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Meet the Mental Health Needs of People With Dementia

Posted: 1/10/12 11:22 AM ET

People living with Alzheimer's or other dementias often have mental health problems -- especially depression and anxiety disorders -- as well as dementia. Memories they have always relied on become hazy and uncertain. Knowledge and skills cultivated over a lifetime diminish. Relationships change or are lost. Ordinary activities at work, home or leisure become difficult. Eventually, other people may be needed to help manage finances, make plans, get back and forth from home, eat, stay clean or go to the bathroom. As these sources of identity, personal pride and satisfaction are lost, people with dementia can become deeply sad, fearful and/or angry. Sometimes their behavior becomes a challenge for people who care for them.

These obvious facts should be part of what drives our nation's preparation for the vast growth of the number of people with Alzheimer's or other dementias that will take place over the next two decades.

The good news is that pursuant to <u>The National Alzheimer's Project Act (NAPA)</u> signed into law in January 2011, the U.S. Department of Health and Human Services (HHS) has begun to develop a long-term plan regarding dementia. The planning advisory committee for this project includes a representative of the Substance Abuse and Services Administration (SAMHSA) as well as representatives of many other federal agencies. In mid-December SAMHSA brought together a small group of experts who recommended that SAMHSA speak to the critical importance of addressing mental health problems experienced by people with dementia, Hopefully, it will do so at the next meeting of the advisory committee, which will take place on Jan. 17 and 18.

That's the good news. The bad news is that there is a battle shaping up about what the nation's priorities regarding dementia should be.

Some argue that there should be one and only one priority -- investing in research to discover a cure for Alzheimer's or at least to invent medications to stop the ineluctable decline the disease brings with it. For example, in an editorial in *Alzheimer's and Dementia*, Zaven Khachaturian of the Campaign to Prevent Alzheimer's Disease by 2020 argues, "Ultimately, the only deliverable that counts is a credible plan of action that calls for significant and systematic increases in the allocation of resources and funds for Alzheimer's research... particularly in the discovery and development of interventions to prevent disability."[1]

Others of us believe that, however promising biomedical research is, it will probably not bring relief in time for the 5.4 million Americans who already have dementia or for the additional five

to six million people who will develop dementia over the next two decades. [2] We believe that humane care to help them have the best possible quality of life is the critical goal. We see this not as competing with biomedical research but as work that is necessary in addition to it.

But even among those of us who are focused on the need for more humane and more effective services and supports, there is some dispute about the importance of mental health services.

In part, this is the result of an outmoded view about the separation of mind and body. Dementia has physical roots with mental manifestations. Many advocates for better Alzheimer's care and treatment focus on the physical roots and do not regard dementia as a mental health condition. Others of us believe that mind and body are inextricably intertwined and that both physical and mental health perspectives and interventions are needed to help people with dementia and their families to have the best possible quality of life.

Many mental health issues arise in the lives of people with dementia and their caregivers. In a recent article in the same journal that published Khachaturian's editorial, Constantine Lyketsos and others argue that "neuropsychiatric symptoms (NPS) are core features of Alzheimer's disease and related dementias." They cite "depression and apathy ... verbal and physical agitation ... [and in later phases] delusions, hallucinations and aggression" as particularly common and important to address with mental health interventions, preferably non-pharmacological interventions. [3]

Psychological understanding can also contribute to improved quality of life for people with dementia and their families even if they do not have diagnosable mental illnesses. Dementia is often thought of as an unmitigated horror, but the truth is that some people with dementia lead lives that they find satisfying. Helping people with dementia to retain a sense of self-worth and be at peace with who they are is a very important goal for them. [4]

Mental health issues also touch family caregivers who provide 80 percent of the care for their relatives with disabilities. They are at high risk for depression, anxiety and physical illnesses that contribute to burn-out. Solid research by Mary Mittelman has shown that psychological support helps family caregivers live better with the stress they face, resulting in delay in nursing home placement by upward of 18 months. [5]

If the National Alzheimer's Plan does not reflect these facts, life for people with dementia and their families will end up far worse than it needs to be. That is why I and many others <u>are advocating</u> that the plan establish meeting the mental health needs of people with dementia and their families as a core priority for our nation.

References:

- [1] Khachaturian, Z. "Prospects for designating Alzheimer's disease research a national priority" in Alzheimer's and Dementia, November 2011.
- [2] Alzheimer's Association. "Facts and Figures About Alzheimer's."
- [3] Lyketsos, C. et al. "<u>Neuropsychiatric symptoms in Alzheimer's disease</u>" in Alzheimer's and Dementia, September 2011.
- [4] Zeisel, J. I'm Still Here. Avery Press, 2009.
- [5] Mittelman, M. et al. "Improving Caregiver Well-Being Delays Nursing Home Placement of Patients with Alzheimer's Disease" in Neurology, November 14, 2006.