Family Triad Perceptions of Mild Cognitive Impairment

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Objectives. We examined subjective perceptions of memory loss among older adults with mild cognitive impairment (MCI) and two other relatives in order to improve understanding of family coping. We also investigated contextual conditions associated with perceptions of family dynamics and relationships.

Method. We conducted interviews with 56 family triads (the elder with MCI, the primary care partner, and a secondary care partner). Guided by Pearlin and colleagues’ caregiving stress process framework, questions addressed perceptions of memory changes and interpretation of the effects of MCI on family interaction patterns.

Results. Analyses of family triads revealed four degrees of the extent to which family members similarly acknowledged MCI. The acknowledgment groups differed on history of family dynamics, experience with dementia, and perceived extent of memory change in the elder. Families characterized by full acknowledgment coped better with perceived changes in the elder’s functioning than those in which members’ perceptions of MCI were incongruent.

Discussion. Pursuing family-level data on responses to MCI uncovered more nuanced reactions, often differing across triad members, than individual-based research has found. Family perceptions about changes in elders’ memory have important implications for within-family interactions and support that can help families cope successfully with MCI.

Key Words: Family dynamics—Family triads—Memory loss—Mild cognitive impairment.

Mild cognitive impairment (MCI) refers to a noticeable decline in memory and executive functioning that is not severe enough to be considered dementia yet is uncharacteristic for the person’s age (Petersen, 2004). MCI is a much-debated construct; both health care providers and researchers have criticized the lack of standard definition, diagnostic criteria, and treatment options for this syndrome. Moreover, epidemiological and clinical studies suggest that not all persons with MCI will progress to further cognitive impairment. Estimates of conversion to overt Alzheimer’s disease (AD) vary widely across studies but are significantly higher compared with the rate of AD expected in a normal population (Burns & Morris, 2008). Although MCI is receiving growing attention in the biomedical and health sciences literature, scholars are only beginning to focus attention on how mild cognitive problems influence interactions among family members.

Preliminary investigations uncovered discrepancies in the level of memory loss perceived between persons with MCI and their family members (Farias, Mungas, & Jagust, 2005; Onor, Trevisiol, Negro, & Aguglia, 2006; Ready, Ott, & Grace, 2006). Changes in the elders’ memory often result in reports of heightened anxiety and distress for family care providers (Farias et al., 2005; Lu et al., 2007) as well as strained family relationships (Blieszner & Roberto, 2010; Blieszner, Roberto, Wilcox, Barham, & Winston, 2007). Aside from our research program, to our knowledge, only two investigations of family perceptions included information from both the elders with MCI and a close other (McIlvane, Popa, Robinson, Houseweart, & Haley, 2008; Onor et al., 2006); however, data from elders and their partner in care were presented separately. Missing are studies integrating responses to cognitive decline from the perspectives of multiple family members. This type of analysis is important because most elders are embedded in a network of supporters and potential care providers. To advance understanding about the ways in which families adapt to mild cognitive decline, we examined subjective perceptions of memory loss among older adults and two of their family members and explored the circumstances under which changes in elders’ memory functioning were associated with perceptions of family dynamics and relationships.

Individual and Family Responses to MCI

Although the definition of MCI seems straightforward (self-reported changes in cognitive function that do not necessarily interfere with everyday activities; Petersen, 2004), research has shown a more complex picture. For example, elders experiencing mild memory loss differ in their reactions to an MCI diagnosis. Lingler and colleagues (2006) conducted semistructured interviews with 12 community-dwelling adults aged 65 years and older diagnosed with MCI. Individuals who anticipated memory impairment as a normal part of the aging process expressed relief that they did not have AD or felt satisfaction with the diagnosis.
because it confirmed what they already knew about their forgetfulness. Elders with concurrent medical conditions integrated their overall health status into the process of understanding MCI by attributing causation of symptoms to other ailments, focusing on the interactions between health problems and MCI symptoms, or mentioning concurrent illnesses to establish the distinct but specific relative impact of MCI on daily life.

Individuals in the earliest stage of AD report persistent forgetfulness, trouble with numerical tasks and with planning and organizing, and apathy, which can also be indicators of MCI. In fact, MCI is often viewed as a border zone between normal cognitive aging and dementia (Burns & Morris, 2008). Thus, research on individuals in the earliest stage of AD can inform research on MCI. When older adults begin to experience memory deficits, acknowledging and accepting these changes are difficult. Based on an interpretative phenomenological analysis of interviews with 12 persons with early stage AD, Clare (2003) identified five interrelated processes reflecting participants’ awareness of their memory problems: registering, reacting, explaining, difficulty experiencing, and adjusting. These processes represented a reiterative cycle of adjustment to memory problems and other changes associated with AD. Similarly, MacQuarrie’s (2005) narrative interviews with four women and nine men in the early stages of AD revealed that persons often simultaneously acknowledged their memory deficits and resisted aspects of their disease. Acknowledgment involved acceptance of the disease and its symptoms, expression of feelings about the disease, and strategies to cope with the symptoms. Resistance included disavowing memory problems or limitations, minimizing or normalizing memory changes, and promoting achievements and experiences of competence. MacQuarrie concluded that recognition of these opposing tensions enhances understanding of the lived experiences of persons with early stage memory loss.

Recognition of memory changes, however, does not necessarily ensure that older adults and their relatives agree on the amount of cognitive decline experienced or its influence on the family’s daily functioning and relationships. Onor and colleagues’ (2006) examination of older adults’ and their family members’ perceptions of the elders’ memory loss noted that persons with MCI (N = 60) characterized their cognitive deficits as less severe than their relatives did, and family members described more significant behavioral disturbances than the elders reported. In addition, family members professed an inability of elders to interpret and respond appropriately to the emotional cues and needs of others. Conversations between partners where one spouse had early stage AD revealed that when elders with AD described themselves as functioning reasonably well, partners often resisted their face-saving efforts by confronting their partner as having or being a problem (Clare & Shakespeare, 2004). In addition, some spouses showed a lack of empathy in their response to the concerns and emotional pain expressed by their partner with AD, suggesting the difficulty involved in coming to terms with changes in their lives.

Initial studies also have identified elevated burden and concomitant high psychological distress (i.e., anxiety, depressive symptoms) among family members of persons with MCI (Bruce, McQuiggan, Williams, Westervelt, & Tremont, 2008; Lu et al., 2007). Investigators have speculated that the presence of such symptoms among spouses may be associated with the newly found need to provide support and oversight, such as medication management, which serves as a painful daily reminder that their partners have developed memory problems (Garand, Dew, Eazor, Dekosky, & Reynolds, 2005). An analysis of structured focus group discussions among 11 spouses and adult children of persons with MCI revealed substantial burden associated with interacting with these relatives (Frank et al., 2006). Of note were the high level of dependence among those with MCI and the changing roles of other family members. Our own research confirms that husbands and wives are indeed stressed by the changes and challenges associated with both the behaviors of their spouses experiencing MCI (Roberto, McCann, & Blieszner, 2011; Savla, Roberto, Blieszner, Cox, & Gwazdauskas, 2011). The ambiguity married partners experienced as a result of MCI often led to distressing communication problems, conflict, and aggravation of preexisting relationship issues that affected their emotional involvement with one another. The results suggested increased vulnerability of these families to the negative effects of future deterioration in the elders’ functioning.

These preliminary studies of the relational context of MCI highlight the marked influence of subjective experiences and differences in perception on the family’s ability to cope with the daily stressors associated with MCI. Scholars have yet to explore the complex interplay of these facets of family life. Understanding the influence of mild memory changes on family interactions and well-being is important because problems and concerns appearing early may influence family members’ willingness and ability to provide future care and sustain the quality of their relationships (Gaugler, Davey, Pearlin, & Zarit, 2000).

**Conceptual Framework**

We drew theoretical guidance from the caregiving stress process framework of Pearlin, Mullan, Semple, and Skaff (1990) regarding the interactions among stressors, coping mechanisms, and social support in the design of the semistructured open-ended interview protocol for the MCI family project. Pearlin’s framework highlights four aspects of the caregiving stress process (see Figure 1, constructs in bold font). “Background and context variables” focus on demographic characteristics, caregiving history, and interpersonal dynamics. “Primary stressors” include indicators such
as the caregiver’s objective perception of the care receiver’s cognitive status and problematic behaviors as well as subjective indicators of the caregiver’s role overload and relational deprivation. “Secondary stressors” include both role strains (e.g., family or job conflict, economic problems) and intrapsychic strains (e.g., low self-esteem, a change in one’s sense of self). In addition, “protective conditions” such as coping strategies and social support may affect secondary stressors as well as outcomes. Negative outcomes from family stress may include depression, anxiety, or disturbances to cognitive functioning or physical health of any family member. Scholars using this framework have noted that the ability of family members to function well as a unit may directly affect objective burden and distress (Mitriani et al., 2006).

Methods

Sample

The sample comprises family triads: elders with MCI and two people on whom the elders rely when they need support or help. We used purposive sampling techniques (Charmaz, 2006) to obtain a sample in which an elder (age 60+ years) had received a clinical assessment of MCI at six memory clinics in six cities. Although there is no “gold standard” for diagnosing MCI, the clinics incorporated five commonly used criteria in their assessment protocol: (a) complaint of memory loss, (b) minimal interference with activities of daily living, (c) normal cognitive functioning, (d) memory loss uncharacteristic for the person’s age, and (e) no evidence of dementia (Petersen et al., 1999). Specifically, clinic staff diagnosed MCI using comparable batteries of tests to rule out the presence of dementia and potential reversible causes of memory loss and confusion (e.g., depression, nutritional deficiencies, or health problems). All the clinics used the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) and Clock Drawing Task (Royall, Cordes, & Polk, 1998) and ruled out dementia based on Diagnostic and Statistical Manual IV-R (DSM-IV-R) guidelines; however, the clinics differed in the specific instruments used for other health markers. For example, some used the Katz’s index (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and others used the Barthel’s index (Mahoney & Barthel, 1965) to assess activities of daily living and instrumental activities of daily living functioning. The average MMSE score of the elders at the time of our data collection was 26.8 ($SD = 2.5$), which is within the typical
range (24–30) researchers and clinicians use to screen for intact general cognitive functioning (part of the MCI criteria).

In the original interviews based on the 125 elders who agreed to participate (64% response rate), we collected data from 74 triads. Of these triads, 56 were composed of family members (17 triads that included a family/friend mix and 1 family triad for which the recording equipment malfunctioned were excluded from this analysis). We defined family as a spouse or life partner and any other biological or legal relative. In the majority of families, the elders’ spouses assumed the role of primary care partner (PCP; 64.3%) and adult children served as the secondary care partner (SCP; 76.8%). We use the term “care partner” because these supporters and helpers are not caregivers in a strict sense. By definition, elders with MCI retain many of their cognitive skills and functional abilities but often receive some assistance from significant others (Blieszner & Roberto, 2010; Blieszner et al., 2007). Table 1 lists the demographic characteristics of the 56 family triads.

### Procedures

The Institutional Review Boards of Virginia Tech and the participating memory clinics approved this research.

A growing literature attests to the feasibility of obtaining insightful and reliable information about changes in daily life from persons experiencing mild memory problems.
(e.g., Brod, Stewart, Sands, & Walton, 1999; Clare, 2003; Feinberg & Whitlatch, 2001; Logsdon, Gibbons, McCurry, & Teri, 1999; MacQuarrie, 2005; Whitlatch, Feinberg, & Tucke, 2005). We invited newly diagnosed elders with MCI to participate in the study and to identify their PCP. We asked, “Can you give us the name of a close family member or friend who would also be willing to talk with us about your memory loss, the support you provide to each other now, and what might be needed in the future?” We then asked the PCP to identify a SCP using the question, “Would you mind telling me the names and phone numbers of others who should be a part of our study? These would be family members or close friends who know about [elder]’s condition and have been in touch with [her, him] in the past month.” The lag between diagnosis of MCI and the interview date of the 56 families ranged from 0.5 to 40 months (M = 9.5 ± 9.4 months; 23% were interviewed within 1 month, another 26% within 9 months, and another 22% within 15 months).

Doctoral-level researchers with backgrounds in family studies and gerontology or a clinical social worker conducted separate face-to-face guided interviews with the elders and PCPs, usually in their homes. Interviews began and ended with structured scales; open-ended questions (data used in this paper) were asked in the middle to reduce participant fatigue from completing forms. Graduate research assistants in counselor education and human development conducted brief semistructured interviews with SCPs by telephone to obtain an additional perspective on the family situation. Conducting the interviews by telephone allowed the inclusion of SCPs who lived at a distance and was less burdensome than face-to-face interviews for SCPs who often were managing work, family, and civic responsibilities.

The investigators (first two authors) provided all interviewers training on the purposes of the research, the intention of each open-ended question, and the appropriate probes to use with respect to each question. Interviewers read articles on MCI, conducted practice interviews, and received feedback and additional coaching by one of the investigators. To ensure fidelity to the interview guide and quality of the interview data, research team members, including the investigators, met at least biweekly to review procedures and completed interviews.

The interview questions reflected constructs identified in the literature and Pearlin’s caregiving stress process framework. Elders were asked about the changes they noticed in their thinking and memory, what prompted them to go to the memory clinic, how their family members responded to their memory changes, and help they received from family members with tasks they used to do themselves. Questions asked of the PCPs focused on changes they noticed in the elder’s memory, what led to the assessment at the memory clinic, their reaction to the clinic diagnosis, changes in their roles and relationship with the elder, how they managed everyday life with the elder, and involvement of other family members and friends. The SCPs were asked about their perceptions of changes in the elder’s memory, how they believed the elder and PCP were handling the diagnosis and memory problems, how they helped the elder and PCP manage MCI, and about the involvement of other family members. All interviews were tape recorded and transcribed verbatim by a professional transcriptionist. The transcriptions were verified by team members who compared them with the audio recordings of the interviews. We used grounded theory methods to code and analyze the interviews in order to be “purposefully explanatory” (LaRossa, 2005, p. 837) rather than only descriptive in our approach (see also Charmaz, 2006).

Data Coding and Analysis

Open coding.—The research team that completed the initial coding consisted of doctoral and master’s prepared individuals in counseling, human development, family studies, gerontology, and psychology; two team members had direct experience with a family member with memory deficits. An open coding process (Charmaz, 2006) was used to generate a comprehensive understanding of themes and patterns in the data. Team members read through a random selection of interviews multiple times, individually and as a team, paying attention to family context, reactions to diagnosis and memory loss, managing memory loss in everyday life, behaviors and emotions, and relationship dynamics. Next, the coders began the process of combining and organizing codes into substantive categories by critically discussing perceptions of the interviews and determining redundancy in the preliminary codes. This iterative process resulted in the formulation of a final coding scheme reflecting group consensus and consisting of 45 overarching categories, each including multiple subcategories. Each transcript was then coded by two members of the research team. Individual coders discussed and resolved any coding discrepancies or presented them to the entire team for final coding decisions. This intensive coding approach yielded 100% agreement in the development and application of the coding scheme, which enhanced the rigor of the analysis and the dependability of the findings (Anfara, Brown, & Mangione, 2002). Field notes written by interviewers were used to provide a richer understanding of the families’ experiences and verify analytic insights (Lincoln & Guba, 1985). We used ATLAS.ti (Muhr, 2004) to organize and manage the data.

Focused coding.—One of the broad themes that emerged from the initial coding was the importance of acknowledgment of MCI among family triads. In the tradition of grounded theory, we approached the data with research questions concerning this construct in mind, and the “focused coding” step (Charmaz, 2006) centered on the idea of acknowledgment. We reread the transcripts of the 56 families and coded at the
family level the following areas: (a) family background and contextual conditions that might affect acknowledgment, (b) ways in which the PCPs and SCPs acknowledged or denied the elder’s MCI, (c) the elder’s awareness and acceptance of MCI, and (d) consequences of the extent to which families acknowledged MCI. Then, using the family triad as the unit of analysis, we assigned families to one of four acknowledgment groups on the basis of the overall triad’s perception of MCI and description of family dynamics. Study participants were assigned pseudonyms to maintain confidentiality.

**Findings**

First we describe four degrees of acknowledgment of MCI. The first two columns of Table 2 show the prevalence of each acknowledgment group within the sample and provide exemplary comments from each triad member to illustrate the defining characteristics of the groups. Then, we discuss the importance of background and contextual variables associated with responses to MCI, highlighted in the third column of Table 2. Finally, we describe examples of protective conditions evident within each degree of acknowledgment (Table 2, last column), noting that triads acknowledging the elder’s memory problems use coping strategies that appear to strengthen and nurture family relationships and manage the stress associated with MCI.

**Degrees of Acknowledgment of MCI**

We identified four degrees of acknowledgment of MCI within the family members’ interviews: complete acknowledgment, passive acknowledgment, partial acknowledgment, and no acknowledgment. Although we discuss typical attributes of each category, we conceptualized the four groups as being situated on a continuum from complete acknowledgment to complete denial. At the extreme ends of the continuum—complete acknowledgment and lack of acknowledgment—all three family members were similar in their degree of acknowledgment. Either they all revealed awareness and acceptance of MCI or all showed no awareness or acceptance. These two groups represented about two fifths of the sample. When the three family members held discrepant views, we categorized families into the passive or partial acknowledgment groups depending on which dynamic best described their family. These families with incongruent perceptions of MCI represented about three fifths of the sample. A key feature distinguishing families in the passive acknowledgment group from those in the partial acknowledgment group was that the elders in the passive acknowledgment families were receiving instrumental support for reasons other than their memory loss. That is, these families accepted that the elder had problems but had limited awareness of MCI in particular. Conversely, the partial acknowledgers tended to reveal some awareness that the elder had memory or cognitive difficulties, but not all members

**Table 2. Characteristics of Acknowledgment Groups**

<table>
<thead>
<tr>
<th>Acknowledgment group</th>
<th>Complete acknowledgment, n = 16 (31%)</th>
<th>Partial acknowledgment, n = 15 (27%)</th>
<th>No acknowledgment, n = 2 (4%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family context</td>
<td>Elder copes by relying on self</td>
<td>Elder copes by relying on self</td>
<td>Elder copes by relying on self</td>
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<td></td>
<td>Family helps elder maintain social identity</td>
<td>Family helps elder maintain social identity</td>
<td>Family helps elder maintain social identity</td>
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<td></td>
<td>PCP: We accept it and do what we can.</td>
<td>PCP: We accept it and do what we can.</td>
<td>PCP: Elder has always been forgetful.</td>
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<td></td>
<td>SCP: We realize elder can’t help it.</td>
<td>SCP: Elder has always been forgetful.</td>
<td>SCP: Elder has always been forgetful.</td>
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<tr>
<td></td>
<td>Elder: I realize that sometimes I’m being difficult.</td>
<td>Elder: I might have some problems, but it is not so bad.</td>
<td>Elder: I am able to do the things I want to do.</td>
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<tr>
<td></td>
<td>Family geriatric worker (n = 11).</td>
<td>Family geriatric worker (n = 5).</td>
<td>Family geriatric worker (n = 2).</td>
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<td></td>
<td>Family dynamics in which PCP or SCP had always been dominant (n = 12).</td>
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<td>Family dynamics in which PCP or SCP had always been dominant (n = 2).</td>
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<td></td>
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<td></td>
<td>Family receives support because of health conditions other than MCI</td>
<td>Family receives support because of health conditions other than MCI</td>
<td>Elder’s social identity stable</td>
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<td></td>
<td>Elder: I have other needs and a caregiver is already involved.</td>
<td>Elder: I might have some problems, but it is not so bad.</td>
<td>Elder: Elder’s social identity stable</td>
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<td>Other relative with dementia (n = 9)</td>
<td>Other relative with dementia (n = 9)</td>
<td>Other relative with dementia (n = 2).</td>
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<td>Family geriatric worker (n = 3).</td>
<td>Family geriatric worker (n = 3).</td>
<td>Family geriatric worker (n = 1).</td>
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<td></td>
<td>Family dynamics in which elder and PCP shared power (n = 12).</td>
<td>Family dynamics in which elder and PCP shared power (n = 12).</td>
<td>Family dynamics in which elder and PCP shared power (n = 2).</td>
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<td></td>
<td>Elder: Elder has problems and should try harder to remember or pay attention.</td>
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<td>Family dynamics had shifted, so PCP or SCP was not trusted.</td>
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<td>Family dynamics in which elder and PCP shared power (n = 2).</td>
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<td>Family dynamics in which elder and PCP shared power (n = 2).</td>
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Notes: MCI = mild cognitive impairment; PCP = primary care partner; SCP = secondary care partner.
indicated that they accepted it as a legitimate medical condition over which the elder had no control.

Although we placed each family in one of these mutually exclusive categories, some families within a given group also displayed a salient attribute of families in another group. For example, in the Harper family (passive acknowledged), Hester (PCP, wife) noted that she had always been in charge of household matters, similar to PCPs in the complete acknowledgment group. However, Hester had trouble acknowledging that Herman’s (elder) memory problems and personality changes were legitimate because of Herman’s long-term drinking problem. She said, “I had seen changes, but I thought he was just getting ornery.” However, Hester said that as she learned more about cognitive problems, she felt she was becoming more aware and accepting of the cause of changes she observed in Herman. Although the overall degree of acknowledgment of the Harper triad was one of passive acceptance, it seemed possible that full acknowledgment would likely emerge over time.

Complete acknowledgment.—Thirty-four percent of the sample included families in which all members indicated they fully acknowledged the diagnosis of MCI. These complete acknowledgment families were in agreement about the extent of the elder’s MCI and worked together to devise effective strategies to deal with the elder’s mild memory loss and subtle personality changes. For instance, Larry (elder) reported that in spite of his difficulties, he made a great effort to remember people’s names and used notes to help him remember information. Louise (PCP, wife) and LeRoy (SCP, son) respected Larry’s desire for autonomy, and although they sometimes felt frustrated when they had to give Larry frequent reminders, they acknowledged that it was not his fault. LeRoy reported giving as much assistance to his parents as they needed throughout the week, typically with household tasks, and Louise and Larry both discussed the importance of staying active in order to prevent any further memory deterioration.

Passive acknowledgment.—A slightly higher proportion of families (36%) were passive acknowledgers. In these triads, family members claimed they expected to have problems or see memory problems in the elders because of old age. Key family members noted that the elder had some forgetfulness, but the elder or the family members passed it off as “no big deal.” Typically, in these families, the PCP and SCP had already been involved in providing support to the elder because of more significant physical health issues. In cases where an adult child was the PCP, the elder’s spouse usually had severe health problems that had required prior intervention by other family members, and the elder received help as well. For example, in the Kimball family, Katrina (elder) did not believe her forgetfulness was a problem and still managed many of her affairs independently. She was evaluated for MCI because her doctor noticed a change in her cognitive functioning after the death of Katrina’s husband. Two of her daughters, Kathryn (PCP) and Kennedy (SCP), who were in the habit of visiting their mother often because of their father’s illness and subsequent death, helped with some household tasks. Although Katrina said she did not have a real problem, she commented that her daughters did not give her the same kind of help that her husband did, suggesting that her husband may have been compensating for her memory loss before he became ill, helping her in household tasks that depended on short-term memory, such as keeping appointments and social engagements. Thus, in families characterized by passive acknowledgment, the elder usually received some support, but it was not necessarily because of problems directly associated with MCI.

Partial acknowledgment.—Family members who partially acknowledged memory changes (27%) tended to personalize the elder’s MCI symptoms (e.g., believing the elder’s forgetfulness was intentional), or the elders tended to personalize the way in which the PCP or SCP interacted with them (e.g., believing that family members were picking on them). Thus, from one to all three of these family members tended to view MCI symptoms as indicative of family dynamics rather than a medical problem. PCPs or SCPs may have acknowledged that the elder had legitimate memory problems but wanted the elder to “try harder” to remember information (e.g., the time; a telephone conversation) or resist subtle personality changes (e.g., believing the elder could be less irritable if he really wanted). This performance pressure often led to the elder feeling stressed and frustrated.

Sometimes the elders did not seem to understand the extent of their memory problems or personality changes and felt that others exaggerated the issue. For example, Otto (elder) was typical in that he took care of the Olson family finances and did not want to cede control to his wife, Oriana (PCP), nor reduce his full-time work as an accountant. He reported keeping elaborate calendars and to-do lists so that he did not forget important information. Oriana supported Otto’s desire to work but worried that he was becoming more withdrawn. She could not tell if his withdrawal was a lasting change related to MCI or if she was misreading him because Otto had a quiet, reserved personality. Also, Oprah (SCP, Otto’s sister) said that she thought Otto could improve his memory if he were more social. The Olsons acknowledged certain changes in Otto but were reluctant to accept the possibility that changes in his abilities and thus their family dynamics were permanent.

No acknowledgment.—Only two families (4%) showed a lack of acknowledgment that the elder really had MCI. No members of these family triads noticed major memory changes, and any minor changes they mentioned did not seem to concern them. Both elders in these families experienced a single dramatic episode related to memory loss (e.g., got lost one time), which prompted a visit to the
memory clinic. Nevertheless, in the opinion of all family members, the elders had recovered (despite the diagnosis) and did not need any help because of cognitive problems.

**Background and Family Context of MCI**

For the analysis of background and contextual conditions that might be linked to MCI acknowledgment, we began by examining variation in degree of acknowledgment by demographic characteristics. No clear pattern of acknowledgment emerged for sex, race, income, relationship type, frequency of family contact, or time between initial diagnosis and the interview. Although responses to demographic items showed some variation in the acknowledgment groups by living arrangements and geographic distance from elder (e.g., PCPs in the complete acknowledgment group lived closer to the elders and the SCPs lived further from the elders than other PCPs and SCPs, respectively; see Table 1), such differences were not evident in the families’ qualitative responses. We speculate that such variation did not occur because prior experience with dementia was more salient for group placement than demographic differences.

*Dementia experience in the family.*—The most striking pattern to emerge from the focused coding was that families who demonstrated more acknowledgment either included a member with a health care background and professional experience with dementia or had a relative with dementia. In the complete acknowledgment group, 58% of the families reported familiarity with cognitive impairment via a family member’s employment—from certified nursing assistants to geriatric social workers to physicians. Only 5% of passive acknowledgers and 20% of partial acknowledgers (but no lack of acknowledgment triads) had a health care professional in their family to help them understand MCI. Moreover, previous experience from having a relative diagnosed with AD or another dementia also differentiated the family groups: 33% of complete acknowledgers, 43% of passive acknowledgers, and 67% of partial acknowledgers but no nonacknowledgers reported previous familial experience with dementia.

Participants who had witnessed the cognitive decline of another family member typically did not express awareness that the elder’s memory functioning could get worse but rather compared MCI with extreme dementia (e.g., “At the end, my sister didn’t know me. I’m not that bad.”). They tended to base their assessment on their experience with only one person whom they knew with dementia as compared with families with a health care professional who likely had contact with numerous people exhibiting a wide range of cognitive impairment. For example in the McDonald family, who were partial acknowledgers, Maddox (elder) was the caregiver for his wife who had severe physical and cognitive problems (e.g., extreme memory loss, wandering). Both Maddox and Mickey (SCP, Maddox’s brother) focused on the problems of Maddox’s wife rather than Maddox’s own MCI limitations. Marnie (PCP, Maddox’s daughter) recognized the problems of both her parents but felt powerless to help much because Maddox did not want to relinquish control of his wife’s care to his adult children. He focused on his wife’s problems to the detriment of his own well-being as both an elder with MCI and a caregiver. According to Marnie, Maddox limited the amount and kind of help he would accept from his children, even though by all accounts, he was struggling to provide proper care for his wife, partly because of his MCI. Comparatively, families with a person working in a health care field tended to handle the problems associated with MCI matter-of-factly and did not necessarily equate MCI with AD or advanced dementia.

*Previous family dynamics.*—Patterns related to family-level power dynamics varied among the four degrees of acknowledgment. Sixty-seven percent of complete acknowledgers reported that the PCP (or occasionally the SCP) had always been in charge in the family and that the elder had been dependent on the PCP for years. For example, Whitney (SPC, daughter) was a nursing home administrator. She provided support to her mother, Wendy (PCP, wife), such as helping her mother interpret medical information, and was careful not to put pressure on her father, Walter (elder), such as asking him to do nonroutine things, which seemed to cause him stress. All three family members, however, noted that Wendy had always been in charge of the family, and Whitney deferred to her mother’s needs. Wendy called herself “the family secretary” in that she handled the Wilson’s financial business and arranged appointments. Moreover, both Wendy and Walter reported that Walter had always depended on Wendy and that the couple had been emotionally closer to her family than to his. Thus, with Walter’s MCI, family dynamics intensified rather than changing substantially. Generally, intensification, rather than change, better described interaction dynamics in families who completely acknowledged MCI. Conversely, for the two no acknowledgment families, the elder had always been in charge, made family decisions, and still retained much control in the family or over personal affairs.

All families characterized by passive acknowledgment reported family dynamics where the PCP or SCP took charge because of deteriorating physical health of at least one person in the elder’s household or that the elder had already experienced a severe episode related to memory loss but had improved significantly after being treated with medication. Thus, family dynamics had already shifted a great deal for passive acknowledgers. For example, Sandra (elder) sought medical attention because she was having unexplained weight loss. While at the clinic, she also received MCI evaluation and a positive diagnosis. Collectively, the Swift family thought that Sandra’s mild memory loss was no cause for concern. Both Sharon (PCP, daughter-in-law) and Sam (SCP, son) provided needed assistance to Sandra because of their concern about her weight loss. They also anticipated that Sandra would need to move in with
them eventually because she was getting older. This family was typical of other passive acknowledgers who had experienced a change in family dynamics, with the elder receiving more care or help, but were not addressing issues specific to MCI in their help and care.

Most partial acknowledgers (80%) described families in which the elder and PCP shared power in the relationship. Typically, in these situations, the elder was reluctant to relinquish family responsibilities. For example, Ivan (elder) fully accepted his memory problems but resented that he had to give up driving and management of his finances. Iris (PCP, wife) and Ian (SCP, son) were sympathetic with Ivan but believed that he did not understand the extent of his impairment. Additionally, Iris noted that Ivan was on “good behavior” when Ian visited, which frustrated her. Ian helped his parents when possible but said that he believed his mother needed more information on how to handle Ivan’s cognitive impairment. An area of frustration for the Ingles concerned meals. Ivan had normally been the family cook, but Iris felt that it was no longer safe for him to cook because of his MCI. However, because of her own poor health, Iris was unable to stand long enough to prepare a meal. Consequently, the couple ate mostly TV dinners, which Ivan did not like. Both Ivan and Iris seemed to have difficulty adjusting to the changes in their relationship and did not actively seek resources that might have given them some support. Families of partial acknowledgers were mostly characterized by a change in family dynamics, suggesting the need to secure outside assistance, but one, two, or all triad members resisted pursuing such support.

**Extent of change in elder.**—A final pattern linking background and context to degree of acknowledgment was the extent of perceived changes in the elder’s memory or personality. These perceptions involved noticing (a) gradual memory change or exaggeration of personality characteristics; (b) sudden memory change, then partial return to presumed normal functioning; or (c) gradual memory change, then sudden personality change (See Table 2, third column). Most acknowledging PCPs and SCPs (89%) reported that the elder had demonstrated personality changes (e.g., apathy, irritability) or a major but temporary loss in memory (e.g., getting lost, suddenly repeating stories). These changes, perhaps only noticed by the elder’s closest family members, helped the triads accept that MCI was a legitimate medical problem. In passive acknowledgers, although elders may have sought treatment because they noticed some personality or memory changes, such as irritability or forgetfulness, most PCPs and SCPs did not report personality changes. In fact, the care partners in this group (67%) and in the partial acknowledgers group (60%) generally had trouble distinguishing MCI from normal variations in the elder’s mood or personality. Neither of the families characterized by no acknowledgment mentioned personality changes.

### Protective Conditions

**Coping.**—As described previously, how the families acknowledged an elder’s MCI had repercussions in terms of their ability to cope. Coping strategies such as making reminder lists were used frequently by elders in all but the passive acknowledgment group. Because elders in this group were receiving help for other reasons (e.g., physical health problems) and normalized their memory problems as expected age-related losses, they tended to rely on others without considering ways in which they might use techniques to help themselves remember. It is important to note, however, that the elders’ use of strategies such as keeping notes or elaborate calendars had limited effectiveness if others in their family did not acknowledge the extent of the elder’s memory problems. For example, Neva (elder, no acknowledgment) was working as a full-time paid childcare provider. Although it seemed that she was managing her duties effectively at the moment, there was little if any oversight of her work. If Neva suddenly became disoriented, those under her charge could suffer dire consequences. Neva had already experienced one episode of disorientation while driving but told the interviewer that she did not tell anyone about it. Thus, while using memory-helping strategies such as note taking was a positive aid in the elders’ lives, it was more effective if other relatives were aware that the elder might need someone to ensure that the elder was taking care of important tasks.

**Social identity and support.**—Related to Neva’s story is the issue of elders’ potential loss of their social identity, involvement, and responsibilities. Families who acknowledged and accepted MCI were able to assist the elders in maintaining their social identity by helping them remember engagements and by facilitating meaningful activities. PCPs and SCPs in these families compensated for the elders’ memory losses without infantilizing them. Partial acknowledgers had the most difficulty with this aspect of MCI because they had difficulty adjusting to changes in family dynamics (i.e., secondary stressor). In such cases, family members tended to experience tension (e.g., frustration) among themselves and expected the elders to try harder to resist memory loss or personality changes. Compared with complete and passive acknowledging families who accomplished a timely transition of responsibilities from the elders to others, elders in partial acknowledging and no acknowledging families wanted to retain control of their responsibilities. Likewise, PCPs and SCPs in these families tended to report feeling overwhelmed with new responsibilities they had to assume (i.e., primary stressor).

**Instrumental support.**—Another way in which degree of acknowledgment mattered was in the support PCPs and SCPs received from one another or from other relatives and community services. In families in which triad members disagreed about the elders’ memory changes, the elders...
most often denied experiencing any problems, claiming that “nothing was wrong” with their memory or that it was “pretty good” for someone their age. Such responses contributed to the PCPs’ distress at the elders’ unawareness about the extent of their memory problems. This primary stressor can exacerbate PCP and SCP stress (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Onor et al., 2006; Savundranayagam, Hummert, & Montgomery, 2005) when elders resist receiving instrumental support. Families who acknowledged MCI tended to provide appropriate support for PCPs, especially as the PCPs took on different types and increasing amounts of family responsibility. PCPs in passive acknowledgment families usually received instrumental support as well, but these families may not have been getting appropriate support related to the elder’s MCI as they tended to discuss help in terms of support for physical rather than cognitive limitations. Likewise, PCPs in families that partially acknowledged the elder’s MCI usually got little or no support, even when they acknowledged MCI, as the elder or the SCP usually did not take the memory problems seriously and did not think the PCP needed help. When PCPs did not accept changes in the elders’ behavior as memory related, the ways in which they communicated and behaved toward the elder were sometimes interpreted by elders and SCPs as antagonistic. Such contrasting views (i.e., secondary stressor) may lead to dissension among family members and interfere with elders and PCPs receiving the support both may need (Miller et al., 2001).

Discussion

Most investigations of cognitive decline in late-life families have focused on primary caregivers of relatives with dementia, particularly mid- to late-stage AD when changes in memory are undeniable. Our research extends this work in two important ways: from a focus on the primary caregiver to an analysis of multiple family members including the diagnosed person and a more distal, yet involved relative and divided into those adopting a more passive stance toward any observed changes and those who exhibited some degree of acknowledgment and acceptance of memory impairment. Similar to the families with AD in MacQuarrie’s (2005) investigation, families in these three acknowledgment groups both recognized and dismissed certain aspects of MCI-associated changes. In only two families did all triad members deny the existence of memory loss despite having received a clinical diagnosis. These heterogeneous patterns have implications for potential interventions as discussed later.

Basing interview questions on the Pearlin model resulted in data showing that family context, primary stressors, and secondary stressors were associated with different degrees of MCI acknowledgment. Discovering this construct is a novel finding in MCI research as is identification of an important contextual condition that emerged in this study: the value of familiarity with the situation. Families that had some experience with dementia, either through a relative working in geriatric health services or from knowing a relative with dementia, seemed to understand and accept the MCI diagnosis more readily, utilize coping strategies more effectively, and seek and accept help and support more willingly. The location of these constructs in the original Pearlin model is shown by italic font in Figure 1.

As noted in previous research (Frank et al., 2006; Garand et al., 2007; Lu & Haase, 2009), primary stressors, such as observing memory and personality changes, and associated emotions, such as frustration from having to provide repeated reminders, were apparent in this precaregiving MCI stage of cognitive impairment across all degrees of acknowledgment. However, because families in the complete acknowledgment group all viewed changes in the elder’s memory as nonnormative, their shared perspective enhanced their understanding of the elder’s memory and behavior changes and enabled them to cope with minimum distress. Although they reported having to adjust the ways in which they interacted, they appeared open to each other’s observations and concerns, and they banded together to support one another while managing the changes all were experiencing. Working together to manage the situation resulted in less negative consequences, corroborating the observations of Mitriani and colleagues (2006). In contrast, passive acknowledgment families seemed less bothered than others by such primary stressors and focused more on coping with physical health problems.

Evidence of secondary stressors, such as exacerbation of within-family conflicts or believing the person with MCI

MCI-Related Stress and Coping

Examining concepts from the caregiving stress model of Pearlin and colleagues (1990; Figure 1, bold font) enabled us to identify family stressors and coping strategies associated with MCI. Based on our family-level design, we discovered not only sources of stressors and the effects of this condition on family functioning and well-being but also the existence of perceptual differences about the nature and extent of memory loss both within and across families. In about one third of the cases, the three triad members agreed on the presence of memory loss and used coping strategies in response. The triads in about two thirds of the families diverged in their perceptions of the memory loss situation and divided into those adopting a more passive stance toward any observed changes and those who exhibited some degree of acknowledgment and acceptance of memory impairment. Similar to the families with AD in MacQuarrie’s (2005) investigation, families in these three acknowledgment groups both recognized and dismissed certain aspects of MCI-associated changes. In only two families did all triad members deny the existence of memory loss despite having received a clinical diagnosis. These heterogeneous patterns have implications for potential interventions as discussed later.
was not trying hard enough to overcome memory problems, also was evident at this early precaregiving stage. As we noted previously (Roberto et al., 2011; Savla et al., 2011), fluctuations in the elders’ functioning often affected the PCPs’ interpretation of their spouse’s memory changes and marital interactions. Triads in the partial acknowledgment group were especially likely to have elders with MCI who minimized their memory problems and PCPs and SCPs who attributed the memory and behavior problems to the elder’s personality or motivation. Such contrasting views of the situation within the triad contributed to distress and interfered with arriving at helpful management plans.

The model of Pearlin and colleagues (1990) conceptualizes caregiving stress as a dynamic process. Likewise in our study, the differing degrees of acknowledgment found among the family groups suggest that coming to accept memory loss is a process that takes some family members longer to work through than others. Because individual lives typically are embedded within family relationships, family members have a significant influence on each other as they adapt to memory-related challenges. For example, family members holding normative beliefs or expectations about age-appropriate behaviors may have either an enabling or an inhibiting effect on how they and others deal with memory changes (Aneeshensel et al., 1995; Fisher & Lieberman, 1994). The significance of differing degrees of acknowledgment in the present research suggests the value of continued examination of this construct as a potential protective condition that may either alleviate or exacerbate the stresses and strains of caregiving.

Methodological Considerations

Two unique features of our design, interviewing multiple members of families and seeking participants via memory clinics, reflect both strengths and limitations of this research. Interviewing three relatives permitted a family level of analysis that furthered understanding of responses to MCI and uncovered nuances about family situations and relationships that would have been less likely to emerge from interviews with just one person. Although recruiting families and analyzing triadic data present practical and logistical challenges, family-level investigations are important for advancing understanding of personal and relational complexities in this early stage of memory loss. Because the elders were patients of specialized memory clinics, we were assured they had MCI, not more advanced dementia nor treatable causes of cognitive impairment. At the same time, they and their family members likely were more aware of their cognitive changes than persons not seeking a medical evaluation. In addition, because our study protocol required participation from three family members, the families who participated in the study may differ from those who did not have two other family members willing to be interviewed. It also is possible that dysfunctional or less cohesive families were less likely to participate. Even so, the differing degrees of acknowledgment found among the elders and their relatives demonstrate heterogeneity of responses even within this more select group. Those who receive a diagnosis but resist associating observed behaviors with MCI may, in fact, be similar to those who do not seek a medical evaluation. Community-based education programs, discussed later, may be helpful to families that do not seek a diagnosis as well as those that do.

Because supportive relationships can positively alter appraisal of memory-related stressors and improve well-being despite sustained stress (Roth, Mittelman, Clay, Madan, & Haley, 2005), how families collectively respond to and manage daily life when a relative experiences mild memory loss warrants further attention in longitudinal designs. Perceptual discrepancies among key family supporters for elders showing early memory loss should be addressed over time to determine whether consensus eventually emerges among family members who do not initially agree on the definition of the situation as well as the implications of long-term disagreement for individual and family coping. Examining stability or change in degree of acknowledgment, acceptance of help and support, perceptions of stress and burden, and health and well-being among multiple family members over time would yield important information about differing trajectories of family responses to early memory loss. These analyses are particularly crucial for projecting implications for both individuals and families in cases where MCI progresses to more advanced dementia. Understanding different patterns of responses at the MCI stage might inform development of more tailored interventions for subsequent AD situations.

Implications for Practice

Family perceptions about changes in elders’ memory and personality have important implications for within-family support as well as for approaches to delivering community-based services to families with MCI. Although in most families we interviewed the elders’ needs were being met regardless of degree of acknowledgment of MCI, we theorize that the families’ early acknowledgment of MCI may be especially important in helping families cope if more severe symptoms develop later on. Research by Gaugler and colleagues (2000) showed that experiencing disruptive behaviors over a long period of time is deleterious to caregivers’ emotional health. In families that completely acknowledged and accepted MCI, PCPs and SCPs reported actively trying to be kind to elders, knowing that minor memory problems or personality changes were not the elders’ fault. For their part, elders who acknowledged MCI sometimes were not fully aware of the extent of their problems but tended to defer to PCPs and SCPs. With these dynamics in place, if more severe symptoms develop, key family members may be able to cope better with frustrations.
in a spirit of cooperation and acceptance rather than confusion and strife. Professionals could encourage such families to continue working together to find mutually acceptable strategies and solutions as new challenges arise. In contrast, elders and their care partners characterized by passive, partial, or no acknowledgment of MCI may benefit from receiving detailed information about changes in the brain and resultant behavior and personality manifestations, direct guidance for managing elders’ memory loss and frustrating behaviors, and assistance with identifying and acquiring supportive help from relatives, friends, and community agencies. They may also need counseling on effective conflict resolution strategies and assistance with planning for the future should the elders’ memory impairment worsen.

Relatedly, it is important to note that although elders may admit to experiencing cognitive problems to their physicians, they may be reluctant to share the extent of their limitations with others and may not request or receive appropriate help in a timely manner, perhaps putting themselves or others at risk. Community education programs aimed at recognizing and managing MCI rather than attributing behavior changes to personality or motivation may aide families of such elders to provide some supportive assistance even before the elders are willing to admit their need. Teri, McCurry, Logsdon, and Gibbons (2005) demonstrated the efficacy of community-based interventions for families dealing with AD; similar programs targeted specifically to MCI could be developed and evaluated.

In sum, the findings of this study contribute new insights to the small but growing literature on mild cognitive loss and family relationships. Successful coping with stressors associated with failing memory required families to reconstruct their daily realities in the face of their relatives’ unpredictable responses and behavioral changes (Aneshensel et al., 1995). Family dynamics influence, and are influenced by, the extent of family agreement about the elders’ memory loss. Further research is needed to investigate trajectories of acknowledgment patterns over time and to ascertain the efficacy of interventions targeted at this population.

Funding
This work was supported by the Alzheimer’s Association (IIRG-03-5926 and IIRG-07-59078).

Acknowledgments
The authors gratefully acknowledge participation of the Center for Healthy Aging in Roanoke, VA, the Eastern Virginia Medical School’s Glennen Center for Geriatrics and Gerontology in Norfolk, VA, the Veterans Affairs Medical Center in Salem, VA, the University of Chicago’s Center for Comprehensive Care and Research on Memory Disorders in Chicago, IL, the Indiana University Center for Aging Research’s Regenstrief Institute in Indianapolis, IN, and the Emory University Alzheimer’s Disease and Related Disorders Memory Clinic in Atlanta, GA, as well as the assistance of Martha Anderson, Carlene Arthur, Nancy Brossioe, William Dale, Gail Evans, Stefan Gravenstein, Kye Y. Kim, Greg Sachs, and Karen Wilcox. Contributions: K. A. Roberto and R. Bleszner planned and directed the study. All authors contributed to conceptualizing the research question, planning and conducting the analyses, interpreting the results, and writing the manuscript.

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This work was supported by the Alzheimer’s Association (IIRG-03-5926 and IIRG-07-59078).


