, J. T., & Achterberg, W. P. (2016). Characteristics associated with quality of life in long-term care residents with dementia: A cross-sectional study. *Dementia and Geriatric Cognitive Disorders*, *42*(3–4), 186–197. https://doi.org/10.1159/000448806

Koch, J., Amos, J. G., Beattie, E., Lautenschlager, N. T., Doyle, C., Anstey, K. J., & Mortby, M. E. (2022). Non-pharmacological interventions for neuropsychiatric symptoms of dementia in residential aged care settings: An umbrella review. *International journal of Nursing Studies*, *128*, 104187. https://doi.org/10.1016/j.ijnurstu.2022.104187

Koopmans, R. T., Lavrijsen, J. C., & Hoek, F. (2013). Concrete steps toward academic medicine in long term care. *Journal of the American Medical Directors Association*, *14*(11), 781–783. https://doi.org/10.1016/j.jamda.2013.08.004

Koopmans, R. T. C. M., Leerink, B., & Festen, D. A. M. (2022). Dutch long-term care in transition: A guide for other countries. *Journal of the American Medical Directors Association*, *23*(2), 204–206. https://doi.org/10.1016/j.jamda.2021.09.013

Krein, S. L., Turnwald, M., Anderson, B., & Maust, D. T. (2022). "Sometimes it's not about the money… it's the way you treat people…": A qualitative study of nursing home staff turnover. *Journal of the American Medical Directors Association*, *23*(7), 1178–1184. https://doi.org/10.1016/j.jamda.2021.11.036

Livingston, G., Barber, J., Marston, L., Rapaport, P., Livingston, D., Cousins, S., Robertson, S., La Frenais, F., & Cooper, C. (2017). Prevalence of and associations with agitation in residents with dementia living in care homes: MARQUE cross-sectional study. *BJPsych open*, *3*(4), 171–178. https://doi.org/10.1192/bjpo.bp.117.005181

Moniz Cook, E. D., Swift, K., James, I., Malouf, R., De Vugt, M., & Verhey, F. (2012). Functional analysis-based interventions for challenging behaviour in dementia. *Cochrane Database of Systematic Reviews (Online)*, (2), Cd006929. https://doi.org/10.1002/14651858.CD006929.pub2

Nabitz, U., van Randeraad-van der Zee, C., Kok, I., van Bon-Martens, M., & Serverens, P. (2017). An overview of concept mapping in Dutch mental health care. *Evaluation and Program Planning*, *60*, 202–212. https://doi.org/10.1016/j.evalprogplan.2016.08.012

Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond person-centred care: A new vision for gerontological nursing. *Journal of Clinical Nursing*, *13*(3a), 45–53. https://doi.org/10.1111/j.1365-2702.2004.00926.x

Palm, R., Sorg, C. G. G., Strobel, A., Gerritsen, D. L., & Holle, B. (2018). Severe agitation in dementia: An explorative secondary data analysis on the prevalence and associated factors in nursing home residents. *Journal of Alzheimer's Disease*, *66*(4), 1463–1470. https://doi.org/10.3233/JAD-180647

Rapaport, P., Livingston, G., Hamilton, O., Turner, R., Stringer, A., Robertson, S., & Cooper, C. (2018). How do care home staff understand, manage and respond to agitation in people with dementia? A qualitative study. *BMJ Open*, *8*(6), e022260. https://doi.org/10.1136/bmjopen-2018-022260

Rasheed, S. P., Younas, A., & Sundus, A. (2019). Self-awareness in nursing: A scoping review. *Journal of Clinical Nursing*, *28*(5–6), 762–774. https://doi.org/10.1111/jocn.14708

Rutten, J. E. R., Backhaus, R., Tan, F., Prins, M., van der Roest, H., Heijkants, C., Hamers, J. P. H., & Verbeek, H. (2021). Work environment and person-centred dementia care in nursing homes—A cross-sectional study. *Journal of Nursing Management*, *29*(7), 2314–2322. https://doi.org/10.1111/jonm.13386

Selbaek, G., Engedal, K., & Bergh, S. (2013). The prevalence and course of neuropsychiatric symptoms in nursing home patients with dementia: A systematic review. *Journal of the American Medical Directors Association*, *14*(3), 161–169. https://doi.org/10.1016/j.jamda.2012.09.027

Trochim, W. M. K. (1989). An introduction to concept mapping for planning and evaluation. *Evaluation and Program Planning*, *12*, 1–16.

Van Voorden, G., Lips, M., Zuidema, S., Voshaar, R. C. O., Smalbrugge, M., Van Den Brink, A. M. A., Persoon, A., Koopmans, R. T., & Gerritsen, D. L. (2021). 423—Characteristics of specialized units for people with dementia and very severe challenging behavior in the Netherlands: A mixed method study. *International Psychogeriatrics*, *33*(S1), 45–45. https://doi.org/10.1017/S1041610221001824

Veldwijk-Rouwenhorst, A. E., Smalbrugge, M., Wetzels, R., Bor, H., Zuidema, S. U., Koopmans, R. T. C. M., & Gerritsen, D. L. (2017). Nursing home residents with dementia and very frequent agitation: A particular group. *American Journal of Geriatric Psychiatry*, *25* (12), 1339–1348. http://dx.doi.org/10.1016/j.jagp.2017.08.002

Veldwijk-Rouwenhorst, A. E., Zuidema, S. U., Smalbrugge, M., Persoon, A., Koopmans, R., & Gerritsen, D. L. (2022). 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. *BMC geriatrics*, *22*(1), 758. https://doi.org/10.1186/s12877-022-03438-0

Visser, S. M., McCabe, M. P., Hudgson, C., Buchanan, G., Davison, T. E., & George, K. (2008). Managing behavioural symptoms of dementia: Effectiveness of staff education and peer support. *Aging & Mental Health*, *12*(1), 47–55. https://doi.org/10.1080/13607860701366012

Winzelberg, G. S., Williams, C. S., Preisser, J. S., Zimmerman, S., & Sloane, P. D. (2005). Factors associated with nursing assistant quality-of-life ratings for residents with dementia in long-term care facilities. *The Gerontologist*, *45*(suppl_1), 106–114. https://doi.org/10.1093/geront/45.suppl_1.106

Younas, A., Rasheed, S. P., Sundus, A., & Inayat, S. (2020). Nurses' perspectives of self-awareness in nursing practice: A descriptive qualitative study. *Nursing & Health Sciences*, *22*(2), 398–405. https://doi.org/10.1111/nhs.12671