

## Caregivers of Persons with Mild Cognitive Impairment: Information and Support Needs

Final Report – Abstract

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Mild cognitive impairment (MCI) reflects self-reported changes in cognitive function that do not markedly interfere with work or social relations; it is viewed as a transitional phase between normal cognitive aging and dementia. Early identification of memory loss has critical profound implications for clinical practice and the delivery of health care and social services to older individuals and their relatives. The purpose of this study is to identify the issues and needs of family members in the beginning stages of the care cycle.

Recruitment of 99 families began in November 2003 and was completed in October 2005. Memory clinic patients, 60 years of age and older, who agreed to participate in the study were asked to name the primary family member who was most involved in their lives. In turn, these family members were invited to participate in the study and asked to identify a secondary family member who was then contacted by telephone and invited to participate in the study. Interviews were completed with 99 patients, 99 primary family members, and 57 secondary family members. The primary family members were usually spouses/partners (74%); adult children were most likely to be the secondary family members (77%).

Findings suggest that persons with MCI respond in one of three ways. Some patients were *strategists*; their memory loss was apparent to them and they wanted to find out all they could about what it is, why it is occurring, and what they could do about it. They had already begun working through potential changes in their lives. Patients in the second group appeared more *ambiguous* about the changes they were experiencing. They were friendly during the interview, but did not appear to recognize that they have memory changes and did not understand why they needed to be tested. A few patients appeared *troubled* by their condition. They are not accepting of the memory changes. Although they did not acknowledge problems very willingly, interviewers sensed that they realize things were not quite right.

Primary family members reported that their relatives were experiencing memory-related changes that interfere with their daily activities and responsibilities, decision-making processes, and relationships. The current definition of MCI suggests that this condition has no or minimal influence in elders' daily activities and social lives. Our findings suggest that the existing definition is not sufficient to capture fully the day-to-day implications of having MCI; rather, there may be a progression of decline within those diagnosed with MCI that involves gradual changes in functional abilities and social relationships. It may be that these subtle changes have gone unnoticed in routine clinical evaluations, suggesting the need for more sensitive assessment of daily and social functioning in community memory clinics.

Primary family members tended to express more negative than positive emotional responses to the changes experienced by the person with MCI. Their comments about the negative aspects of their situation suggested that they were frustrated by the continual support they provided for their relative and the changes this has brought to their lives. This finding is significant because longitudinal research shows that problems appearing early in the care cycle have long-term implications for caregivers' psychosocial outcomes such as feelings of burden and depression. These findings suggest the need for professionals to provide information, assistance, coping strategies, and support

to family members at this stage in the care process rather than waiting until Alzheimer's disease is diagnosed.

Secondary family members provided emotional support for the primary family members, but typically were not involved in their or the patients' day-to-day lives. They believed that primary family members needed more or better information about MCI, changes the patient may experience in the future, and how to manage these changes. They perceived MCI as taking a toll on the entire family and were worried about the future care needs for both the patients and the primary family members.

Overall, study findings suggest the need for education, counseling, and mental health services to assist family members in this pre-caregiving stage in dealing with feelings of stress and burden and changes in their relationship with the person with MCI. To begin to address these needs, we developed an educational brochure for family caregivers and health/human service providers who assist families experiencing MCI, as well for community leaders who plan and implement public policy in support of these families (see <http://www.gerontology.vt.edu/Gerontology%20MCI%20.pdf>). This type of information is essential for enabling more informed public policies and services for this understudied yet vulnerable population.