



Research Recommendations

Stakeholder Group Paper

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Prepared by:
**Family Caregiver
Stakeholder Workgroup**

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.

Family Caregiver Stakeholder Workgroup Research Recommendations

These research recommendations were developed as a result of six meetings with the members of the Family Caregiver Stakeholder workgroup. The recommendations are submitted by the three co-chairs of the stakeholder workgroup: Gail Hunt, Laurie G. Lindberg, and Donna Walberg.

Employment / Work

1. Caregiving has not been compelling for employers to address. Are there steps employer can take to help employees who are caregivers? Offer flexible work schedules?

What employer-supports would significantly increase / improve productivity, product quality, and work quantity while being sensitive to and supportive of the caregiver's situation and needs?

Offer an intervention that has been shown to help employed caregivers. Conduct research to compare results for employer who uses the intervention vs. employers who don't use it. Measure outcomes for the employer and outcomes for the employee (caregiver).

2. How does the type of caregiving affect employment issues? For example, with cancer diagnosis, the caring is episodic and has different outcomes. With dementia, it's constant and progressive. Conduct a study that looks at employed caregivers with different care partner diagnoses to determine whether employer supports affect the caregivers differently.

3. Caregivers shuffle their work life to accommodate caring requirements, quit their jobs, or – the opposite- go back to work in order to “keep one's head above water” financially.

Conduct a survey of caregivers to see how a dementia caregiver's ability to be employed change over time and with the progression of demands as the disease worsens?

Do caregivers lose promotions or raises because of the stigma of being a caregiver or because of reduced professional engagement because of the caregiving?

Financial and Legal

Financial destitution is a very real concern for caregivers, especially with diagnosis of younger-onset dementia, although can affect all dementia caregivers. Research needs in this area are numerous.

1. Need research on financial impact of caregiving, not just anecdotal evidence. The research should increase our knowledge about the financial impact of caregiving.

2. Conduct research on the knowledge level of financial planners, elder law attorneys, family lawyers about the specific issues affecting persons living with dementia and their caregivers. The research should increase our understanding of what these professionals know and the guidance they provide. This will enable the proper educational curricula to be developed for these professions on the topic of dementia and dementia caregiving.

3. Conduct research on legal and financial options that caregivers must consider and make decisions about and how to offer these options in ways that caregivers can understand and use easily. The research should show how financial options and advice have improved the financial situation of the caregiver/person with the disease.

4. Many elderly parents are caring for a younger family member with an intellectual disability and dementia. What is the frequency of depletion of financial resources for those who are no longer able to work due to age or infirmity? How many continue to work into their 80's to support the family members' needs?

Health and Well-being

1. Caregivers neglect their health. Research is needed to determine what characteristics of caregivers make them most at risk of having their health affected negatively. What demographic/diversity issues contribute to differences in caregiver health? Which characteristics influence caregiver ability to negotiate successfully the systems/programs/resources that might be available? In addition, what are the different aspects of "health" that should be measured?

2. Many useful programs exist to assist family caregivers, e.g., REACH, Savvy Caregiver, NYUCI. What is it about the intervention that makes it valuable for certain people at certain points in the caregiving trajectory? What solutions or interventions do you apply at different points – financial, legal advice, training on how to deal with behaviors, health considerations? Target the right intervention at the right time for the right person.

3. How to adapt existing resources and programs to be more effective for caregivers of people living with a dementia diagnosis? For example, in Minnesota, REACH VA is being applied to the Native American community with great success. However, many programs like Savvy Caregiver, REACH, etc., do not feel equipped to address the needs of individuals with an ID and dementia. How can we increase the skill set of these providers so that they can support this population of caregivers?

4. Conduct survey research to start looking at how caregiving affects the spousal relationship or the child-parent relationship. Examine social work curricula and guidelines to see if they meet the needs of caregivers and care partners experiencing the evolution of their relationship.

5. What elements of caregiver burden are most associated with caregiver crisis, institutionalization, etc.?
6. If person with dementia has improved outcomes, does the caregiver have improved outcomes? How do outcomes differ between the caregiver and the care partner?
7. Support groups can be valuable for dementia caregivers. Research is needed to measure the effect of support groups. Efforts should be made in dementia care to organize such groups, and make information about them available to caregivers.

Health Care System and Services

1. Research that focuses on the impact of improved outcomes for patient and caregiver when the caregiver is an integral part of the health care team *versus* just being recognized (which is also important).
2. There is general agreement that there isn't a single service that will address all issues or needs but rather a combination of services that the caregiver cobbles together. The availability and use of services varies by cultural group, geographic location, economics/affordability, disability, etc. Design and fund research that describes the sets of services that have the greatest impact at each stage of the disease. Does the availability and use of a "navigator" significantly improve the use of services/positively impact caregiver health and wellbeing/impact person with dementia disease progression? Conduct research with a variety of independent variables with the dependent variable being health and well-being of the caregiver and the care partner.

Individuals with ID have no access to Navigators or Care Coordinators available to the general population especially in small studies that are community based. How do we include them in any study that assesses caregiver outcome?

3. Privacy concerns make it difficult for caregivers to assist in the care of their care partner within the health care system. Conduct research that would look at HIPAA regulations that would regard **the dyad as the unit** and compare to the usual implementation of HIPAA regulations. Outcome measures would be improvements in caregiver burden, shorter or fewer hospital stays and fewer or more manageable medical issues for person with dementia diagnosis, etc.
4. Develop and test theories about the concept of "the right care at the right time" for dementia caregivers and persons living with dementia
5. How can services be re-framed to serve people with dementia and their caregivers? What needs to be learned in order to make services more effective for diverse populations? Does a dementia-friendly community help caregivers?

Miscellaneous

1. We need to know more about how cultural, ethnic, and racial disparities in health care specifically affect dementia caregivers and caregivers of those with intellectual disabilities and dementia. Research studies should be conducted that will disclose the causes and impact of such disparities.
2. We also need to encourage more translational research and better dissemination of research findings as they become known.

Dated: September 29, 2017