RESEARCH SUMMIT ON
DEMENTIA CARE
Building Evidence for Services and Supports

Review Session Recommendations

Day 3 Summit Paper

October 18, 2017

Prepared by:
Summit Co-Chairs
Session Chairs

Additional information can be found at the Summit website (https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers) or the National Alzheimer's Project Act website (https://aspe.hhs.gov/national-alzheimers-project-act). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

RESEARCH SUMMIT ON DEMENTIA CARE
Building Evidence for Services and Supports

Summit Recommendations from the Session Co-Chairs,

Recommendations Review Session October 18, 2017

Recommendations from Summit Session I: Research on Care Needs and Supportive Approaches for Persons with Dementia

Session Co-Chairs:
Richard H. Fortinsky, PhD
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1. <u>Develop/identify measures that capture intervention outcomes that are meaningful to people living with dementia.</u>
   a. Refine current measures of function, pain, and quality of life so they can be used in these populations.
   b. Develop measures of cognition and function that are sensitive to stage of dementia.
   c. Develop measures that adequately assess specific BPSD (aggression, apathy, etc.).
   d. Develop methods to improve the validity of self-report of outcomes.

2. <u>Identify specific determinants of behavioral and psychological symptoms and function so that interventions can be tailored with greater precision (for example, determine the impact of circadian rhythms, caregiver, and environmental factors on BPSD and function).</u>

3. <u>Determine the impact of, and ways to overcome, financial burden on access to care and services, research participation and quality of life for diverse populations living with dementia.</u>

4. <u>Improve methodological approaches used in studies of dementia care, services and supports.</u>
   a. For interventions: determine stage of dementia, timing of intervention, duration and dose when the intervention is most effective; determine mechanisms of intervention action and identify for what outcomes interventions are effective.
   b. Select appropriate control conditions that avoid outcome expectancy.
   c. Conduct studies that test combinations of treatments using adaptive designs.
   d. Use mixed methods with special attention to capturing outcomes meaningful to people living with dementia.

5. Conduct dissemination and implementation trials of effective approaches/models of care.

6. Conduct developmental research on technology solutions that are responsive to the needs of different stakeholders in dementia care across settings and that build on existing technologies.

7. Conduct epidemiological studies using new or existing data sets that describe and explain the needs and care circumstances of people living with dementia in diverse contexts, including those living alone with dementia.

8. Build capacity to conduct care research through existing or new centers on diverse populations with dementia (e.g., individuals with intellectual disabilities, LGBT individuals).

9. Determine optimal staff mix, ratios, and models of care in assisted living, to promote health and well-being.

10. Determine desired housing/living options for persons with dementia, and the related outcomes for persons with dementia (e.g., engagement, mood/affect), their family members (e.g., satisfaction, participation), and the staff who serve as care partners (e.g., satisfaction, turnover).

Recommendations from Session II: Research on Supportive Approaches for Family and Other Caregivers

Session Co-Chairs:
Linda Teri, PhD
University of Washington
Lisa Fredman, PhD
Boston University School of Public Health

1. Fund research that promotes translation, implementation, and dissemination of existing evidence-based programs in real-world settings (such as private homes, community agencies, congregate care, clinics, and hospitals) using existing staffing (professional and nonprofessional) for the full-spectrum of carers and providers. These include family and non-family members, diverse ethnic and minority groups, varied income and educational levels, different geographic locations, formal and informal providers.

2. Encourage the development and application of innovative and rigorous methods in study design, measurement, data collection, and analysis. Specific attention should be paid to improving measurement of caregiver and patient satisfaction, person-centered outcomes (including those of care providers), and cost-effectiveness. Measurement should include careful analysis of intervention fidelity, and the settings in which interventions are taking place. Both short- and

long-term outcomes should be addressed, and where feasible, the full spectrum of disease and caring should be considered.

3. Acknowledge a solid research base for effective psychosocial/behavioral dementia programs. New interventions should expand these programs, focus on those underserved persons affected by cognitive impairment (including persons with dementia and their family and non-family caregivers) that are not adequately represented in existing studies; and strive to be culturally sensitive.

4. One size does not fit all. Research should identify subgroups who are more or less likely to benefit from existing programs with an eye toward improving the risk/benefit ratio for all involved.

5. Research should take into account multiple domains and contextual situations because care provision is complex, dynamic, and occurs in a variety of settings with a variety of people. For example, there are dyads of caregiver-care receivers; there are small and large family groups; there are LGBTQ relationships; there are community and social support systems; and organizational factors.

6. Evidence-based research is needed to address what technology applications (existing and emerging) work, for whom, and in what context. This should expand beyond the examination of the delivery of technology-based intervention programs and include other technology applications such as sensing/monitoring systems, assessment programs, EMRs, robotic applications. This research should assess cost-effectiveness, usability, challenges and unintended consequences, and include diverse populations across a variety of settings.

7. Funding agencies should work together to fund research on the translation, implementation and sustainability of effective programs. This includes federal and non-federal research and health care agencies (including but not limited to NIH, PCORI, ACL, AHRQ, HRSA, state and local health and service departments, VA, Medicare, Medicaid, CMS, and HMOs), insurance payers, industry-partners, and private foundations.

8. Research should partner with stakeholders at all stages of the research, from identifying important problems, conceptualization, design, implementation, interpretation and dissemination of results. For example, research teams should include individuals who represent the target population.

9. Research should include an interdisciplinary team in all phases of research development and implementation. Research teams should also take into account the real world nature of services to persons with dementia and their caregivers such that varied professional and nonprofessional groups are targeted (including nurses; social workers; psychologists; care managers; certified nursing, home health, and personal care aides).

Recommendations from Session III: Involving Persons with Dementia and Caregivers as Members of the Research Team

Session Co-Chairs:

Mark Snowden, MD, MPH
University of Washington
Lee Jennings, MD, MSHS
University of Oklahoma

1. Acknowledge the moral imperative to involve people with dementia, and their care partners in the design, delivery, and dissemination of research and in setting research priorities.

2. Address skepticism about the feasibility and value of engaging people with dementia in research. Fund research on how engagement of persons with dementia and care partners can improve the validity and value of the research at each stage of the research project.

3. Engage persons with dementia and care partners at all stages of research.
   a. Development of interventions.
   b. Outcomes needed to change practice—what is clinically meaningful?
   c. Recruitment and retention of persons with cognitive impairment.
   d. Data collection strategies.
   e. Interpretation of results.
   f. Publication/Dissemination of findings.

4. Seek out diversity to ensure different perspectives and ideas inform research.
   a. Caregivers: spouse vs. adult children; gender; working status.
   b. Professional caregivers (health care assistants, homecare workers, etc.).
   c. Dementia types/different cognitive disorders.
   d. Severity of dementia (i.e., those in later stages or with profound communication problems).
   e. Younger adults with dementia.
   f. Persons with cognitive impairment living alone.
   g. Community and care settings: community, home, nursing home, health care settings, rural vs. urban, etc.

5. Fund research on how best to engage persons living with dementia and their care partners in research.
   a. Fund the development of methodologically robust practices for engaging people with dementia and their care partners.
   b. Fund the establishment and maintenance of local, state and national research groups and networks doing this well (e.g. PCOR-Net).
   c. Share and develop international best practice/common terminology.
   d. Research improved methods of self-report, proxy report, level of cognitive impairment for determining degree of engagement.

6. Include people living with dementia and their care partners in governance for research and Introduce ‘nudges’ that require and reward good practice.
   a. Make reporting on inclusion within a project a requirement of funder reports.
   b. Require application forms for funding have a section on this inclusion.
   c. Report method of inclusion as part of journal articles or as separate papers.
   d. Create career incentives for such inclusion (e.g. awards, recognition, funding).
   e. Embed methods for inclusion in graduate research training.
   f. Publicize where best practices for inclusion is implemented.

7. Develop and disseminate best practices for engaging persons with cognitive impairment and care partners in research.
   a. Apply existing engagement models to dementia care and services research.
   b. Develop guidance for ethics committees on including people affected by dementia as members of a study team.
   c. Develop guidelines/processes for supporting involvement and participation of people affected by dementia in research. e.g. how to best financially reimburse people for participating in research, tailored approaches to communication, support and training.
   d. Use elicitation interviews, surveys, review and comment periods to gather input from persons living with dementia and their care partners.

Recommendations from Session IV: Involving Persons with Dementia as Study Participants

Session Co-Chairs:

Darby Morhardt, PhD, LCSW
Northwestern University
David M. Bass, PhD
Benjamin Rose Institute on Aging

1. More quantitative and qualitative research studies are needed that collect self-reported data directly from persons living with dementia to: a) understand their subjective experiences with the illness and care, b) develop programs and interventions to be tested, and c) develop outcome measures that represent all aspects of the illness experience.

2. New tools need to be developed and tested for determining when persons living with dementia are able to directly self-report on their subjective experiences. Mental status tests and performance-based functional status measures are not adequate for this purpose.

3. Study protocols and data-collection procedures should enhance the ability of persons living with dementia to participate in research, and increase validity and reliability of data. This should include:
    a. Tailoring protocols and data-collection procedures to accommodate variation in neurocognitive capacity associated with different types and severity of dementia, and building upon remaining cognitive strengths of persons living with dementia.
    b. Using easy to understand consent forms; not basing the persons' eligibility on having a family/friend caregiver; minimizing logistic barriers to participation; using brief data-collection instruments; simplifying questions and response choices; using visual, auditory, and technology-based data-collection tools; and allowing flexibility in modes of data collection.

4. In research dissemination, always include clear and detailed descriptions for how the experiences of persons living with dementia were represented, including: data sources, data-collection methods, and criteria for determining whether self-reported data were collected.

Recommendations from Session V: Research on Models of Care for Persons Living with Dementia and Their Families across the Disease Trajectory

Session Co-Chairs:

Vincent Mor, PhD
Brown University
David B. Reuben, MD
University of California, Los Angeles

1. What is the effectiveness of interventions for dementia care?
    a. Pragmatic trials using a core set of outcomes.
    b. Develop a network of health systems, residential settings, clinic practices and community based organizations willing to participate in large intervention implementation trials including organizations serving large minority populations.
    c. Comparative effectiveness studies.
    d. Costs and cost-effectiveness studies (including determining who benefits from cost savings, and potential cost shifting).
    e. Studies testing how well models perform across the continuum of the disease severity and decision-making capacity, the spectrum of types of dementias, and across setting.

2. Develop new models of dementia care (e.g., those aimed at specific populations such as rural).

3. What are the mechanisms underlying effective care models? For example:
    a. How to enumerate the components embedded in a model known to be effective?
    b. How much of the observed success/positive outcome can be attributable to the organizational or environmental context?

   c. Is this effective intervention viable for scalable implementation?
   d. Synthesize the evidence from trials and observational replication projects regarding the relationship between intervention model fidelity and intervention impact.

4. How can existing models be refined to improve efficiency and cost-effectiveness? For example:
   a. Technology.
   b. Stand alone (e.g., newly developed).
   c. Automating existing models to reduce labor costs.
   d. Optimizing the work force so that people are working to the tops of their licenses.

5. Do models of chronic care that are not specifically focused on dementia result in better care for persons with dementia compared to not being in these models? Examples include:
   a. Self-directed.
   b. What level and types of cognitive impairment that still allow patients to participate in their care planning and management?
   c. Financial Alignment Demonstrations.
   d. VA Models (e.g., Medical Foster Homes, Hospital-based Home Care).

6. Development of new and more appropriate outcome measures (e.g., goal attainment scaling, how well preferences are met, unobtrusive observations, patient-reported outcome measures) of dementia care.

7. How can partnerships between organizations (e.g., health system-CBO) be optimized? For example:
   a. Communication.
   b. Contracting and financial alignment.
   c. Roles and responsibilities.

8. How can the workforce be optimized? For example:
   a. What are effective training strategies?
   b. What are the implications of widespread implementation of evidence-based models of care on the required workforce composition?
   c. What factors influence workforce recruitment and retention for dementia care?
   d. What is the effect of matching ethnic and cultural providers in the care of persons with dementia?

9. Research on implementation and dissemination
   a. Are proven interventions effective in new settings?
   b. How to influence adoption decisions?
   c. How to facilitate spread while maintaining fidelity?

Recommendations from Session VI: Thinking Outside the Box

Session Co-Chairs:

Christopher Callahan, MD
Indiana University School of Medicine
Alan B. Stevens, PhD
Scott & White Health

Themes

- Evidence-based models but poor diffusion, incomplete fidelity in adaptation, under-recognition of end-user needs.
- Few if any models are self-sustaining financially.
- Emerging consensus about key components of models but little understanding of mechanisms or active ingredients.
- Uncertainty about how to translate into practice.
- Agreement:
  - To move resources, decision-making, and site of care to community.
  - About importance of partnerships to reach needed continuum and duration (years) of care.
  - About increasing the voice of the consumer.
  - That academics needs partners with other skill sets.
  - Develop the workforce.

1. Support Diffusion Research and Development.
   a. Funding to support professional production of user guides and implementation materials and expert consultations to assist health systems in adopting dementia care programs but also studying the most effective training and behavior change approaches:
      - These projects would require scientists at academic programs to partner with colleagues in the professions of adult learning/training/ education.
      - Require adoption of behavioral economics, organizational change, and behavior change.
      - Require adaptation to varying funding, regulatory, population, and organizational environments.

2. Support Implementation Research.
   a. Fund research to improve our understanding of how complex interventions diffuse into practice (e.g. consortia projects requiring 3 or more different sites of care all attempting to implement the same intervention).
   b. Fund research to study the process of implementation:
      - Some should focus on large group partnerships including business, engineering, marketing, information technology, and end-user experience expertise.
      - Some should focus on identifying common barriers including financial disincentives, competing priorities, complexity across individuals.
   c. This type of implementation process research requires investment in the research infrastructure to develop consortia similar to VA capacities or to the ADCs (“ADCs for dementia care or ADCCs”).

3. Support Innovative Research Designs.
    a. Funding for research that seeks to improve the generalizability and applicability of research findings by loosening internal validity:
        - Basic research on the impact of innovative research designs.
        - Applied research on practical barriers to new research designs.
        - Applied research to test care models and complex or multi-components designs using adaptive designs and other novel study designs (e.g., Mittman list).
    b. Funding that seeks to understand the mechanisms of care models using approaches similar to drug development.

4. Support Longitudinal Needs Assessment.
    a. Fund a longitudinal cohort study of a nationally representative sample of persons with dementia and their caregivers (HRS for caregiving) for a minimum of 10 years. Design must account for diversity and how this diversity translates into different care needs.
    b. Fund ongoing real-time needs assessments of persons living with dementia and their caregivers to determine most pressing needs and largest financial outlays for out-of-pocket expenses for caregiving.
    c. Fund research on home redesigning the American home for persons living with neurocognitive disorders.

5. Support Community Redesign.
    a. Fund the continued development of practical strategies and roadmaps that different communities can use to become dementia-friendly.
    b. Stimulate large-scale partnerships between employers, health systems, government, and community agencies to support dementia-friendly communities.
    c. Fund the infrastructure that would allow networking between dementia-friendly communities.
    d. Fund the development and implementation of community education campaigns to increase the awareness of persons living with dementia in the community.

6. Support Consensus Development.
    a. Support a biannual consensus conference on:
        - Principles of excellent care for persons living with dementia and their caregivers.
        - Principles of dementia-friendly health systems.
        - Principle of dementia-friendly communities.
        - Elements of quality for revealing a dementia diagnosis.
        - Elements of quality on longitudinal care management.

7. Support Workforce Development.
    a. Fund a nationwide infrastructure for formal and informal family caregiving training and certification in partnership with community agencies and local health care systems (community college for caregiving).

   b. Fund research on understanding the key capacities of formal caregivers and how to train new workers in these capacities or competencies.

8. Recommendation from Teri with edits:
   a. The field would benefit from a systematic review of evidence-based programs that have been successfully translated from the empirically literature into service programs and practice models to identify predictors of success translation. Successful translation should be objectively defined with input from all stakeholders -- i.e., persons with AD/family caregivers, those adopting programs into their service line, payers of acute services for person with AD/family caregivers, payers of LTSS for person with AD/family caregivers. Important subtopics include:
      - Residential location of person with AD (e.g., ALF, NH, private homes).
      - Availability of clear strategic and financial paths for dissemination and sustainability.
      - Explore barriers to generalization of current findings to diverse populations and (languages other than English) not represented in the existing translational programs.

9. Recommendation from Mittelman with edits:
   a. Research is needed to better understand the needs and preferences of care and support services for persons with AD and their family caregivers within the context of what is feasible within the current provider system and what may be acceptable to potential third party payers. Findings from this research is essential in efforts to translate existing evidence and to the design of future project for which evidence needs to be established. Key components to be included in this effort are:
      - How to appeal to consumers:
         - How to create awareness.
         - Understand how and why caregivers seek help.
         - Understand why caregivers choose a service.
         - Potential consumers need to be persuaded that a psychosocial intervention is currently the best available treatment.
      - How to get buy-in from providers:
         - Dissemination of information about evidence-based interventions to providers in user friendly format.
         - Widely available training and certification for providers.
         - Forum for providers to share experiences of success and barriers.
      - How to convince payers to fund evidence-based interventions:
         - How to reach decision-makers.
         - What mandates do they have that we can help them fulfill?

10. Recommendation from Fortinsky with edits:
   a. Medicaid/State revenue funded LTSS: determine which ingredients within evidence-based dementia care programs are already reimbursable and conduct translational studies at the state or multi-state level to determine their effectiveness.

b. Medicare Advantage: Test the effectiveness of evidence-based dementia care programs within target populations of persons with dementia insured by Medicare Advantage plans and these insured members' family caregivers (who also might be insured by same plan).

c. Overarching questions:
   - How to preserve all or most ingredients of evidence-based dementia care programs within ever-changing Medicaid and Medicare reimbursement systems?
   - How to enable reimbursement for entire programs if found effective in translational studies?

d. All of these need to address the need to link between health delivery/payers/outcomes of the CR and CG.

e. Linking claims between certain groups of CR/CGs could be worthwhile (e.g., spousal dyads within the same advantage plan).