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Long Term Caregiving: Helping Families of Persons with Mild Cognitive Impairment Cope

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Abstract

The purpose of the paper is to describe common psychological and caregiving issues that can cause stress in family members of persons with mild cognitive impairment (PwMCI) in order to assist family members in providing care and support to the PwMCI while also caring for themselves over long periods of time. Because PwMCI and their family members have time to prepare for the future should the PwMCI no longer be able to participate in their own care, it is important that clinicians offer support, education, and referrals for services and interventions when needed. The results of a review and synthesis of the caregiving literature found that much information exists from educational and intervention programs designed to help caregivers of Alzheimer disease however little empirical information is available for clinicians to assist PwMCI and their family members. This paper provides valuable and practical information for clinicians and other care providers to assist family members of PwMCI to cope with the uncertainty of the diagnosis, prepare for the future, and manage their stress over the long-term.

Keywords

Coping strategies; mild cognitive impairment; education; family members

INTRODUCTION

Most research on family members of persons with cognitive impairment has involved primarily caregivers of persons with Alzheimer disease (AD). However, as research on diagnosing AD in its earliest stages has evolved, the time between healthy cognitive aging and changes in cognition has been identified as mild cognitive impairment (MCI). MCI is currently recognized as a syndrome of cognitive decline greater than expected for an individual's age and educational level that interferes with functioning performance, but without other symptoms leading to a diagnosis of AD [1–4]. It is important to note that there is controversy concerning MCI as a diagnosis and the rate of conversion to AD [5]. Some research has suggested that persons with mild cognitive impairment (PwMCI) progress to a diagnosis of AD at an accelerated rate [6]. For example, Petersen [7] reports that 12% of individuals with MCI convert to AD per year and within 6 years, 80% have converted. However, some individuals never convert to an AD diagnosis and others even revert back to normal [8,9]. Because MCI is so heterogeneous and

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the possibility of conversion uncertain, helping PwMCI and their family members cope with both the diagnosis and care is especially important but there is very little empirical evidence available concerning interventions and support for PwMCI and their family members.

Related to the uncertain outcome of a diagnosis of MCI, is the nature of the role that family members or significant others play in the daily routine of PwMCI. There has been little attention to this in the literature, thus making it difficult to find a common language to describe such roles. The terms “caregiver” or “care partner” are now well recognized in the AD and dementia literature but may not be appropriate to use for those people who live with, care about and provide assistance to PwMCI. Because PwMCI are still functional and relatively independent and the term “caregiver” implies significant levels of assistance and supervision, for the purposes of this paper, we have used the term “family member(s)” to refer to those individuals who live with, care about, and provide support to a PwMCI and could benefit from the suggested intervention strategies. Previous reports have used terms such as “care partner” or spouse when the sample was limited to married couples [5,10]. We realize and acknowledge that individuals other than “family members” in the strictest of sense also provide support and assistance to PwMCI and suggest that the strategies suggested in this paper apply to non-relatives as well.

While the literature on family members of PwMCI may be limited, there does exist an extremely large and growing literature on AD caregivers that we believe can be applied to family members of PwMCI or at the very least suggest possible strategies for interventions. Indeed, the fact that a diagnosis of MCI means that the patient’s cognitive impairment is not yet severe enough to be diagnosed as AD, gives the PwMCI and the family members valuable time in which to prepare for the future, obtain necessary legal, financial, medical, and social service information before the cognitive impairment does progress and interferes with the PwMCI’s decision-making skills. At this early stage of cognitive decline, PwMCI and their family members may have a critical window to address needs and hopefully prevent premature disability and disengagement, improve the quality of life for both PwMCI and their family members, and reduce health care burden to society by hundreds of millions of dollars [10].

Persons with MCI have less awareness of their deficits than those adults without cognitive impairment [11,12], and they may engage in unsafe tasks (e.g. driving), experience communication conflicts, and increase the burden of care to family members [12]. Yet, despite such deficits, PwMCI have many cognitive and functional abilities still intact. Therefore, it is essential for PwMCI and family members to identify and discuss areas of congruence and differences in their perspectives of the PwMCI’s cognitive and functional abilities. Congruence in understanding by the family members of the PwMCI’s level of awareness of deficits, may be valuable regarding decision-making about the appropriate amount of supervision required and the extent to which activities should be restricted or adjusted to meet the PwMCI’s needs [13]. An understanding of the level of awareness of deficits may also help the dyad talk about and make mutually acceptable plans for their future should the cognitive impairment progress.

Results from educational interventions designed to help family members cope with AD can guide the development of interventions to improve the quality of life of both the PwMCI and their family members. Lessons learned from the caregiving literature may be especially helpful as MCI family members face both the long term nature of the disease if conversion to AD does occur and eventually may lose the PwMCI to a devastating degenerative dementia. The purpose of this paper is to provide a review of the issues that family members report as particularly stressful and suggest strategies to help family members assist the PwMCI when needed while helping the PwMCI maintain as much independence as possible and not losing sight of their own [the family member’s] physical and mental health.

Common Issues of Concern for Family Members

Clinical practice with caregivers of persons AD can provide valuable insight into helping PwMCI's family members manage care over long periods of time. A key step in assisting any caregiver is to do an initial assessment of the family's current coping status assessing both psychological issues and problems involving patient care. Kaplan provides a useful structure for identifying the key psychological issues facing a caregiver [14]. Not all family members necessarily experience psychological distress and need intervention. While it is important to offer support, it is equally important to recognize situations that do not require intervention. We recommend acknowledging the PwMCI and their family members' success at dealing with the diagnosis and managing their daily activities and leaving the door open should they require assistance later on. For PwMCI and family members who may be having some problems in coping, the stages of emotional adjustment as described by Kaplan that may be helpful to clinicians and include:

Denial:	making excuses for patient; attributing problems to other causes
Over-involvement:	compensating for the patient's losses
Anger:	embarrassment caused by patient's behavior problems; frustration over the inability to halt the disease progression; anger because of the caregiving burden; displaced anger toward other family members or health care professionals
Guilt:	over the inability to accommodate patient's behavior and care needs; suppression of negative feelings often associated with caregiver depression
Acceptance:	of the diagnosis and appropriate grieving [14, p 32]

In addition to the emotional adjustment of the caregiver, clinicians should also identify any problems that the family members might be experiencing that are associated with issues related specifically to the diagnosis. Based on Dopper [15], Kaplan suggests the following clustering of such issues:

Family disruptions:	role changes; role overload; family conflicts
Psychological stress:	resentment; anger; deterioration of patient; other demands; self-blame; loneliness, <u>depression</u>
Physical fatigue:	caregiving demands of a deteriorating patient
Social isolation:	lack of time and energy; embarrassment over patient's behavior leading to an avoidance of friends and social situations
Financial issues:	reduced income of patient or caregiver; medical expenses; <u>anxiety about long term care costs</u>
Legal issues:	mental competence of patient [14]

[NB: underscored items were added by the authors]

Such categories or clusters can be extremely helpful not only in identifying the key issues facing family members, but also in designing targeted interventions to help them cope better and longer. In the AD caregiving literature coping better and longer has traditionally been defined as reducing depression in the caregiver and delaying institutionalization for the patient—both reasonable goals for family members of PwMCI as well.

Recommended Interventions for Family Members

For the purposes of this paper, the clusters suggested by Kaplan will be used to structure the recommendations for working with and interventions for family members experiencing those issues. As stated previously most interventions to assist with self-care or caregiver management have been targeted towards those with more advanced (middle to late) stages of cognitive impairment, that is, AD. Generally speaking, the literature on educational and psychological interventions for AD caregivers is mixed, with some reports of improvement in outcomes [c.f. 16–27] while others report only weak to moderate benefits for caregivers of dementia patients [28].

Clearly, some family members will have some issues with which they could use help, and clinicians should provide some guidance or referrals to local social service agencies that can assist family members in need. Naturally, PwMCI and their family members will vary in their resources and ability to cope; therefore, not all PwMCI and their family members will necessarily need all of the information or recommendations at the same time. Individualized or tailored interventions based on an initial caregiver assessment have been shown to be particularly useful [16]. The PREVENT study protocols have been found to be helpful with caregivers of persons in various stages of dementia [16,29]. Based on those protocols, the following guidelines to help the PwMCI and their family members cope over long periods of time are offered here:

EMOTIONAL ADJUSTMENT ISSUES AND RECOMMENDED INTERVENTIONS

Denial

Many PwMCI and their family members need long periods of time to accept the fact that they are indeed experiencing memory problems. Lu has described this phenomenon with both the persons with MCI and their spouses [10,31]. Additionally, once the PwMCI and their spouse can no longer deny or ignore memory problems, others in the family may still be experiencing denial or are not yet ready to admit changes in their parents' or in-laws' cognition. The spouses then often report feeling frustrated and lonely about this as others in the family may question or challenge their decisions concerning treatment and future care plans for the PwMCI [10]. As one spouse put it "*Others in my family and friends don't understand he has memory problems and they don't know how to ask about it. They don't realize how difficult it is.*" An effective strategy for dealing with denial in the family was for this spouse to include her adult children in the PwMCI's physician appointments: "*I asked my daughter to go with us to my spouse's follow-up examination at the clinic and to go over the update results*". The spouse found this to be a good way to educate the adult children about their father's needs.

In Lu and Hasse's work with PwMCI and their spouses, concerns about the future were common. These included concerns about appropriate treatment plans, e.g., the use of medications; relocation and downsizing property; and legal documents such as a power attorney and a living will. Spouses described the stressors associated with the time involved in selling property, for example, but both the PwMCI and the spouses expressed relief once the decisions were made and legal documents were in place [10].

Beyond providing referrals and information about where to get legal and financial advice, the clinician or social worker on the care team should ensure that the tough decisions are being made and that plans for the future that have been put in place. It is also recommended that family members have a back-up plan should someone else need to assume care and supervision for the PwMCI. For example, a very common concern raised by spouses was: "*What will happen to the PwMCI if something happens to me?*" Family members are encouraged to answer that question and have a back-up plan in place.

Over-Involvement

While it is understandable that loving, supportive family members may compensate for the PwMCI's losses, this can often make the person more dependent than necessary more quickly. Therefore, it is generally accepted that a major goal of care is to keep the PwMCI as independent as possible for as long as possible [17]. Family members can be taught how to simplify tasks for the PwMCI in order to keep them engaged in the activity and how to modify the environment for success *if necessary*. Specific protocols to help individuals maintain independence in their activities of daily living are available [16]. Indeed, in the Lu and Haase [10] paper in this issue, it is clear that the PwMCI still wants to maintain function and independence as well. As one

PwMCI stated it: *“There’s another young man that I’ve met just out of prison not long ago, and I know I’ll start mentoring him and that’s what I need in my life. I **need** to be useful; I **need** to be active.”*

Anger

Given the stressors associated with providing care and support to an adult who has been independent for many decades, anger at the situation, anger about the diagnosis, anger about the possible loss of future plans is quite understandable. However, when anger and resentment get in the way of appropriate care for the PwMCI and self-care for the care-giver, intervention may be necessary. The more the PwMCI and family members learn about the diagnosis and possible manifestations of the MCI the better. Teaching the family members to blame the nature of MCI but not the PwMCI is a useful strategy. Showing the PwMCI and family members images of the brain and explaining changes in the areas of the cortex associated for decision-making, language, and memory has been especially useful in educational settings. Attending support groups, while admittedly not for everyone, is useful for some PwMCI and family members because they realize they are not alone in their experiences.

Anger at other family members is very common depending on the involvement of the others. Typically one family member becomes identified as having primary responsibility for care and support. If not the spouse, that family member has typically not volunteered for the role, but insidiously has become very involved in the PwMCI’s activities of daily living. This can create frustration and anger. If the other family members are willing to participate in a family session where, with a clinician/therapist, the issues can be voiced and a mutually agreeable care plan involving all family members can be designed and implemented. Otherwise, it is usually best to support all family members in their roles and teach them ways to accept that others **may** or **may not** want to be as involved in the PwMCI’s daily routine. Encourage those providing support not to judge others but to concentrate on what they themselves can reasonably do to help the PwMCI.

Guilt

Recent studies have found that the prevalence of depressed mood among 769 family members of persons with MCI was 24.6% (95% confidence interval, 21.5–27.7) two times higher than the general population [30]. Given the number of issues a family member can be angry about, guilt is also an understandable response. Indeed, given the increased risk for depression that a family member experiences, it is important that the clinician assess the family member for depression and **treat** it using both pharmacological and non-pharmacological interventions as needed.

Lack of Acceptance

Helping family members reach a level of acceptance of the diagnosis, the future and their own caregiving role is extremely beneficial as they may be providing care over extended periods of time.

Regarding interventions or recommendations for specific issues requiring assistance, the PREVENT study protocols are available for use [16]. The general coping guidelines will be most useful for PwMCI and their family members. Some of the specific protocols on behavioral issues will be helpful should the PwMCI decline [29,16]. As reported in the PREVENT studies, the protocols and interventions were most effective when tailored to the individual person with dementia and their caregiver. However, using Kaplan’s [14] clusters of specific types of caregiving issues, recommended strategies for clinicians to consider implementing should the need arise are included below:

Family Disruptions

The type and number of family disruptions will vary based on various demographic issues. For example, a spouse caregiver typically lives with the PwMCI and generally the children have left home. The adult children often do not live with the parent and have many other demands on their time, which can and do compete with providing care to the parent. Family members, both spouses and adult children, are often surprised by the emotions associated with the changing roles as they provide more supervision for a PwMCI. Despite the relatively high level of function that most PwMCI maintain, many spouses in the Lu and Hasse [10] study reported frustrations in assuming greater levels of supervision. The family members gradually recognized their quality of life was significantly affected by the PwMCI's cognitive impairment, but at the same time, they gradually began to take on roles and activities that were usually performed by the PwMCI as they experienced an increased sense of obligation to take care of the PwMCI.

Most of the family members met the challenges in making decisions for the PwMCI. Some decision-making required new knowledge and skills, or professional assistance, such as selling property (house or husband's company), relocating to retirement housing, filing taxes, and selecting treatment. The PwMCI/spouse dyads in Lu and Haase's study had been married over 40 years and traditional roles were the norm. For wives, their husbands were most often the key decision maker [10]. As the husbands' executive functions declined, their spouses had to take on decision-making roles for a wide range of issues. Family members' concerns for a manageable living space, and safe environment, as well as financial pressures, led them to reluctantly and often prematurely begin the process of selling their own home or business and moving into a smaller house, condo, or retirement community. As one spouse noted "*Since this came on his memory, we had to get rid of our business. My husband was the owner of a business. So we sold our business and in September and moved out of the house because it was too big. It was too much of a financial burden.*" Although most family members carefully selected and planned for relocation, the process of adjustment to a new environment/community was challenging and stressful.

In addition, family members experienced concerns about communicating and using "white lies" because of the conflict between inner values and reality. One wife commented, "*I did the preparation for our income taxes and sent them to our accountant because I would rather have him be angry with me for an hour about doing that than have him anxious and agitated for a week while he is trying to put those figures together unsuccessfully. So I have changed my definition of what is ethical behavior and I trust God understands that... I can't tell him everything I've done and everything I'm going to do every time, every day. I can't do it. I just don't have the energy to do it or to cope with the results of it.*" Family members also reported providing increasingly more detailed help to enable the PwMCI to remain engaged in daily activities. One wife explained, "*If I tell him or give him directions, he's fine. But left alone it's like he's floundering...*" Offering information about the potential decline over time is also helpful as it encourages family members to anticipate changes and this, in turn, can help reduce the element of surprise over time.

Since MCI can appear in people as young as 40 years of age, spouses of persons with MCI not only need to take care of their own grief process, but also devote significant emotional energy and time to talk with their young children or teens, as well as with others in the family (e.g. in-laws and extended family members), and friends, particularly in dealing with their denial and anger.

Family conflicts are extremely common, especially if a decision must be made by the family members that seems to go against the wishes of the PwMCI who is still able to speak for themselves. Helping the family members focus on the issue at hand and not get distracted by

family history or old resentments is important. An objective clinician helping to keep the family members focused on manageable issues is especially useful.

Psychological Stress

A common response to caregiver stress is depression and caregivers tend to be at much higher risk for depression than the general population. Even at a stage as early as MCI, spouses of persons with MCI reported gradual loss of intimacy in their relationship, loss of communication with their spouse, loss of the hoped-for future and loss of social and recreational interactions [1,30]. Family members should, therefore, be given information about the warning signs of depression and encouraged to seek appropriate treatment if necessary. In addition, encouraging the family member to remain involved in things that they were interested prior to their family member being diagnosed is very important for a couple of reasons. First, it is helpful for family members to have something that they can do as a distraction to their potentially consuming caregiving role. Second, at some point, their involvement in the PwMCI's care will end and they will need other activities to occupy their time. Without maintaining some outside interests, family members are at an increased risk for social isolation (described below).

Physical Fatigue

Naturally, caring for another person is physically demanding. As the memory loss progresses so will the physical strain on the family member. It is imperative that family members are encouraged to maintain their optimal health, including their diet, sleep and exercise. Spouses of persons with MCI are often themselves elderly with their own health care challenges. They must be encouraged to seek health care for their own needs, follow their doctor's advice and recommendations, take their medications as prescribed, and so on. Assisting family members to find respite care for themselves is helpful. Respite can come from a variety of sources: family, friends, church groups, friendly visitor programs, and social adult day services if needed.

Social Isolation

It is not unusual for family members and PwMCI to experience social isolation; often it is self-imposed [10,31]. PwMCI may not want to see their friends as they are worried about their own limitations. Their family members may be embarrassed by the PwMCI's behavior and will reduce the number of social outings. Before long, the PwMCI and their family members are in a type of "exile". This may have as much to do with disclosure of the diagnosis to friends and families at the appropriate time, whenever that might be for each individual PwMCI and family members. Along with disclosure about the diagnosis should come some information sharing to family, friends, and neighbors about what they can expect will happen to the person diagnosed with MCI.

Our preliminary studies found that PwMCI focus on their abilities as much as, or more than, their deficits. They engage in diverse daily activities, and gain a sense of fulfillment and meaning from ongoing participation in desired or meaningful activities (those that they define as interesting and pleasurable) and setting and meeting daily goals [31]. Failure to challenge individuals to remain engaged in their meaningful activities, lack of support to maintain their autonomy as long as possible, and loss of meaningful social interactions with others are major concerns in regard to family support of those with MCI. These unsolved issues could prematurely diminish social interaction participation and increase emotional distress for those with MCI. In addition, depression is commonly experienced by persons with MCI [32,33]. Copeland et al found that PwMCI with higher levels of depression were more likely convert to AD than those without depression [34]. Therefore, a major skill-building area for the family members may be to assist PwMCI to manage their emotional distress and depression, seeking treatment when necessary.

Decision Making Issues

Decision making regarding medication treatment for PwMCI and MCI screening for others in family is a challenge for the families and the PwMCI, due to the limited benefits and short-lived duration of treatment and the potential side effects of cholinesterase inhibitors (e.g., diarrhea, nausea, vomiting, muscle cramps, and abnormal dreams) [35,36]. Since MCI is not yet fully characterized, with an uncertain prognosis, the potential “labeling” effect of a diagnosis of MCI, and with limited effective treatment options available, older adults are less likely to consider MCI screening and treatment [37,38]. The decision to screen for MCI in other members of the family is difficult to make. Thus, it is important for the clinicians and other health care providers to provide the updated information of screening tests, the diagnostic process, and treatment of MCI to the family members, and PwMCI as well as to extended family if necessary.

Financial Issues

A diagnosis of MCI can interrupt a career. The ensuing financial strain on a PwMCI and family creates concerns for the present and the future. Aside from the decrease in income if a PwMCI’s career ends, many family members must reduce their work hours in order to provide care and supervision. In addition, plans for retirement are also interrupted and hopes for their “golden years” are shattered. Planning well in advance of a health care crisis is the best course of action. Despite good intentions, many people are unprepared when a crisis hits.

Of special concern are those individuals who have been diagnosed with MCI as young as 40, because they have often struggled with financial issues such as unemployment, unexpected early retirement, and getting disability. Lu’s pilot study of PwMCI and spouses found that the younger persons with MCI (one 48 year old and one 50 year old PwMCI) both experienced difficulty in navigating the social welfare and health insurance systems.¹ Thus, assisting PwMCI and their family members to manage and prepare for the possibility of unemployment and financial strain is critical. As described above, this is not the time to engage in a long process of denial. It is best to get legal and financial help as soon as possible in order to best prepare financially and legally for the future. While most family members worry about having enough money in the future, spending some money for good legal and financial advice early may prove to be quite valuable over time.

Legal Issues

Helping PwMCI and family members prepare for the future and addressing legal issues is paramount. Legions of legal experts are available to assist with the preparation of the appropriate legal documents, including durable power of attorney, health care representatives, wills and trusts. If finances are a concern, check with the local chapter of the Alzheimer’s Association, the Bar Association and Area Agency on Aging for referrals to legal aid programs. Executing legal documents for PwMCI should be relatively straightforward, as their mental competence should not be called into question. Compared to a diagnosis of AD, MCI gives families more time to address legal/financial issues.

IMPLICATIONS

Much can be done to help family members of PwMCI both prepare for the future and cope with the inevitable changes in the care recipient over time. While it is difficult for a primary care physician to provide the level of education and guidance to family members over time, the physician can play a key role in encouraging caregivers to seek out social service agencies

¹Lu, Y-F (2008). Personal communication about the financial issues affecting the younger persons diagnosed with MCI in her 2006 pilot study funded by the Indiana ADC NIH P30AG10133.

in the community that can provide valuable information, education, support and/or referrals. Since PwMCI are often aware of their losses and their risk of developing dementia, health care providers can encourage them and their primary caregivers (e.g. spouse caregivers) to make decisions together about remaining engaged in daily meaningful activities, addressing legal and financial issues early (e.g. living will, durable power of attorney), and designing an appropriate care plan for the future. As there is still no cure treatment for MCI and AD, the clinicians and other health care providers need to provide the updated information of MCI diagnosis and treatment to the PwMCI and their families in order to help them to make decisions regarding diagnosis, treatment and care planning.

Education about interventions during this valuable window of time offers an opportunity to provide early training in interventions to prepare the spouses for possible behavioral disturbances in the future. It is important to assist PwMCI and their family members to make balanced and mutually agreed-upon decisions relative to future plans (for example, financial and medical plans, driving cessation if necessary) based on the caregivers' and the PwMCI's strengths and limitations as well as available community resources. By intervening early one can assist PwMCI and their family members to have a more realistic view of both the strengths and limitations of PwMCI, to engage in meaningful daily activities, to manage negative emotions, to provide the dyad with skill sets that would help manage the challenges of memory decline, and to guide them to utilize appropriate community resources to deal with legal and social welfare issues. In addition, as PwMCI are encouraged to remain active or increase meaningful daily activities with their family members' appropriate supervision or assistance, it may have a beneficial effect on their cognitive function through its impact on mood and physical activity, as well as reducing family members' emotional distress.

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