Caregivers Learning to Manage Illness also Helped in Coping with Death

Original goal was easing burden of caring for relative with dementia

August 3, 2006 - An intervention aimed at preventing depression and easing the burden of caring for a relative with dementia also helps to prevent complicated grief and depression following the death of the loved one, according to a University of Pittsburgh-led study. The findings could help the millions of American families caring for relatives with dementia. Approximately 4.5 million Americans with Alzheimer's disease live at home with 75 percent cared for by family members.

The study, published in the August issue of the American Journal of Geriatric Psychiatry, was initially designed to establish methods for preventing depression and increasing coping skills during the caregiving process, sought to determine who among caregivers were at risk for complicated grief and depression after their care-recipients died.

Surprisingly, the interventions aimed at helping the caregiver cope while the care-recipient was living also helped the caregiver cope with the recipient's death, preventing complicated grief and depression. According to principal investigator and lead author Richard Schulz, Ph.D., professor of psychiatry at the University of Pittsburgh, the finding was totally unexpected.

Complicated grief most often occurs following the death of someone in a very close and loving relationship. Key features include:

- a sense of disbelief regarding the death,
- anger and bitterness over the death,
- recurrent pangs of painful emotions with intense yearning and longing for the deceased,
- avoidance of situations and activities that are reminders of the loss, and a preoccupation with thoughts of the loved one, often including distressing, intrusive thoughts related to the death.

Since it is a newly characterized condition, not yet included in the American Psychiatric Association's Diagnostic and Statistical Manual, little is known about how to treat and prevent complicated grief. In fact, report the authors, the results of this study are the first to demonstrate the effectiveness of such interventions -- which include education, skills training and group support -- on preventing complicated grief and depression after death.

Twenty percent of the caregivers in the study experienced symptoms of complicated grief after their loved ones died. Most of these did not receive the interventions, had depressive
symptoms and/or saw the caregiving process as positive, usually because they derived a sense of purpose from the situation, and were most likely to experience severe depression and complicated grief post-death.

"Taking care of a relative with dementia can be very stressful. Most caregivers respond well to their loved one's death, seeing it as a relief for the patient, which is why we focused on helping during the caregiving process, rather than after," said Dr. Schulz, who is associate director of the University of Pittsburgh Institute on Aging and director of the Center for Social and Urban Research. "Given that in our previous studies we have found that a large number, some 30 percent of caregivers, are still at risk for severe depression after the death of their loved one, it's encouraging to know that these interventions can help both before and after death."

The Resources for Enhancing Alzheimer's Caregiver Health (REACH) study followed 1,222 caregivers and their loved ones in Boston; Birmingham, Ala.; Memphis, Tenn.; Miami; Philadelphia; and Palo Alto, Calif., between 1996 and 2000. During the course of the study, 265 of the care-recipients died; 217 of their caregivers were followed for this study.

According to the authors, the caregivers were generally representative of individuals who provide in-home care for relatives with Alzheimer's disease. They were an average of 64 years old; 84 percent were women; and nearly half were caring for a spouse. Care-recipients were on average 81 years old and 54 percent were men.

Caregivers were initially randomized to receive either six months of an active intervention or a control intervention, and were assessed at the onset of the study and at six, 12 and 18 months. The caregivers whose loved ones died during the study were assessed following the death, around 15 weeks post-death, and at six, 12 and 18 months.

The researchers found that reducing caregiver burden, treating depression prior to death and providing supportive psychosocial or skills training caregiver interventions helped the caregivers to better manage with their loved one's deaths.

"Our findings show that caregiving is closely intertwined with the bereavement experience that follows. Family members caring for relatives with advanced disease would not only benefit from traditional caregiving interventions designed to ease the burden of care but also from pre-bereavement treatments that would better prepare them for the impending death of their loved one," said Dr. Schulz.

Notes on study:
Co-authors of the study include: Kathrin Boerner, Ph.D., Lighthouse College of Medicine of Yeshiva University and Montefiore Medical Center. The initiative, funded by the Donal W. Reynolds Foundation of Las Vegas, is known as the GeriEd Program, which will contain both educational and clinical components. Read more...

Hospice Organization to Launch National Quality Initiative to Improve Care
Goal to improve hospice and palliative care delivery and outcomes
July 3, 2006 - This September, the National Hospice and Palliative Care Organization will launch a national, quality initiative designed to help hospice providers build organizational excellence and improve hospice and palliative care delivery and outcomes. The Quality Partners program will be unveiled at NHPCO's annual Management and Leadership Conference in New York City, September 11 – 13, 2006. Read more...

Geriatric Care Managers Emerging as Important Contributors to Eldercare
National association now has over two thousand members
June 6, 2006 – Geriatric care managers, unknown 20 years ago, are emerging into an important piece of the network for the care of the elderly. The New York Times explored the industry in an article on Saturday and found they "are growing increasingly popular as people live longer and want to grow old in their homes." The number of certified geriatric managers totals about 2,041 today, compared with about 50 in 1985.
International, N.Y.; Katherine Shear, M.D., formerly of the University of Pittsburgh and now at the Columbia School of Social Work, New York City; Song Zang, M.S., University of Pittsburgh; and Laura N. Gitlin, Ph.D., Thomas Jefferson University, Philadelphia.

The study was supported by grants from the National Institute on Aging, the National Institute of Nursing Research, the National Institute of Mental Health and the National Heart, Lung and Blood Institute, all of the National Institutes of Health.