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The Voices of Persons Living With Dementia

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Invited Perspective

The Voices of Persons Living With Dementia

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In the second decade of the 21st century, the importance of the patient voice in designing and providing healthcare has been increasingly recognized. Initiatives that plan care around meeting patient preferences, such as priority care,[1] and goal-oriented care,[2] including for persons living with dementia (PLWD),[3] are gaining more attention. Input from individuals living with diseases has also extended to the framing and conduct of clinical research, especially that funded by the Patient-Centered Outcomes Research Institute (PCORI).[4]

When convening the 2017 National Research Summit on Care, Services, and Support for Persons with Dementia and their Caregivers, the US Department of Health and Human Services deliberately included PLWD as one of six stakeholder groups involved in the planning and conduct of this meeting; six members of this group also participated in the Summit as panelists. Inclusion of their voices in a meeting of this stature broke new ground with potential for high impact. Nevertheless, the participation of PLWD carried considerable risk, including the progression of disease during the time period from planning the Summit to finalizing the recommendations, the possibility of drawing increased attention to PLWD's cognitive losses with consequent adverse effects on mood and well-being, the logistics of travel, and the need to reduce the stimulus generated by a large meeting in an unfamiliar space.

The papers by Frank et al.,[5,6] in this issue chronicle the experience and impact of successfully including PLWD in the 2017 Summit. The lessons learned generated a "best practices" guide for future inclusion in research planning conferences. Although the participants had mild or moderate disease, there were several challenges (e.g., difficulty understanding the initial recommendations and with a self-evaluation process that included answering questionnaires) that required adaptations, technology solutions (e.g., videoconferencing), monitoring the process and the state of individual participants by a Leadership Committee, and on-site special accommodations. Despite these challenges, PLWD found the experience meaningful. Yet they expressed some disappointment that they were not involved in as many dissemination activities as expected.

This inclusion process, while successful, had limitations. As the authors note, the personal experiences

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of the participants resulted in emphasis on research recommendations addressing dementia early in the disease. Some of the experiences of earlier stage PLWD are heart-wrenching with delays in diagnosis, stigmatism, disruption of their work, depression, strain with family, and fear of the likely further decline. Their recommendations included knowing more about the progression of disease, including behavior and psychological symptoms, and research on what kind care will be most beneficial for them. This input was invaluable in generating recommendations for research that will lead to better outcomes that matter to them.

Nevertheless, the voice of those who participated used for the 2017 Summit is not that of persons living with severe dementia, who could not be included in the process because of limited cognition, insight, or ability to participate in a longitudinal process. This subgroup of PLWD may face a different set of challenges, including inability to find a place to live because of behavior or psychological complications, abuse or neglect by those who have loved them but whose stress has now exceeded their capacity for caregiving, and deciding when to switch to palliative or hospice care. Their voices must be conveyed by surrogates, most of whom are their caregivers. When included as stakeholders, however, caregivers are generally asked about their perspectives about caregiving burden. Yet, caregivers and other surrogates need to serve an equally important role-giving voice to the patient's point of view. This perspective can be constrained by the difficulty in understanding the impact of specific symptoms. In advanced dementia, the PLWD may exhibit symptoms that appear bothersome (e.g., repetitive questions and behaviors) or horrid (e.g., agitation, or screaming). Some, such as folding towels in a supervised setting, may actually be soothing whereas others may indicate ongoing anguish. How much distress do various symptoms cause in persons with very advanced dementia? At present, there is little insight beyond what can interpreted from the perspective of an observer with normal cognition (i.e., how would we feel if we had these symptoms?).

Obtaining the full range of diverse voices of PLWD will be extremely difficult. Frank et al. are to be congratulated on taking an important first step in meeting this challenge but more will need to follow. So much more to listen to. . .and respond.

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