Family Matters
Family Quality of Life in Dementia

The number of adults 65 and older in the United States with Alzheimer’s disease (AD) is projected to increase from current figures of 5.2 million to 11 to 16 million by 2050 (Alzheimer’s Association, 2011). The 2011 report from the Alzheimer’s Association indicates that every 69 seconds someone in the United States develops AD. As the medical community and the general public increasingly advocate for early evaluation and identification of memory loss, the number of people who are diagnosed with dementia is anticipated to grow.

Dementia affects not only the individuals with the disease but also the quality of life of the people closest to them—usually their family members or caregivers. Family members provide the majority of care to people with dementia. Unpaid family caregivers will likely continue to be the largest source of long-term care services in the country and are estimated to reach
37 million by 2050, an increase of 85% from 2000 (U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, 2003). However, limited data are available on the quality of life of the family as a result of a dementia diagnosis in a loved one.

Previous literature on quality of life in dementia has suggested that patient and caregiver reports on quality of life are needed, but research has typically focused on the patient only, regardless of who provides the data (Logsdon, Gibbons, McCurry, & Teri, 2002). Although family caregivers are often asked to give a proxy report of the quality of life of the person with dementia and ratings of their own quality of life, few studies explore the impact of dementia on family quality of life. Thus, conventional methods of measuring quality of life that involve only a single-person perspective (i.e., caregiver) are unable to capture the full breadth of all individuals... affected by living with a person with dementia.

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...ies have shown is that the number of problems experienced by both patients and caregivers is related to their distress levels. Similar to caregiving relationships among those with dementia, the family as a whole is affected, and each member has to adjust to the illness.

In our recent work, we explored the concept of family quality of life in dementia. Through the use of Delphi methods with an expert consensus panel and interviews with family members of people with AD, we are pilot testing an instrument to objectively measure this concept. Preliminary results from our testing indicate the following domains are important to measure: family interactions, direct care/activities of daily living support, emotional/behavioral well-being, physical and cognitive well-being, and disease-related support/medical care. Further pilot testing of our instrument is ongoing, and we anticipate disseminating the results in the near future.

Our goal is to gain greater understanding of quality of life not only from the perspective of the individual with the disease or a single family caregiver, but from the entire family perspective. Our vision is that the instrument will provide a means by which health care professionals and community-based providers can measure the outcomes of their services as they plan interventions to enhance family quality of life.

REFERENCES

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The authors disclose that they have no significant financial interests in any product or class of products discussed directly or indirectly in this activity, including research support.
doi:10.3928/00989134-20110503-06