

Caring for the caregiver: Redefining the definition of patient

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One quarter of all family caregivers of Alzheimer's disease patients succumb to the stress of providing care to a loved one and become hospital patients themselves, according to an Indiana University study published in the November 2008 issue of the *Journal of General Internal Medicine*.

Researchers from the Indiana University School of Medicine, the Regenstrief Institute and the Indiana University Center for Aging Research report in a new study that a quarter of family caregivers of Alzheimer's dementia patients had at least one emergency room visit or hospitalization every six months.

While it has long been anecdotally recognized that caring for a family member with Alzheimer's disease is stressful, this work is the first to measure just how stressful providing care is and to examine the impact of this stress on both the physical and mental health of the family caregiver.

The study found that the behavior and functioning of the individual with Alzheimer's dementia, rather than cognitive ability, were the major factors determining whether the caregiver went to the emergency room or was hospitalized.

"Our findings opened our minds to the fact that society needs to expand the definition of patient to include both the person with Alzheimer's dementia and that individual's family caregiver," said Malaz Boustani,

M.D., corresponding author. Dr. Boustani is assistant professor of medicine and a Regenstrief Institute research scientist.

The researchers looked at 153 individuals with Alzheimer's disease and their family caregivers, a total of 366 people. Forty-four percent of the caregivers were spouses. Seventy percent of the caregivers resided with their charges.

The average caregiver was 61 years of age. The researchers found that age, education and relationship to the individual with Alzheimer's disease did not impact caregiver use of acute medical services – either emergency room or inpatient facilities.

"While we've long known that Alzheimer's is a devastating disease to the patient, this study offers a look at how it also impacts the caregiver's health. If we don't offer help and support to the caregiver, too, the stress of caring for someone with dementia can be overwhelming, both mentally and physically," said Cathy C. Schubert, M.D., IU School of Medicine assistant professor of clinical medicine.

Approximately four million older adults in the United States have Alzheimer's disease and three million of them live in the community, often cared for by family members. This number is growing rapidly and by 2050 it is estimated that there will be 18.5 million cases of Alzheimer's dementia in the United States.

"For American society to respond to the growing epidemic of Alzheimer's disease, the health-care system needs to rethink the definition of patient. These findings alert health-care delivery planners that they need to restructure the health-care system to accommodate our new inclusive definition of patient," said Dr. Boustani.

Dr. Boustani directs the Healthy Aging Brain Center. Using the findings

of this study, the center is leading the nation in expanding the definition of patient to include the individual with Alzheimer's disease and family caregivers and to provide care to both. The Healthy Aging Brain Center is part of the IU Center for Senior Health at Wishard Health Services.

Source: Indiana University

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