Medical Xpress

# Caregivers and their relatives disagree about care given, received

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Caregivers and their relatives who suffer from mild to moderate dementia often have different perceptions regarding the amount and quality of care given and received. A study by researchers at Penn State and the Benjamin Rose Institute on Aging examined a major source of those differences -- caregivers do not understand the things that are important to their relatives with dementia.

"Family caregivers often become the surrogate decision makers of relatives who have dementia, so the two groups need to communicate well and to understand each other," said Steven Zarit, a professor and head of the Department of Human Development and Family Studies at Penn State and the study's leader. "Unfortunately, in our study we found that family caregivers and their relatives often do not understand each other well when it comes to the values they hold about giving and receiving care."

The team interviewed 266 pairs of people, each composed of an individual with mild to moderate dementia and his or her family caregiver. To participate in the study, caregivers had to be the primary family caregiver of the dementia patient and the dementia patient had to be living in his or her own home. The researchers interviewed members of the pairs separately, asking questions related to how much value they place on five core values: autonomy, burden, control, family and safety. For example, one question focused on the level of importance a dementia patient gave to the ability to spend his or her own money in the way he or she wants.

"Our results demonstrate that adult children underestimate the importance that their relatives with dementia placed on all five core values," said Zarit. "For example, the person with dementia might think it is very important to continue to be part of family celebrations, but his or her caregiver might not." The team's results will appear in the August issue of The Gerontologist.

According to Zarit, a major reason for differences in these perceptions is that caregivers come to view people with dementia as unable to make their own decisions about daily life. "That is something that does happen as the disease progresses, but the people in our study remained capable of making decisions for themselves and could express their values in a clear and direct way," said Zarit. "Caregivers who still saw the person with dementia as able to direct his or her daily life were also more in tune with that person's values and beliefs."

This lack of agreement about how care is provided has ominous implications for when the dementia worsens. "As people's cognitive abilities decline," Zarit said, "they can no longer express clearly what they want. Family members have to act as surrogate decision makers, but if they don't understand the dementia patients' preferences about care, they may not be able to make the best choices."

Zarit plans to continue this research by developing and evaluating protocols for improving communication between caregivers and their relatives to ensure that medical and social decisions are made in such a way that reflect dementia patients' actual values.

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