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Abstract

One of the newer concepts of age-related memory deficit is mild cognitive impairment (MCI). MCI reflects self-reported changes in cognitive function that do not necessarily interfere with work or social relations; it is viewed as a transitional phase between normal cognitive aging and dementia. Researchers and practitioners lack a comprehensive understanding of what relatives of persons with MCI are actually experiencing and what they realistically believe would be helpful to manage their situation now and in the future. In a multi-method, mini-longitudinal design that incorporated quantitative and qualitative approaches, we collected information from patient charts and semi-structured family interviews to investigate the information and support needs of 20 (out of 100 to be interviewed) family members of older adults with MCI. We found that, apart from information available about potential later diagnoses such as dementia or Alzheimer's disease, families reported having little information available to them to assist in decision-making and caregiving for early stages of memory loss. Family members were hesitant to think about and plan very far into the future and were more likely to take things a day at a time. Past experiences with family members or friends with memory difficulties or other serious health conditions enabled some family members to feel more at ease and knowledgeable with the process of seeking help for themselves and the older adult they were supporting. Findings suggest that earlier identification of memory loss has implications for clinical practice and the delivery of health care and social services to older individuals and their relatives.

Sample

Semi-structured in-depth interviews with 20 family members of patients with MCI

Patient Characteristics

- 60 – 87 years of age
- 9 females, 11 males
- 65% living with caregiver
- Symptoms began 3 months to 8 years ago

Caregiver Characteristics

- 38 – 89 years of age
- 15 females, 9 males
- 30% employed
- 60% spouse/partner
- 35% child
- 5% sibling

Common Symptoms

- forgetfulness
- depression
- anxiety
- frustration

Caregiver Concerns About Patient

- inactivity
- staying alone / loneliness
- increasing dependence
- increasing forgetfulness, repeating questions, having to do things for patient
- loss of independence

Reaction to Memory Loss

Qualitative Data Revealed at Least Three Distinct Responses

Ready for anything – these caregivers take care of themselves physically and emotionally, seek out information about community services and alternate housing options, and help patients think through their future needs

Worried about the future – these caregivers express concern about the severity of memory loss that can be expected, where they will find support to care for the patient, and who will provide care for the patient should they not be able to do so

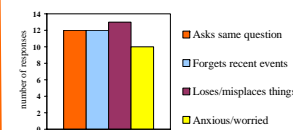
Just use it – these caregivers appear to have a difficult time accepting the patient's memory changes; they suggest if their impaired relatives would just try harder, be more active, or participate in stimulating exercises they would not have as much difficulty remembering

Management of Daily Life

Practical Strategies

- write everything down
- keep calendar
- provide respectful reminders
- simplify things
- assist with medications
- keep patient engaged
- focus on the moment
- secure outside help
- slow down and be flexible

Most Common Problem Behaviors

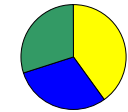


Coping Strategies

- deal with every day as it comes
- collect available information
- use support network
- keep patient as highly functioning as possible
- pick your battles

Future Planning

Plans for the Future



- No Plans
- Tentative Plans
- Already Changed Living Situation

Caregiver Responses to: What do you think will happen in the future?

- hope s/he doesn't get too bad
- hope s/he will improve
- hard to make plans, don't know how condition will progress
- worried about what will happen if caregiver passes away first
- expect memory will get worse

Caregiver Responses to: What will you need in the future?

- information on available options
- information on Medicare and Medicaid
- assistance with patient's finances
- someone to come in and help with ADLs

Advice to Other MCI Caregivers

Caregiver Responses to: What advice would you give to others?

- go to a geriatric center for assessment
- seek help from others – leave no stone unturned
- take care of yourself
- talk to others with similar concerns / join a support group
- let patient do as much as possible for as long as possible
- do the best you can
- learn how to manage anger, personality changes, and depression

Conclusions

MCI Caregivers vs. AD Caregivers: Similarities and Differences

- lack of definitive prognosis provides both hope and despair
- frustration because others do not understand condition
- belief that patient efforts could affect rate of memory change
- family reluctant to reveal changes to larger network
- family history of AD leads to seeking early evaluation of MCI