

DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH

The Role of NIH-supported Research in Improving Quality of Care and Quality of Life for
Individuals with Alzheimer's Disease and Their Caregivers

Witness appearing before the
Senate Special Committee on Aging

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Mr. Chairman and members of the committee, thank you for this opportunity to discuss the research and training activities of the National Institute of Nursing Research (NINR) that address the needs of older adults with Alzheimer's disease, or AD, and their families. I am the Director of NINR, one of the 27 Institutes and Centers at the National Institutes of Health, and one of several NIH Institutes and Centers that support research on AD. My statement today will describe some of NINR's recent research findings and current research efforts focused on older adults with AD and other dementias, and improving quality of life for caregivers. I also will briefly discuss the importance of investing in training opportunities to ensure that the next generation of scientists has the knowledge and tools to serve the needs of our rapidly aging population.

It is estimated that AD affects as many as 2.4 to 5.1 million Americans.¹ With the baby boomers' increased life expectancy, this number is expected to increase dramatically in the coming decades. NIH is dedicated to supporting a broad, interdisciplinary program of research to answer critical questions on what causes AD, how to better diagnose it, how best to treat it, and ultimately, how it can be prevented. Over the past 20 years or so, we have significantly increased our understanding of the biological and genetic underpinnings of this disease. In spite of this progress, however, there is currently no way to prevent the onset of AD, and drug treatments are not very effective in delaying the progression of the disease. Consequently, in addition to focusing on efforts to ultimately prevent AD, we must be equally mindful of improving the care and quality of life for those now suffering from AD, and alleviating the burden faced by the informal caregivers who provide the majority of care for their friends and family members with AD.

¹ Herbert LE et al. Alzheimer's Disease in the US Population: Prevalence Estimates Using the 2000 Census. Arch Neurol. 2003; 60:1119-22.

NINR RESEARCH ON ALZHEIMER'S DISEASE: AN OVERVIEW

It is around these issues that NINR has built its diverse portfolio in AD research. At NINR, we support clinical and basic research to: build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate the symptoms caused by illness, enhance end-of-life and palliative care, and train the next generation of scientists. As part of this mission, NINR focuses on issues related to quality of care and quality of life for older adults with AD and other dementias, as well as their informal caregivers. NINR research on interventions for the older adult with AD focuses on areas such as: alleviating symptoms such as pain, discomfort, and delirium; improving communication for clinicians; and memory support. For example, NINR is currently supporting a project to test the effectiveness of an activity-based intervention designed to increase quality of life by reducing agitation and passivity and increasing engagement and positive mood in nursing home residents with dementia. Another recently funded project is examining an intervention to improve early detection and management of delirium in persons with dementia, which has the potential to improve quality of life and decrease costs of care. A third NINR-funded study that is currently underway focuses on both the older adult and the family caregiver. This study involves an evidence-based, nurse practitioner-guided, intervention for patients with AD or other dementia and their family caregivers. The intervention is expected to improve overall quality of life by decreasing depressive symptoms, reducing burden, and improving self-efficacy for managing dementia in caregivers. A project such as this underscores the fundamental importance of nurse scientists who conduct research to improve the care of older adults with AD.

NINR also emphasizes research on interventions aimed at improving quality of life and reducing burden for caregivers. There are an estimated 10.9 million unpaid caregivers caring for

loved ones with AD.² These caregivers often experience stress, burden, depression, and decline in physical health while taking care of loved ones with chronic illness such as AD and dementia. Interventions are needed to assist caregivers in learning how to care for a loved one, help them manage symptoms and distress related to their illness, and reduce stress so that the caregiver may continue to remain healthy and provide care. Recognizing these challenges, nurse scientists conduct research on strategies to improve the skills caregivers need to provide in-home care, and to teach caregivers health promotion behaviors that will help them to maintain and improve their own health and emotional well-being. For example, NINR currently supports a study that uses a telephone-based intervention for caregivers to enhance emotional support, locate needed resources, improve coping skills, and assist in attending to physical, social and emotional needs. Another current project involves the development and testing of an intervention to promote and improve shared decision-making and communication between caregivers of persons with advanced dementia and clinicians in regards to tube feeding and treatment decisions. A third project is investigating the effects of a psycho-educational and physical exercise intervention in family caregivers of African American dementia patients, and caregivers of heart failure patients, to promote health and reduce cardiovascular risk.

The projects I have described provide just a glimpse of current NIH efforts to improve quality of life and care for those with AD and their caregivers, efforts that offer the promise of a better tomorrow for individuals affected by dementia.

IMPROVING QUALITY OF CARE FOR OLDER ADULTS

² Alzheimer's Association. 2010 Alzheimer's Disease Facts and Figures. 2010. Available at http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf.

Scientists have made great progress in understanding the challenges of living with AD for older adults and in developing interventions to support their caregivers. I would like to draw your attention to recent important findings in these areas from NINR-supported studies.

One of the challenges of providing quality care for older adults with AD is accurately detecting and treating symptoms such as pain and discomfort, which is critical to their quality of life. It is essential for health care providers, as well as informal caregivers, to have the tools to recognize pain in older adults with dementia who may not be able to express their need for pain relief. A recent NINR-funded study on pain showed a discrepancy between pain reported by dementia patients and pain behaviors that were observed. In this study, cognitively impaired older adults self-reported less intense pain after movement activities, such as walking and sitting, than cognitively intact older adults. However, behavioral observations of pain, such as grimacing and verbal complaints, showed no differences between the two groups.³ This suggests that commonly used self-report measures of pain may underestimate pain in older adults with dementia.

Some data suggest promising results of interventions for improving the quality of care and quality of life for older adults with AD and other types of dementia. For instance, a recent NINR-funded study showed that a comprehensive exercise program increased positive mood and decreased negative mood in nursing home residents with AD.⁴ Preliminary findings regarding health promotion interventions for older adults with early-stage dementia living in the

³ Horgas, AN et al. Pain Assessment in Persons with Dementia: Relationship Between Self-Report and Behavioral Observation. *JAGS*. 2009; 57:126-132.

⁴ Williams, CL, & Tappen, RM. Effect of Exercise on Mood in Nursing Home Residents with Alzheimer's Disease. *Am J Alzheimers Dis Other Demen*. 2007; 22:389-397.

community,⁵ as well as interventions to increase activity engagement in nursing home residents with dementia⁶ demonstrate that such interventions have the potential for improving quality of life.

IMPROVING QUALITY OF LIFE FOR CAREGIVERS

Recent findings from NINR-supported investigators are also contributing to the development of evidence-based interventions to support caregivers. One example is the Resources for Enhancing Alzheimer's Caregiver Health program, also known as REACH. Co-funded by NINR and the National Institute on Aging, REACH is a comprehensive, multi-site intervention, to assist AD caregivers. The REACH program teaches caregivers about AD, along with strategies to help them manage troublesome behaviors of the care recipients. It also emphasizes ways for caregivers to manage stress, maintain their social support groups, and enhance their own health and self-care activities. In a recent report of study findings involving almost 500 AD caregivers from diverse racial and ethnic groups, those who received the REACH intervention reported better physical, emotional, and overall health compared to those who received a packet of basic AD educational information and two brief "check-in" telephone calls.⁷ In addition, the REACH caregivers had lower scores for depression, which contributed to reducing their sense of caregiving burden. These findings indicate that the REACH program, by providing information about both AD and self-care, helped AD caregivers from diverse racial and ethnic groups maintain their own physical, emotional, and mental well-being. Multiple

⁵ Buettner, LL, & Fitzsimmons, S. Promoting Health in Early-Stage Dementia. *J Gerontological Nursing*. 2009; 35: 39-49.

⁶ Hill, NL et al. Agreeableness and Activity Engagement in Nursing Home Residents with Dementia. *J Gerontological Nursing*. 2010; 36: 45-52.

⁷ Elliott, AF et al. Enhancing Caregiver Health: Findings from the Resources for Enhancing Alzheimer's Caregiver Health II Intervention. *JAGS*. 2010; 58:30-37.

efforts across the federal government are currently underway to implement REACH in the community.

TRAINING THE NEXT GENERATION OF SCIENTISTS

To ensure continued advancement in improving care for AD and other dementias, it is essential that we also focus on training the next generation of innovative, interdisciplinary scientists with expertise in chronic illness and symptom management, and with the knowledge necessary to translate successful research to clinical practice. To this end, NINR supports extensive training activities across all areas of our scientific portfolio. Current efforts are training future nurse scientists to conduct research on transitional and individualized care for chronically ill older adults, biobehavioral pain research, genetics, and basic neuroscience, among many others.

CONCLUSION

In conclusion, I would like again to thank the Committee for offering me the opportunity to present an overview of efforts at the NINR to support research and training to improve the lives of older adults with AD and their caregivers. As we await the day when AD can be prevented and successfully treated, we must never lose sight of the needs of the individuals suffering from this and other dementias, and the people who care for them. Given this, NINR and NIH will continue our comprehensive efforts to support the science that will provide the evidence-base for improving the quality of care and quality of life for individuals affected by these illnesses, train the next cohort of researchers to generate new discoveries, and translate this evidence into everyday practice.

PATRICIA A. GRADY, PHD, RN, FAAN, DIRECTOR
NATIONAL INSTITUTE OF NURSING RESEARCH

Dr. Patricia A. Grady was appointed Director of National Institute of Nursing Research, on April 3, 1995. She earned her undergraduate degree in nursing from Georgetown University in Washington, DC. She pursued her graduate education at the University of Maryland, receiving a master's degree from the School of Nursing and a doctorate in physiology from the School of Medicine.

An internationally recognized researcher, Dr. Grady's scientific focus has primarily been in stroke, with emphasis on arterial stenosis and cerebral ischemia. She was elected to the Institute of Medicine in 1999 and is a member of several scientific organizations, including the Society for Neuroscience, the American Academy of Nursing, and the American Neurological Association. She is also a fellow of the American Heart Association Stroke Council. In 1988, Dr. Grady joined NIH as an extramural research program administrator in the National Institute of Neurological Disorders and Stroke (NINDS) in the areas of stroke and brain imaging. Two years later, she served on the NIH Task Force for Medical Rehabilitation Research, which established the first long-range research agenda for the field of medical rehabilitation research. In 1992, she assumed the responsibilities of NINDS Assistant Director. From 1993 to 1995, she was Deputy Director and Acting Director of NINDS. Dr. Grady served as a charter member of the NIH Warren Grant Magnuson Clinical Center Board of Governors.

Before coming to NIH, Dr. Grady held several academic positions and served concurrently on the faculties of the University of Maryland School of Medicine and School of Nursing.

Dr. Grady has authored or co-authored numerous articles and papers on hypertension, cerebrovascular permeability, vascular stress, and cerebral edema. She is an editorial board member of the major stroke journals. Dr. Grady lectures and speaks on a wide range of topics, including future directions in nursing research, developments in the neurological sciences, and Federal research opportunities.

Dr. Grady has been recognized with several prestigious honors and awards for her leadership and scientific accomplishments, including the first award of the Centennial Achievement Medal from Georgetown University School of Nursing and Health Sciences, being named the inaugural Rozella M. Schlotfeld distinguished lecturer at the Frances Payne Bolton School of Nursing at Case Western Reserve University, and receiving the honorary degree of Doctor of Public Service from the University of Maryland. Dr. Grady was named the Excellence in Nursing Lecturer by the Council on Cardiovascular Nurses of the American Heart Association. In 2005, Dr. Grady received Doctor of Science, Honoris Causa degrees from the Medical University of South Carolina and Thomas Jefferson University, and Columbia University School of Nursing honored her with its prestigious Second Century Award for Excellence in Health Care. In 2008, Dr. Grady received a Doctor of Science, Honoris Causa degree from the State University of New York Downstate Medical Center. Dr. Grady is a past recipient of the NIH Merit Award and received the Public Health Service Superior Service Award for her exceptional leadership.