

## LETTER

# Measurement to improve care and outcomes for persons with Alzheimer's disease and dementia

To the Editor:

Translational research and clinical interventions in Alzheimer's and dementia embrace basic science, clinical studies, and diversity, inclusion, and health equity.<sup>1</sup> Measurement is critical in all areas, but is especially lacking in the psychosocial realm; in fact, both the 2017 and 2020 National Research Summits on Care, Services, and Supports for Persons with Dementia and their Caregivers stressed the need to develop person-centered measures suitable for heterogeneous populations to better assess care and outcomes.<sup>2,3</sup> Although numerous measures have been recommended for psychosocial research,<sup>4</sup> their limitations are numerous, including time demands for administration<sup>5</sup> and that most are based on a medical model, focus on deficits rather than strengths, were not developed with input from persons living with dementia, are not relevant as the disease progresses or in all care settings, rely on informant reports, are not oriented toward quality improvement, and do not exist for numerous domains.

The concept of domain-specific measurement can be appreciated using a simple example: the measurement of "well-being." Conceptually, well-being can be differentiated in relation to emotional well-being (e.g., positive affect), psychological well-being (e.g., self-determination), social well-being (e.g., belonging), and life satisfaction (e.g., valuing life),<sup>6</sup> – but the specific items may differ depending on the domain under study. The Alzheimer's Association's Dementia Care Practice Recommendations (DCPR) include nine domains,<sup>7</sup> for which well-being would be differently measured based upon the domain: well-being related to detection and diagnosis might best be measured in relation to an individual's ability to accept the diagnosis, whereas well-being related to activities of daily living might best be measured in relation to independence in toileting.

Measurement is also needed to guide and evaluate care, and this is an area largely overlooked in dementia care measurement (e.g., two recent papers focusing on nonpharmacological care for behavioral expressions pointed out that evidence-based care practices lack protocols for administration in daily life).<sup>8,9</sup> The absence of protocols means that caregivers do not have guidance to implement or monitor evidence-based practices, and so are hindered in optimal care provision. The Table 1 below lists the nine DCPR recommendations, example care measures needing development, and domain-specific outcome measures.

In recognition of the need for improved measurement, the National Institute on Aging funded the Alzheimer's Association's LINC-AD – *Leveraging an Interdisciplinary Consortium to Improve Care and Outcomes for Persons Living with Alzheimer's and Dementia* (LINC-AD). Key to this effort is use of the DCPR as a structure around which to organize a thorough review of existing and needed measurement tools to advance psychosocial research, papers of which are being published in a special collection in *Alzheimer's & Dementia: Translational Research & Clinical Interventions* (TRCI). To expand on this effort, TRCI has put forth a Call for Papers on Key Issues in Measurement, hoping to include topics such as person-centered measures that foster a constructive balance between strengths and deficits assessment; evidence-based tools to guide structures and processes of care; community-centric measures and measures for long-term care and international use; measures recognizing diversity and issues of racism, stigma, and discrimination; and stakeholder engagement in measurement development. Already, the special collection includes papers on reconsidering frameworks for dementia care,<sup>10</sup> measures for dementia care planning,<sup>11</sup> and person-centered assessment;<sup>12</sup> a paper on environmental assessment tools is currently in press.<sup>13</sup> Upcoming papers will overview and evaluate measures related to detection and diagnosis and activities of daily living; discuss goal attainment scaling as a person-centered measurement tool useful across individuals and the course of the disease; address recruitment and engagement in dementia research; and explore the operationalization of person-centered care in practice. As an additional effort to promote new measurement development, the Alzheimer's Association is issuing a series of request for research applications on Advancing Research on Care and Outcome Measurement (ARCOM).

LINC-AD encourages the development and use of outcome measures and measures that guide care provision related to the DCPR and embrace five key constructs.

- In both types of measures, person-centeredness is key; care provision and outcome must be relevant and important to, and desired by, persons living with dementia and their caregivers.<sup>14,15</sup>
- Measurement must reflect a strengths-based focus, moving away from the concept of dementia as a negative medicalized experience to one that reflects ongoing abilities to engage, learn, contribute, and have efficacy and quality to life.<sup>10</sup>

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**TABLE 1** Alzheimer's Association dementia care practice recommendation domains<sup>7</sup> and example care and "well-being" measures

Domain	Example measure of care	Example measure of well-being outcome
Detection and diagnosis	Make information available to older adults and family members	Accept diagnosis
Assessment and care planning	Perform regular, comprehensive, person-centered assessments	Be satisfied with care choices
Medical management	Create and implement a person-centered plan for possible medical and social crises	Feel comfort regarding advance care planning
Information, education, and support	Use technology to reach more families in need of education, information, and support	Experience support from persons similar to oneself
Behavioral expressions	Implement nonpharmacological practices that are person-centered, evidence-based, and feasible in the care setting	Enjoy music during previous times of stress
Activities of daily living	When providing support for dressing, attend to dignity, respect, and choice; the dressing process; and the dressing environment	Achieve independence in toileting
Staffing/workforce	Provide a thorough orientation and training program for new staff	Have satisfactory relationships
Supportive and therapeutic environment	Create a sense of community within the care environment	Experience more feelings of choice
Transitions and coordination of services	Ensure complete and timely communication of information between, across, and within settings	Be more prepared for death

- Measures must capture diversity not only in terms of race, ethnicity, and sexual orientation, but also in terms of systems of care, such as for persons with no care partners, with multiple care partners, and who reside in residential care settings.
- Measures must be suited across the progression of disease in terms of both outcomes and care.
- Measures must be pragmatic for use.

Given individual differences, diversity, change over time, and the complexity of care and outcomes, it may be that ultimately a "toolkit" of measures is developed that incorporates measurement of all nine of the DCPR domains and ultimately yields a common lexicon that can embrace all domains. In so doing, it is advisable that efforts across countries be better harmonized, including among LINC-AD, INTERDEM (Early detection and timely INTERvention in DEMentia, composed of European researchers), JPND (a global research initiative focused on neurodegenerative disease), and the US-based IMPACT Collaboratory, which aims to transform dementia care across health care systems and has its own core that focuses on pragmatic measurement related to person/patient and caregiver relevant outcomes.<sup>16</sup> Within the US, both LINC-AD and IMPACT welcome individuals and organizations from across the globe to access the resources on their websites and participate in their educational and networking opportunities; see <https://alz.org/linc-ad/overview.asp> and <https://impactcollaboratory.org/>. Of special relevance is IMPACT's Patient and Caregiver Relevant Outcome iLibrary, which links and critiques existing measures related to the DCPR domains.

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#### CONFLICTS OF INTEREST

Author disclosures are available in the [supporting information](#).

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### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.