New Directions in Measurement for Psychosocial Research on Dementia Care and Services

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Alzheimer’s Association

New Directions in Measurement for Psychosocial Research

• Conducted two pre-summit meetings
  – Alzheimer’s Association International Conference
  – International Association for Geriatrics and Gerontology
• Goal: Bring together expert researchers in dementia care to discuss psychosocial measurement areas in an effort to create a framework where research can be guided with a unified understanding
Pre-Meeting Survey and Discussion

- Distributed to all invited participants in both locations
- Measurement areas, including outcomes for individuals with dementia and their caregivers
- Pros and cons of existing measures
- What Alzheimer’s Association can do

Pre-Summit Meeting Participants

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Pre-Summit Meeting Summary

- Good measures exist in many areas, and good research is taking place
- Rather than listing key measurement areas and measures, we need to step back and re-conceptualize approach because measurement may currently be:
  - Too myopic
  - Stem from a deficiency framework
  - Sometimes derived from biomedical research
  - Missing areas of importance
- Better measurement will allow more individualization and better outcomes
- Need to build a more complete conceptual model—domains, gaps, priority areas and measures

Principles for Re-Conceptualization

New directions in measurement should:
1. Address multiple levels of inquiry—individual, familial/relational, living environment, community
2. Capture perspectives of multiple stakeholders, acknowledging the primacy of the view of the person living with dementia
3. Recognize person-centeredness—the individual experience of change, impact of change, and adaptation to change
4. Focus on strengths, in addition to impairments
5. Take into account time as a variable because dementia is a progressive disease, and experiences differ along the course
Examples of Important Areas of Measurement Development

- Persons living with dementia: measures assessing engagement, optimism, preserved capabilities or development of goal elicitation techniques and methods of assessing goal attainment
- Caregivers: measures of readiness, resilience, family conflict and decision-making
- Measures related to implementation processes including systematic measures of contextual factors

*Not comprehensive or developed by consensus*

Next Steps

- Lead and convene workgroup to build conceptual model based on principles
- Convene larger expert group to:
  - Review model, identify gaps and establish priorities
  - Prioritize measurement areas and build consensus on specific measures
  - Identify gaps in measures
  - Work with partner organizations to build searchable database