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Editorial

Behaviour that severely challenges in dementia care requires focused research

Debby L Gerritsen¹, Sjacko Sobczak², Marieke Perry¹, Ian Davies-Abbott³, Emma Wolverson⁴, Esme Moniz-Cook⁵

¹University Knowledge network for Older adult care Nijmegen (UKON); Department of Primary and Community Care, Research Institute for Medical Innovation, Radboudumc Alzheimer Center, Radboud university medical center, Nijmegen, the Netherlands
Debby.Gerritsen@radboudumc.nl
Marieke.Perry@radboudumc.nl

²Mondriaan Mental Health Center, Heerlen, Maastricht, the Netherlands; Research Center Innovations in Care, Rotterdam University of Applied Sciences (RUAS), Rotterdam, the Netherlands; Department of Neuropsychology and Psychopharmacology, Faculty of Psychology and Neuroscience, Maastricht University.
sjacko.sobczak@maastrichtuniversity.nl

³Faculty of Social & Life Sciences, Wrexham University, Wrexham, UK.
Ian.Davies-Abbott@wrexham.ac.uk

⁴The Geller Institute of Ageing and Memory, The University of West London, London, UK.
emma.wolverson@uwl.ac.uk

⁵University of Hull, Hull, UK
E.D.Moniz-Cook@hull.ac.uk

Email address of corresponding author: debby.gerritsen@radboudumc.nl

Behaviour that severely challenges in dementia care requires focused research

Behaviour that challenges is common in dementia (Selbaek et al., 2013) and can increase to very severe or even extreme and refractory levels that place an excessive burden on the person with dementia themselves, families, and professional caregivers. Despite its impact, behaviour that severely challenges has been understudied, resulting in a persistent lack of evidence-based knowledge and stagnation in care improvement. In this editorial, we argue that 'behaviour that severely challenges' among people with dementia should be a research priority and propose essential research avenues for better understanding this phenomenon and driving meaningful improvements in care and wellbeing.

Conceptualising Behaviour that Severely Challenges

In 1997, the International Psychogeriatric Association introduced the term Behavioural and Psychological Symptoms of Dementia (Finkel et al., 1997). Since then, alternative terms have emerged such as "neuropsychiatric symptoms", "responsive behaviours" and "distress". These constructs have all been examined and critiqued, yet this has not resulted in a consensus on terminology (James et al., 2021; Wolverson et al., 2019; Wolverson et al., 2021). In the absence of agreed terminology, for now, we use the term 'behaviour that challenges' because it reflects the caregiver experiences of behavioural changes associated with dementia (British Psychological Society, 2018). However, we do so, recognising the limitations and concerns associated with this term (Wolverson et al., 2019; Wolverson et al., 2021).

Regarding behaviour that severely challenges (or similar terms), a clear definition is currently lacking in literature. We propose the following working definition, based on our earlier studies; on a Dutch study among practice experts identifying distinguishing characteristics of behaviour that severely challenges (Timmermans et al., *subm*); and on subsequent discussions among our group: *"Behaviours that severely challenge in dementia represent all types of severe behavioural challenges which 1) are frequent (e.g. daily), persistent (over weeks) and/or markedly unpredictable; 2) cause substantial distress and pose a clear risk of danger or harm for the individual, others and/or their environment; and 3) are resistant to routine care approaches"*. For now, these behaviours are thus defined operationally by thresholds of frequency, intensity, and impact, and can be further understood along three key dimensions: severity, risk, and refractoriness. Examples include persistent screaming, continuous hitting or biting caregivers or oneself, and repeatedly making threats or frequently acting violently towards others. It negatively impacts quality of life in people with dementia and their families (Schmüdderich et al., 2021) and puts significant burden on care staff (Verhees et al., 2024). The needs of people with dementia within this subgroup remain difficult to understand and meet. Current responses lack the immediacy

required to effectively support individuals in acute and severe distress or have unacceptable side effects (Veldwijk-Rouwenhorst et al., 2022). Often, risk management strategies are activated such as restraint and seclusion, thus limiting the person's human rights such as autonomy and dignity (James et al., 2023), and possibly traumatising the person with dementia (Flannery, 2003). Such approaches may compromise care by overlooking person-centred responses including comprehensive support aimed at psychosocial and emotional wellbeing (Clarke & Mantle, 2016). This raises important questions about how we can improve care and wellbeing for this specific group. Therefore, in this editorial, we consider key studies of prevalence and characteristics of behaviour that severely challenges, its impact on care and caregiver responses, and propose a focused research agenda to advance the field beyond descriptive accounts of behaviours that challenge toward a clinically actionable understanding of these behaviours.

Heterogeneity Shapes the Study of Behaviour that severely challenges

The need to clearly position this subject within the international research field is underscored by the marked heterogeneity in manifestations and underlying factors, which makes behaviour that severely challenges difficult to define, assess, and compare across studies. To our knowledge, the only framework published is that of Brodaty et al. (2003) who proposed a seven-tiered dementia clinical framework for behavioural and psychological symptoms of dementia with tiers 5-7 estimated as severe (10%), very severe (1%) and extreme (rare) behavioural and psychological symptoms. This tiered model has been used in Australian dementia units for policy purposes and recently for categorizing patient groups into non-severe (tiers 1-4) and severe behavioural and psychological symptoms (tiers 5-7) in a descriptive study (Djekovic et al., 2022). Although the framework currently is too general to function as a guidance tool for behavioural approaches in behaviour that severely challenges, it may be applicable and operationalizable in further conceptual research.

To examine prevalence, frequency and patterns of behaviour that severely challenges, most of the existing literature defines and studies "severe" behaviour using measurement tools and score thresholds, rather than a clear conceptual framework. Prevalence data in long-term care settings varies significantly, which may at least partly be explained by the use of various descriptions of the group under study and applied measurement instruments. A UK study of 2185 care home residents found that 37.7% were reported with severe behavioural challenges on the 25-item Challenging Behaviour Scale where several groups of behaviour such as agitation, disinhibition and aggression could be seen in a person (James et al., 2017). In Germany, severe agitation was observed in 6.3% of residents using several items of the Neuropsychiatric Inventory (NPI) (Palm et al., 2018). In the Netherlands, very frequent agitation, physical aggression, and vocalizations were reported at rates of 7.4%, 2.2%, and 11.5%, respectively,

using high scores on various item groups of the Cohen-Mansfield Agitation Inventory (Veldwijk-Rouwenhorst et al., 2017; Veldwijk-Rouwenhorst et al., 2021). In Norway, total NPI scores were used in longitudinal studies spanning five and twelve years to track behaviour that severely challenges overtime (Vik-Mo et al., 2018; Vik-Mo et al., 2020). Importantly, the authors of these various papers highlight limitations in using standardised scales to define or fully understand the complexity of these behavioural challenges.

For those with severe behavioural challenges, etiology (i.e. Lewy body, Parkinsons and frontotemporal dementia) may contribute to presentations, but this does not apply to people with Alzheimer's or Vascular dementia (Cognat et al., 2023). Overall, the exhibited behaviour is heterogeneous, and a person can show several types of behaviour simultaneously (James et al., 2017; van Voorden, Koopmans et al., 2025). Furthermore, their care needs can vary widely. Many have significant pre-morbid psychiatric or post traumatic conditions (Havermans et al., 2024; van Voorden, Koopmans et al., 2025), and many are approaching the end of their life (Gallop et al., 2025; van Voorden, Oude Voshaar, et al., 2025; Van den Bulcke et al., 2024; Wolverson et al., 2024). This heterogeneity makes behaviour that severely challenges not only difficult to define and operationalise; it also makes it difficult for caregivers to understand and respond to.

The Need for Practice-Based Research

In regular dementia care contexts, caregivers (both professionals and family members) encounter considerable complexity, yet behaviours that severely challenge and the most effective responses to them remain insufficiently understood. Caregivers often find the behaviour itself particularly challenging due to its nature (e.g. aggression), course (constantly present or varying in frequency), intensity and unpredictability, where for some the triggers for the behaviour are unclear. Sometimes they consider the behaviour as intentional, which reduces its acceptability (Veldwijk-Rouwenhorst et al., 2022) and potentially undermines use of helpful management strategies.

Behaviour that severely challenges often has a disruptive impact on the care environment. Increased stimulus levels (e.g. noise), and very extensive time investment and attention from staff are common. The behaviour also negatively affects others living in the facility, sometimes resulting in incidents of violence and aggression towards other residents (Ferrah et al., 2015). Caregivers may also suffer physical injuries (Edmans et al., 2022) or experience emotional distress and feelings of helplessness due to their limited ability to intervene effectively (Kim et al., 2025; Veldwijk-Rouwenhorst et al., 2022; Zwijsen et al., 2014). Inadequate communication and collaboration within monodisciplinary or multidisciplinary care teams and relatives can

further exacerbate these situations up to a point where relationships and trust between those involved are severely compromised. For example, inadequate care and ineffective treatment in cases of people with severe behavioural challenges can result in support becoming untenable in regular dementia units (Veldwijk-Rouwenhorst et al., 2022; Verhees et al., 2024). Consequently, individuals may be rejected from care homes, bounced around the health-care system and have increased (long duration) hospital admissions (Atee, et al., 2025).

Given the intensity of care and treatment required, behaviour that severely challenges is increasingly managed in specialised settings that provide intensive multidisciplinary care. These include specialist mental health wards dedicated to dementia (Jones et al., 2023), or general older adult mental health wards in the UK (Royal College of Psychiatrists, 2019); short-term, specialized inpatient Challenging Behaviour Units designed to manage acute behaviour that severely challenges in France (Rouch et al., 2017); highly specialized temporary treatment units within a nursing home that serve a regional function in the Netherlands (van Voorden et al., 2024); and specialist dementia care accommodation in Australia (Atee et al., 2025). Currently, there is limited evidence on the effectiveness of approaches used in these settings to address and manage behaviour that severely challenges, underscoring the need for international practice-based research.

Care Gaps as a Starting Point: Towards Contextual Interventions

A person-centred approach emphasises understanding and addressing underlying causes of behaviour, often through individually tailored interventions aimed at meeting unmet needs. While this approach is essential, in our view, behaviour that severely challenges presents difficulties extending beyond person-centred strategies that are focused only on the needs of the person with dementia; it requires strategies addressing the needs of caregivers. Professional staff find it particularly difficult to find a balance between care and setting boundaries (van Voorden et al., 2023). Even for nursing staff working in specialized units who have specific knowledge and skills, such as reflectiveness on one's own behaviour and being able to cope with stressful situations (van Voorden et al., 2024), severe behavioural challenges remain a source of substantial distress, affecting work with one in four people admitted to these units (van Voorden, Koopmans, et al., 2025). This is concerning, particularly given the significant known difficulties of staff recruitment and retention in mental health care services (Long et al., 2023).

It is known that good dementia care and treatment are not possible without explicitly addressing the needs of caregivers (Hazelhof et al., 2016; McPherson et al., 2016; Partridge et al., 2025; Wolverson et al., 2023). For example, the relationship between the family caregiver and the person with dementia, and the caregiver's own personality

or management style are all important considerations (Chunga et al., 2021; Baharudin et al., 2019; De Vugt et al., 2004) as is staff anxiety (Moniz-Cook et al., 2000). When caring for a person with behaviour that severely challenges, caregivers are even more required to act as key change agents in balancing the powerful emotionally charged situations that often occur.

We argue that care should be understood within a network of the person with dementia, involved care professionals, and informal caregivers, and that a single care professional cannot represent the different perspectives of the care team members; each caregiver should be understood if care is to be tailored to both the person and the caregiver's needs. Then, care gaps can serve as a starting point for developing contextual interventions in behaviour that severely challenges and providing evidence on effective care approaches.

Research priorities

People with dementia who exhibit behaviour that severely challenges represent a particularly vulnerable group whose needs are difficult to understand and address. We have outlined studies among this group and identified key points relating to definitional lack of clarity, heterogeneity of the group requiring high levels of skilled individualisation of care, the importance of caregivers' own needs and of specialised settings and highly skilled multidisciplinary staff teams (e.g. Atee et al., 2025). These findings represent important areas of future research. Building on the perspective that care gaps offer a concrete starting point, we advocate that the complexity of caring for persons with dementia and behaviours that severely challenge requires research that crosses paradigm borders. Research is needed that combines medical and social scientific expertise with that of the humanities, especially ethics. For the coming years, we selected the following three areas as research priorities:

To start with, psychometric studies into suitable measurement tools based on a clear conceptual framework are needed. In addition to research on the adequate assessment of the specific features of severe behaviour challenges, we advocate a nuanced approach to measurement outcomes that extends beyond behavioural reduction alone. In our view, behavior that severely challenges can be so difficult to reduce that the primary aim of treatment and care may evolve into acceptance and ongoing support, requiring alternative outcome measures. Also, since research has shown that care professionals can also consider treatment successful when they evaluate the quality of the treatment process itself as high (van Voorden et al., 2023), effect measures may be developed that address the quality of the care and treatment process.

Second, intervention trials and implementation studies into care approaches are needed. These should evaluate how current approaches can benefit from principles of

other care domains such as palliative care (Wolverson et al. 2024), recovery oriented care (Anthony, 1993), trauma informed care (Cations et al., 2021; MacRae et al., 2023; Couzner et al., 2022), and presence and relation based care (Timmerman & Baart, 2022). These studies should focus on what works, for whom, and in what circumstances, and should adopt a network approach addressing the needs of both people with dementia and those who care for them.

Thirdly, ethical considerations need prompt attention. Various care and treatment approaches raise ethical questions, for instance regarding the tension between wellbeing, (relational) autonomy, coercion and beneficence/safety among all involved. Examples are pharmacotherapy, which is highly common in care and a huge area of (psychiatric) research but also controversial, as well as tent beds (Kroll et al., 2020; van Wijngaarden 2025) and Electro Convulsive Therapy (Lapid et al., 2024). This is also the case for environmental requirements and technological advances, such as wearable sensor-based products (MacFarlane et al., 2025; Han et al., 2025) and monitoring devices, which may encounter resistance.

To conclude, behaviour that severely challenges represents an extreme expression of distress in people with dementia and poses significant challenges for individuals, caregivers, and care systems. Improving care and treatment for this group requires humane (van Wijngaarden, 2025), and evidence-informed responses that recognise the complexity of behaviour and the central role and needs of caregivers. These need to be based on cross paradigm and cross sector initiatives that do justice to the complexity of supporting the wellbeing of those involved. Cross-sector collaborations are needed between academia, clinical providers, and government bodies to translate research findings into implementable guidelines, education materials and practical tools and also to prioritize resource allocation for specialized staffing and environmental modifications. Advancing understanding and support for behaviour that severely challenges may not only improve care and treatment for those most severely affected but also offer valuable insights for addressing behaviours that challenge across the broader spectrum of dementia care.

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