Clinical Care and Long-Term Services and Supports for People with Alzheimer's Disease and their Caregivers: Setting a Research Agenda

In May 2012, NIH held an international Alzheimer's Disease Research Summit to solicit input from experts on how to achieve the first goal of the National Plan to Address Alzheimer's Disease to "Prevent and Effectively Treat Alzheimer's Disease by 2025." The summit provided a mechanism for receiving input and identifying research priorities. As a result, NIH has issued Request for Applications in priority research areas.

Members of the Advisory Council on Alzheimer's Research, Care, and Services recognize the need identify research needed to improve the clinical care and services and supports for people with AD and their caregivers. These two areas are very broad and include many relevant topics. The stakeholder communities for these two areas are large and very diverse.

Federal staff met in early July 2013 to identify a process for establishing a research agenda for these two areas. The group felt that the best way to narrow down the topics was to begin from the perspective of people with the disease and their caregivers to identify where they experience gaps in care and support or where they feel improvement is needed. The group also felt that there are opportunities to identify existing research that is ready for translation into practice to fill these gaps quickly. Finally, it would be most useful to focus on the areas of care and supports that are specifically relevant for people with AD and their caregivers. The draft approach they developed is described below.

Please note that this is a draft for discussion. We have not secured the support necessary to carry out this work.

Step 1: Describe the experience of care and supports received by people with AD and their caregivers.

The first step will be to describe the experience of people with Alzheimer's disease, their caregivers, and the care providers. Using data from national surveys such as the National Health and Aging Trends Study and the Health and Retirement Survey, we will begin to identify issues related to care and services and supports for people with AD and their caregivers, such as unmet needs for services. We will also assess the published research literature for more information on issues related to care and support. We will explore data sources to describe the experience of providers in addressing the needs of people with AD.

This quantitative review will be supplemented with qualitative information gathered from a variety of stakeholders with differing perspectives. It will be essential in this process to identify what outcomes are meaningful to persons with dementia and their caregivers. This would permit us to better identify and describe care processes that are suboptimal or that require improvement. For example, unnecessary hospital readmissions are likely to be an area that patients and family members say needs improvement. Some of the key questions to gather information on the meaningful outcomes and the experiences of care and support may include:

    -What care/supports could you not get?
    -What was important to you in the care experience? Were those priorities identified and
    addressed by providers?
    -What care/supports could you have used earlier but did not know about? What information did
    you need earlier?
    -What was your experience with diagnosis? How could that experience have been improved?

-What was your experience with transitions of care? How could those experiences have been improved?
-In your experience, what are the unique challenges in caring for someone with AD?
-What special training do informal and formal caregivers of people with AD need?
-What information do you, as a provider, need to help you care for people with AD?

Federal staff will work with partners such as advocacy and provider organizations to identify stakeholders and populations to gather information from to ensure coverage of diverse perspectives, including people in different care delivery systems (i.e., VHA, Medicare, Medicaid), at different socioeconomic levels, in different points along the course of the disease, in different care settings (i.e., home, adult day care, assisted living, nursing home) and from different cultural backgrounds. Partners will be asked to gather this information from these groups and bring it back to federal staff. The federal staff, partners, and representatives of the research community will synthesize the information gathered into a report that includes a list of gaps areas in care and support.

Step 2: Synthesize evidence on gap areas

Next we will synthesize the existing evidence for each of the gap areas. We recognize that it may not be possible to undertake such an effort for all gap areas, but will identify a process for choosing those most appropriate for a synthesis. The synthesis will include international comparisons and inquiry into whether other nations have similar gaps, as well as an examination of practices and policies in different systems within the US such as the VHA and managed care providers.

The evidence synthesis will summarize what is known about each of the gap areas. This will help us categorize the knowledge into what is (1) ready for translation, (2) ready for translation but facing difficulties in implementing, and (3) information that is needed.

Step 3: Set criteria and principles of prioritization

We will convene a meeting with stakeholders to identify driving principles or core criteria that will be used to drive the prioritization process. These may include, for example, that research should have clearly defined outcomes, well-described patient populations that include co-morbidities, or that disease severity indicators. Other criteria may be that research should inform management of patients with dementia, provide means to improving outcomes, or can be used to inform decision-making by patients and their families.

Step 4: Prioritization and Creation of Research Agenda

The results of the evidence syntheses will form the basis for a draft research agenda. Applying the criteria set in Step 3 to the evidence syntheses, the federal staff, partners, and researchers will develop a research agenda. The research agenda will identify areas where research is needed, research that is needed to understand ways to overcome barriers to implementation, and areas of need in practice but where there are research results currently available that could be implemented or used to make policy changes.