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## **Study Shows Placing Relative with Dementia into Long-Term Care Facility Does Little to Ease the Emotional Burden of Caregivers**

A new study shows that caregivers of dementia patients who must make the difficult decision to place their relatives into institutionalized care get no relief from depression and anxiety, and in fact suffer additional emotional trauma following their decision. The study, funded by the National Institute of Nursing Research and the National Institute on Aging, part of the National Institutes of Health, appears in the August 25, 2004 issue of the *Journal of the American Medical Association (JAMA)*.

The four year investigation, which was coordinated by the University of Pittsburgh School of Medicine and led by Richard Schulz, Ph.D., Director of the Center for Social and Urban Research at Pitt, determined that clinical intervention may greatly benefit caregivers by helping them to prepare for the placement of their relatives and by treating their depression and anxiety during the placement process.

This is the first study to provide a comprehensive analysis of the emotional turmoil caregivers experience during the transition of their loved one from home to a long-term care facility, according to Dr. Schulz. The investigators looked at a number of factors including the conditions that led to placement, the nature of contact between the caregivers and their relatives after institutionalization, and the impact of these factors on health outcomes among caregivers following the placement.

Participants of the study were recruited from six U.S. sites and included 1,222 caregiver-patient pairs. For the 180 caregivers who had to turn over care of their loved one to an institution, symptoms of depression and anxiety stayed as high as when they were in-home caregivers. These findings stand in sharp contrast to earlier findings reported by Schulz and his group showing that death of a loved one after care giving results in improvement in depression.

“Caregivers who place their loved ones in an institution do not get the sense of relief or experience the closure observed among caregivers whose loved ones pass away,” said Dr. Schulz. “They continue to feel distressed because of the suffering and decline of their loved one as well as having to face new challenges such as frequent trips to the long-term facility, reduced control over the care provided their relative, and taking on responsibilities such as coordinating and monitoring care,” he added.

According to Dr. Schulz, “cognitive and functional declines are common in patients who go into long-term care, and caregivers often blame themselves for this decline and question their decision to institutionalize their loved one.”

Caregivers who were married to the patient and those who visited most frequently had the most difficult transition. Spouses reported higher levels of depression both before and after placement and more anxiety after placement than their non-spouse counterparts. Almost half of the caregivers in the study visited the patient daily and continued to provide some form of physical care during their visits.

The study recommends that spouses, caregivers who remain actively involved with the care recipient, caregivers who have high levels of depression, and those who lack adequate support from others should receive interventions. “We need to help caregivers who place their relatives, said Dr. Schulz.. “We need to treat their emotional distress, educate them about the nature of long-term care facilities and their impact on patient functioning, engage them in end-of-life planning, and prepare them for the eventual death of their loved one,” he added.

The patients in this study were all diagnosed with moderate to severe Alzheimer’s disease and had a median age of 80 years. Caregivers were mostly female with a median age of 63 years. The sample was 56 percent white, 24.2 percent African American, and 19 percent Hispanic; most were spouses or children.

The researchers found that African American and Hispanic caregivers were less likely to place their relative in a facility than whites; caregivers reporting greater burden were more likely to place their loved one in long-term care; caregivers who reported that their care giving experience made them feel useful and important were less likely to place their relative in a facility.

“The findings of Dr. Schulz and his associates are particularly relevant as Americans live longer and the number of families faced with placing their loved ones into institutional care grows,” said NINR Director Patricia A. Grady, PhD, RN, FAAN.. “Knowing that these caregivers are vulnerable to ongoing depression and anxiety following such a placement, health professionals can make a difference in these people’s wellbeing by helping them with their emotional distress, and by helping them prepare for and deal with these often difficult transitions,” Dr. Grady added.

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