

COMMENTARY

Like beauty and contact lenses, the meaning of dementia behavioral changes is in the eyes of the beholder

Dementia, called Major Neurocognitive Disorder in the DSM-5, is a syndrome associated with progressive and irreversible decline of brain functioning, leading inevitably to dependent on others to perform activities of daily living. Dementia can be the result of a variety of diseases, but 60–70% of the cases are caused by Alzheimer's disease (AD). Recent epidemiological estimations suggest that the number of people living with dementia worldwide will increase from about 55 million today to approximately 78 million in 2030 and 139 million in 2050 (World Health Organization, 2022).

Although the main clinical manifestation of dementia is a significant decrease in cognitive functioning (thinking, remembering, and reasoning), most individuals with the diagnosis also display noncognitive symptoms at some stage of the disorder. These are commonly referred to as behavioral and psychological symptoms of dementia (BPSD) and may be classified into four clusters: psychosis (delusions and hallucinations), affective syndrome (anxiety and depression), psychomotor syndrome (agitation, aberrant motor behavior, irritability), and mania (euphoria, disinhibition, apathy). A recent systematic review based on 30 cross-sectional studies showed that the prevalence of BPSD in the community ranged from 4% (for mania disturbances) to 56% (for anxiety), depending on the type and severity of dementia and the behavior examined (Kwon and Lee, 2021). Higher rates were reported by other reviews, including longitudinal studies and those conducted in acute care and long-term institutions. Overall, it is estimated that up to 90% of people living with dementia display at least one type of BPSD during the course of their illness.

Such extremely high prevalence rates are worrisome especially given the harmful consequences of BPSD. These include decreased quality of life and quality of treatment and increased distress and health deterioration of both people living with dementia and their caregivers. Other negative effects of BPSD include increased stigma, frequent hospitalization, and early institutionalization. Clarifying the causes and the meaning of BPSD is, therefore, crucial for preventing, managing, and reducing their economic and emotional costs (Burley *et al.*, 2020).

Recent studies have started moving away from an understanding of BPSD as a series of pathophysiological changes in the brain to the recognition that it involves a complex interaction between biological, psychological, and social factors (Werner *et al.*, 2022). Today, three main models are used to explain BPSD: (a) the *unmet needs model* (also called the *need-driven, dementia-compromised behavior model*) conceptualizes BPSD as the manifestation of distress provoked by physical or psychological needs (such as pain or loneliness) that the person with dementia is unable to communicate and satisfy, often as a result of caregivers' inability to understand them (Cohen-Mansfield, 2000); (b) the *behavioral/learning model* postulates that BPSD is the result of a conditioning process emerging in response to environmental triggers, especially caregivers reinforcing disruptive behavior. This model led to the development of the Antecedent-Behavior-Consequence (A-B-C) approach for the management of BPSD which seeks to identify and reduce the antecedents by providing adequate responses; (c) the *environmental vulnerability/reduced stress-threshold model* explains the manifestation of BPSD as a reaction to discrepancies between the needs and capacities of the person with dementia and the over- or understimulating environment (Cohen-Mansfield, 2000).

These psychosocial models for the understanding and treatment of BPSD are not mutually exclusive and are all based on a person-centered approach. Dementia person-centered care, initiated by Kitwood (1997), proposes to expand the reductionist biomedical view of dementia through a holistic perspective aimed at improving the quality of life and care of people with dementia based on their remaining strengths, individual needs, values, and preferences. Yet, the well-being of people with dementia is closely tied to that of their caregivers, especially when dealing with the onset of BPSD, which is closely related to caregivers' distress and burden. Recently, dementia person-centered care has been expanded into a "relationship-centered" approach that includes the views and preferences of the person with dementia and the caregiver, their relationship, and communication patterns (Mohr *et al.*, 2021). The work by Burley *et al.* (2022) is

one of the few studies that adopt this much-needed approach.

Using a qualitative design, these authors explored the opinions of people with dementia and their caregivers about behavioral changes, their management, and the terminology used to label them. This is a timely study of both scientific and clinical importance. It shows that except for a general agreement about the lack of knowledge, awareness, and empathy toward people with dementia and their caregivers, study participants expressed different views about behavioral changes and their management. This finding, supported by a previous bi-national study examining the meaning of fear for different stakeholders (Werner *et al.*, 2021), suggests that before choosing the adequate intervention to reduce the noxious effects of behavioral changes, it is necessary to consider the unique causes for their manifestation, as well as the characteristics, perceptions, and preferences of both caregivers and carereceivers.

Although Burley's publication focuses on people with dementia and their caregivers in the community, the topic applies also to long-term care facilities. It has been consistently documented that, likely as a result of the severity of the disorder, the prevalence of BPSD is higher in people with dementia in nursing homes than in the community. Applying patient-centered care practices to manage BPSD is challenging and complicated in these settings because of difficulties at the facility level (lack of resources and staff turnover), staff level (high levels of caregivers' stress), resident level (advanced cognitive impairment and communication difficulties), and family level (lack of knowledge about the severity of the situation and lack of understanding of care practices) (Sefcik *et al.*, 2020). Examining how the views and preferences of those involved in providing care and support to nursing home residents can be integrated with care plans for managing BPSD is of utmost importance. A promising approach to reducing the manifestations of BPSD in various settings is the Describe, Investigate, Create, and Evaluate model (Kales *et al.*, 2015), which incorporates inputs from family and professionals, but it does not solicit input from the person living with dementia.

Another important question raised by Burley and colleagues is whether the views of people with dementia and their caregivers about BPSD vary with the type of dementia, with any particular symptom, or both. Although similar manifestations of BPSD have been reported in different types of dementia (Schwertner *et al.*, 2022), given the differences in their complexity, the degree of disturbance, and the challenges involved in their management, it

is reasonable to expect different views for different situations and realities.

Burley and colleagues also addressed the terminology used by people with dementia and their caregivers to describe behavioral changes. Language shapes the way we conceptualize, perceive, and feel the world and other people. The choice of language or terminology we use can either empower or undervalue the identity, self-esteem, and behavior of a person, and intentionally or unintentionally generate or perpetuate the stigma ascribed to a person or a group with a disease or disability (Werner *et al.*, 2022). This is especially true in the case of BPSD. In the last years, we have witnessed social media campaigns identified under the tag #BanBPSD calling to avoid the use of this umbrella term because of its strong association with a biomedical rather than a person-centered philosophy, leading to the overuse of chemical and physical restraints and reinforcing stigmatic beliefs about people with dementia and their family caregivers (Cunningham *et al.*, 2019; Warren, 2022). By examining the preferred terminology used by people with dementia and their caregivers, Burley *et al.* confirm the findings of a few others that BPSD is not the term of choice of caregivers despite being the one most commonly used in clinical settings (Gilmore-Bykovskiy *et al.*, 2020; Wolverson *et al.*, 2022).

In sum, the complexity of the treatment and care of dementia became generally accepted in the last years, leading to the need for an individualized, relationship-centered approach. At the NIH Alzheimer's Disease Research Summit in 2018, more than 80 experts in the area recommended that the main strategy to be implemented until 2025 should be to individualize and differentiate the treatment provided to people with dementia according to their characteristics. The discussions and recommendations at this meeting, however, concerned only the use of precision medicine, concentrating fully on biological and genetic characteristics to tailor prevention and care to the needs of the person (NIH, 2022). In 2019, the Alzheimer's Association convened the Dementia Care Provider Roundtable to clarify and define how to provide person-centered care specifically for BPSD (Fazio *et al.*, 2020). Twenty-three experts produced five practice recommendations to implement a person-centered approach in the community and in long-term institutions, conceptualizing changes in behavior as expressions of needs, stressing the requirement to examine antecedents, and displaying clinical and administrative flexibility before implementing rigorous identical protocols to different individuals. The group also recommended changing the use of the

terms “BPSD” and “challenging behaviors” to “behavioral expressions of dementia.”

The study by Burley and colleagues adds to this new initiative by supporting the adoption of a person-centered research and clinical approach in dementia in general and in the management of BPSD in particular. The authors should be commended for conducting one of the few published studies allowing persons with dementia and their caregivers to express their needs and preferences in their own voices.

Conflict of interest

None.

Description of author's role

PW conceptualized, wrote, read, revised, and approved the submitted version.

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References

- Burley, C. V., Casey, A. N., Chenoweth, L. and Brodaty, H.** (2022). Views of people living with dementia and their families/care partners: helpful and unhelpful responses to behavioral changes. *International Psychogeriatrics*, 35, 77–93. <https://doi.org/10.1017/S1041610222000849>.
- Burley, C. V., Livingston, G., Knapp, M., Wimo, A., Norman, R. and Brodaty, H.** (2020). Time to invest in prevention and better care of behaviors and psychological symptoms associated with dementia. *International Psychogeriatrics*, 32, 567–572. <https://doi.org/10.1017/S104161022000037X>.
- Cohen-Mansfield, J.** (2000). Theoretical frameworks for behavioral problems in dementia. *Alzheimer's Care Quarterly*, 1, 8–21. https://hsrc.himmelfarb.gwu.edu/sphhs_prev_facpubs/451
- Cunningham, C., Macfarlane, S. and Brodaty, H.** (2019). Language paradigms when behaviour changes with dementia: #BanBPSD. *International Journal of Geriatric Psychiatry*, 34, 1109–1113. <https://doi.org/10.1002/gps.5122>.
- Fazio, S. et al.** (2020). What is really needed to provide effective, person-centered care for behavioral expressions of dementia? Guidance from the Alzheimer's association dementia care provider roundtable. *JAMDA*, 21, 1582–1586. <https://doi.org/10.106/j.jamda.2020.05.017>.
- Gilmore-Bykovskiy, A., Mullen, S., Block, L., Jacobs, A. and Werner, N. E.** (2020). Nomenclature used by family caregivers to describe and characterize neuropsychiatric symptoms. *The Gerontologist*, 60, 896–904. <https://doi.org/10.1093/geront/gnz140>.
- Kales, H. C., Gitlin, L. N. and Lyketsos, C. G.** (2015). Assessment and management of behavioral and psychological symptoms of dementia. *BMJ*, 350, h369. <https://doi.org/10.1136/bmj.h369>.
- Kitwood, T. M.** (1997). *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press. <https://bit.ly/34eQlkj>
- Kwon, C. H. and Lee, B.** (2021). Prevalence of behavioral and psychological symptoms of dementia in community-dwelling dementia patients: a systematic review. *Frontiers in Psychiatry*. <https://doi.org/10.3389/fpsy.2021.741059>.
- Mohr, W. et al.** (2021). Key intervention categories to provide person-centered dementia care: a systematic review of person-centered interventions. *Journal of Alzheimer's Disease*, 84, 343–366. <https://doi.org/10.3233/JAD-210647>.
- National Institutes of Health.** (2022). Recommendations from the NIH AD research summit 2018. Available at: nia.nih.gov/research/administration/recommendations-nih-ad-research-summit-2018; last accessed 30 November 2022.
- Schwertner, E. et al.** (2022). Behavioral and psychological symptoms of dementia in different dementia disorders: a large-scale study of 10,000 individuals. *Journal of Alzheimer's Disease*, 87, 1307–1318. <https://doi.org/10.3233/JAD-215198>.
- Sefcik, J. S. et al.** (2020). Person-centered care plans for nursing home residents with behavioral and psychological symptoms of dementia. *Journal of Gerontological Nursing*, 46, 17–27. <https://doi.org/10.3928/00989134-20201012-03>.
- Warren, A.** (2022). Behavioral and psychological symptoms of dementia as a means of communication: considerations for reducing stigma and promoting person-centered care. *Frontiers in Psychology*, 13, 875246. <https://doi.org/10.3389/fpsyg.2022.875246>.
- Werner, P., Ulitsa, N., Shepheth, D., Abojabel, H., Alpinar-Sencan, Z. and Schickltanz, S.** (2021). Fear about Alzheimer's disease among Israeli and German laypersons, persons with mild neurocognitive disorder and their relatives: a qualitative study. *International Psychogeriatrics*, 33, 1019–1034. <https://doi.org/10.1017/S1041610220003397>.
- Werner, P., Vermeulen, P., Van Gorp, B. and Simonsen, P.** (2022). From history to intervention: a socio-cultural analysis of dementia stigma. In: M. Vandenbulcke, R. M. Dröes and E. Schokkaert (Eds.), *Dementia and Society: An Interdisciplinary Approach* (pp 25–42). Cambridge: Cambridge Press.
- Wolverson, E., Moniz-Cook, E., Dunn, R. and Dunning, R.** (2022). Family carer perspectives on the language of behavior change in dementia: an online mixed methods survey. *Age and Ageing*, 51, afac047. <https://doi.org/10.1093/ageing/afac047>.
- World Health Organization.** (2022). Facts sheets of dementia. Available at: <https://www.who.int/news-room/factsheets/detail/dementia>; last accessed 20 November 2022.