



Family Caregivers

Stakeholder Group Interviews

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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.



Interview with Family Caregiver Stakeholder Group
Co-Chairs Gail Hunt (not present), Laurie Lindberg, and Donna Walberg
August 9, 2017, 2:00–3:00 pm ET

Interview Questions

1. What are the main concerns of this group in relation to care and support services for people with dementia and their caregivers?
2. There are many types of services and supports for people with dementia and their caregivers, including education programs, training on caregiving skills, counseling/support, respite care, home modification and other safety services, and support in navigating medical care and other supports. What services and supports do members of the group think are most effective for people with dementia? For caregivers? Are there any that are less important or helpful?
3. How do members of this group define “effectiveness” when it comes to services and supports? What kinds of outcomes or results are most meaningful for people with dementia? For caregivers? What research is needed to test those beliefs about effectiveness?
4. Among people with dementia, are there groups whose experience needs to be better understood? What do we need to know?
5. Among caregivers, are there groups whose experience needs to be better understood? What do we need to know?
6. How can people with dementia become more involved in the research process? How can caregivers become more involved in the research process? What concerns might these groups have that would prevent them from participating in research?
7. What do we most need to know to better serve people with dementia and their caregivers? What questions should researchers be asking?
8. Are there any topics related to care and support services that generated a lot of debate or discussion within your stakeholder group? If yes, what are the topics, and how would you describe the different positions or ideas that have been shared?
9. Have there been any topics of discussion or ideas that have surprised you?

Summary of Caregiver Interview

1. Developing a dementia-capable health care system

One of the key recommendations of this group is to increase the knowledge level of professionals serving people with dementia. Health professionals are receiving more education and training now than in the past, but training usually relates to the basics of dementia and the disease process. There is very little training on how to deliver care and what types of care delivery systems might be effective.

We need to look at fundamental changes in how care is delivered. A key piece of this is acknowledging the central role played by caregivers and finding ways to work more effectively with both the person with dementia and the caregiver. Often, the caregiver role is not acknowledged unless the caregiver is present at medical appointments.

HIPAA restrictions can also create problems for caregivers. If a caregiver misses a medical appointment, he or she does not have a way of finding out what was discussed without having a power of attorney. However, many health care organizations will not generally recognize a caregiver's power of attorney. The caregiver must go through additional steps and hassle of filling out a clinic-specific form and must do this for each new clinic or doctor. The coordination of care is very cumbersome. HIPAA problems are universal among caregivers.

The health care system's interpretation of HIPAA creates many of these challenges. Providers have more ability to communicate information than they use, but they err on the side of withholding information, which becomes very difficult for caregivers.

Questions to inform research:

- How can we ensure that all health care professionals receive education on dementia and the caregiver role?
- How can we ensure that providers receive continuing education as new discoveries are made and new information is available?
- What is the impact of training programs for professionals? Does training change the behavior of health care professionals and to what extent?
- How do HIPAA regulations affect quality of care?

2. Services caregivers need

Navigation

Caregivers are juggling many things in addition to caregiving. They are limited in their time, finances, and energy. The disease can be overwhelming, and many are in shock

after receiving a relative's diagnosis. The information that is presented may also be overwhelming.

Caregivers and people with dementia need a “navigator” who can help provide information a little at a time, as it is needed. Services are also frequently fragmented and offered by different agencies. A “navigator” who is in touch regularly can help caregivers and people with dementia put together the services they need.

The timing of services can also make a big difference in outcomes. Often, by the time people seek services, they are already in crisis. People need to get information and supports in place *before* they need them.

Financial and legal services

Financial and legal help is another key area where caregivers need help, but these services can be expensive. Some families use an attorney to help connect them to other community resources and information, but this is not a cost-effective use of services. Also, the attorney may or may not have good information. Finding ways to protect assets as the person with dementia's capacity to make good decisions declines is important to caregivers, and attorneys are helpful in setting up powers of attorney and assisting with financial planning.

Questions to inform research:

- What types of information and support are most needed at which points of the disease?
- How can dementia care specialists build trust with families? Offering a free initial appointment or consultation might be one approach.
- When do people access services and how does that affect their outcomes?

3. Improving service delivery

Access

Participants in this stakeholder group usually found a way to get the services they needed, but they felt the process was more difficult and frustrating than it needed to be.

The group noted that people who know the most get access to more services because they know how to navigate the system. People who know less get fewer services and are less satisfied. The caregiver group believes that there is a direct correlation between how savvy you are and your satisfaction with services. The quantity and quality of services also depends greatly on where you live.

How services are delivered

The group noted that it is just as important, or maybe even more so, to consider *how* services are delivered. Sometimes the way services are delivered makes the difference between their being a critical support versus an additional burden. For example, home care services have the potential to be a significant support for caregivers. But when a different aide comes every time, the service may be more of a hindrance than a help. Routine care is so important for people with dementia, and constantly having to orient new workers may be more trouble for the caregiver than just providing the care themselves.

Services that rely on volunteers can also be challenging because it requires finding a good match between the volunteer and the person with dementia. Restrictions and guidelines that come with services can also be complicated; every program has different guidelines.

Transportation services are another example of how delivery makes a difference. Providing transportation as part of another program, such as adult day services, can be helpful and may make the difference between being able to use the service or not. But if the transportation service is not able to accommodate the needs of the person with dementia, it is no longer a help.

Cultural disparities

Different cultural groups may have different expectations about what qualifies as a helpful service or support. For example, some groups may look to their own community for assistance while others look to health care providers or community agencies.

There are also significant disparities in how different groups are treated within the health care system, which creates an extra layer of burden for some caregivers. Some groups, such as African Americans, have found their experiences questioned and discounted by providers. They have felt unsupported, invisible, and sometimes mistreated within the system. One example is an African American man with dementia, who when he acted out at the hospital was treated as a “violent black man” rather than someone whose aggression was a symptom of dementia.

Hospitalization seems to be one of the most vulnerable times for poor treatment. People with dementia are sensitive to any changes in routine and environment and need the support of providers to manage this. It is not uncommon for providers to ignore or overlook issues related to dementia, and caregivers must spend a lot of extra time educating staff on how to provide good care.

End-of-life care

The way people think and talk about end-of-life issues can vary considerably among different cultures. For example, people across many cultures may want hospice care, but they may want it delivered a particular way. The African American community is also more reluctant to engage in discussions of end-of-life issues because of distrust of the medical community.

Questions to inform research:

- How can awareness of and access to resources and services be improved for people who may need it most?
- How can we disseminate information and services in a way that is more accessible to all?
- What factors are important to caregivers in making services accessible or useful?
- How can services be made more flexible to meet the different needs of families?
- How can health care professionals better approach these topics with their patients and their families?
- How can disparities in treatment among different racial and ethnic groups be reduced or eliminated within the health care system?

4. Caregiver depression and burden

In examining caregiver outcomes, depression and burden are two of the most common measures. Researchers need to be more specific in their measure of these outcomes. For example, the group suggested that all caregivers are depressed to some degree, but the question is, how severe is the depression? When, and in what ways, does depression affect the caregiver and the person with dementia?

Caregiver burden is a big topic and can encompass many factors such as time constraints, caregiver health, depression, and stress. The type of burden makes a difference. People expect some level of burden, but certain kinds or degrees of burden might lead to breakdown or crisis in a caregiving situation. We need a better understanding of this.

Questions to inform research:

- How do different levels of depression severity affect caregiving?
- How do different domains of caregiver burden affect caregiving?
- What elements of caregiver burden are most associated with caregiver crisis, institutionalization, etc.?
- How can services be delivered in a way that helps alleviate caregiver depression and burden?

5. Groups that need greater focus from service providers and researchers

- *African American caregivers*

This group has faced greater marginalization. Their dementia is less likely to be acknowledged by the medical community and they are less likely to get the support they need.

- *Down syndrome and developmentally disabled*
- *Low-income people*
- *Middle-income and working class families*

Middle-income and working class families cannot afford to pay for the services they need but do not qualify for government subsidies, such as Medicaid. They must make hard decisions about how to spend limited resources.

- *People under age 65*

People with dementia under age 65 are eligible for Medicare but there is a 2-year waiting period, so there is a period that is very expensive.

6. Involving people with dementia and caregivers in research

Participating in research takes a lot of time and effort for people with dementia and their caregivers. It is often a major time commitment and often requires compliance with protocols at home and transportation to the research site. Nonetheless, this stakeholder group expressed a very positive attitude toward participating.

The group also expressed the need for much more collaboration among researchers and caregivers and people with dementia. They expressed disappointment that many research studies are based on interventions that are not practical for most people, such as interventions that involve 12 separate visits. Researchers need to better understand how services are delivered and used. Programs like REACH have done a good job assessing what worked and did not work for caregivers and adjusting the intervention accordingly.

Some groups are less likely to participate in research. African American families often do not hear about research opportunities. The research community is not doing effective outreach, and there is also a historical lack of trust with the health care system rooted in abusive research (e.g., vaccine research and syphilis studies). Researchers need to have greater sensitivity and cultural awareness.