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COMMENTARY

Moving toward more person-centered dementia care

By 2030, more than 83 million people worldwide are expected to be living with dementia (World Health Organization, 2020). Despite the significant growth in persons living with this disease and prioritization of federal research funding to study Alzheimer's disease and related dementias, the voice of patients with dementia is too often missing in research (Dementia Action Alliance, 2016; Hung *et al.*, 2017). There remains an unfortunate misperception that given the cognitive decline associated with dementia, persons living with dementia cannot consent or contribute to clinical research. This stigma has led to the exclusion of persons living with dementia from participating in research trials (Howe, 2012). While cognitive changes such as memory loss and communication difficulty can impair the ability to provide informed consent in advanced stages of the illness, persons with dementia can contribute meaningfully. However, historically the voices, opinions, and preferences of persons with dementia are not routinely assessed, included, or prioritized in research.

Additional concerns have been raised that research outcomes studied do not adequately reflect the actual priorities of persons living with dementia (Dementia Action Alliance, 2016). Proxies such as care partners and providers are often asked to infer what patients with dementia "would want" to inform research priorities. Performing research about dementia without incorporating the actual perspectives and priorities of persons living with the disease is a disservice and can lead to faulty assumptions about what matters most to patients themselves. This can lead to bias in research results as previous studies demonstrate that both care partner and provider perspectives may be dissimilar from what patients with dementia themselves want or prioritize (Innes *et al.*, 2016; Wilkins *et al.*, 2020).

In order for dementia care and research to become truly person-centered, providers, researchers, and policy-makers must seek and incorporate the critical perspectives of people living with dementia (Hanson *et al.*, 2020). Numerous professional organizations, funding bodies, and dementia advocacy groups have urged for the involvement of persons living with dementia and care partners in all stages of research including advising on research priorities, serving on advisory boards for research planning, and ensuring equitable participation in research studies (Dementia Action Alliance, 2016; Bethell *et al.*, 2018, Hanson *et al.*, 2020). The majority of studies focused on preferences for care in dementia have historically been limited to advance care planning and treatment preferences surrounding end-of-life care decision-making (Dening *et al.*, 2013). While important, this discussion generally has little focus on what matters most to patients in terms of their day-to-day interactions and during earlier stages of their disease.

The paper in this month's issue by Wilkins and colleagues (2022) presents an important step forward in addressing what matters most to persons with living dementia. In the study described, the authors used the Preferences for Everyday Living Inventory (Van Haitsma *et al.*, 2013), a validated assessment tool, which has been used to evaluate preferences among both community-dwelling older adults and nursing home residents. The authors specifically evaluated four domains of preferences thought to be important for persons with cognitive impairment. These domains included autonomous choice, social engagement, personal growth, and keeping a routine.

Among 62 community-dwelling participants with either mild cognitive impairment or early dementia, they found that social engagement was ranked as the most important domain. This was followed by the domains of autonomous choice, personal growth, and keeping a routine. Social engagement was defined as regular contact with family, meeting new people, and volunteering. Additionally, the authors found that the female gender was significantly associated with ranking higher importance of social engagement. Further, the presence of depressive symptoms as detected on the Geriatric Depression Scale-15 score was associated with lower rated importance of social engagement. Previous work by the study team suggested that care partners tended to significantly underestimate the importance of social engagement preferences for persons with cognitive impairment (Wilkins *et al.*, 2020).

As the authors highlight, the study population had limited racial, ethnicity, and educational diversity and was confined to community-dwelling older adults, which may limit the generalizability of the

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findings to more diverse populations. The addition of a control group without cognitive impairment, inclusion of noncommunity-dwelling participants, and gaining the perspective of patients with more moderate severity of illness would allow for greater insight into potential variations in preferences across treatment settings and dementia disease severity.

The Preferences for Everyday Living Inventory assessment provides a potentially useful approach for both community-dwelling and institutionalized older adults to assess persons living with dementia preferences. Rather than relying on care partner reports alone, using the Preferences for Everyday Living Inventory could help providers, facilities, care partners, and researchers to identify preferences that are most important to persons living with dementia. For example, for persons living with dementia who most value social engagement, this information can be helpful in informing treatment decisions for providers, such as avoiding the use of medications that can increase sedation, decrease communication, or worsen confusion – all situations that could impede social connection. For facilities, such information could help to align resident activities with those that are most meaningful for the patient. For care partners, continuing to engage, involve, and help foster relationships for persons with dementia can help build and maintain these social connections. The importance of this preference is particularly heightened in the setting of the COVID-19 pandemic where older adults and those with dementia have been particularly at risk of social isolation. Involvement of care partners to help provide technical support to encourage social connection during video chat, text messaging, and video streaming can help to preserve these desired connections. Finally, any future research intervention focused on improving the quality of life for persons with dementia will be far more likely to be impactful when it incorporates the actual preferences of persons with living with dementia themselves.

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Conflict of Interest

The authors have no conflicts of interest.

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