Chapter 11
Disease Awareness, Cognitive Decline, and Communication in Persons with Mild Cognitive Impairment and Caregivers

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ABSTRACT
The purpose of this chapter, which is based on our pilot research, is four-fold: 1) to describe the awareness of persons with mild cognitive impairment (PwMCI) of their cognitive changes and meaning of the diagnosis, and their family caregivers’ perceptions of the same; 2) to identify PwMCI’s concerns about living with MCI; 3) to discuss PwMCI and caregiver perceptions of a patient- and family-centered daily enhancement of meaningful activity (DEMA) program; and 4) to describe the potential benefits of DEMA using case examples. Discussion is based on findings from interviews with PwMCI and family caregivers designed to explore awareness of cognitive changes and the diagnosis, as well as experiences living with MCI. In addition, results from three focus groups to assess content validity and acceptability of the program and from a pilot intervention study to evaluate the feasibility and acceptability of the program contributed to the discussion. Findings support further testing of DEMA in larger and more diverse samples.

INTRODUCTION
The objectives of this chapter are fourfold: 1) to provide a brief introduction to mild cognitive impairment (MCI); 2) to describe the awareness of persons with MCI of their cognitive changes and the meaning of the diagnosis for them, as well as the family caregivers’ perceptions of the same; 3) to identify the needs of and concerns about daily life with MCI; and 4) to discuss the perceptions of persons with MCI and their caregivers as the basis for developing the patient and family-centered intervention program, Daily Enhancement of Meaningful Activity (DEMA) (Lu, Haase, & Weaver, 2013).
BACKGROUND

The symptoms of MCI overlap significantly with those of early Alzheimer disease (AD) (McKhann et al., 2001; Morris, 2012). After cancer, AD is the second most feared disease among American adults, and the majority (62%) of Americans feel unprepared to care for a loved one diagnosed with AD (MetLife Foundation 2011). To date, no pharmacological agent is approved by the US Food and Drug Administration for treating MCI or AD. Persons with MCI (PwMCI) live with prognostic uncertainty and often experience a sense of doubt and powerlessness that may affect the ultimate outcomes of their cognitive trajectory (Austrom & Lu, 2009; Roberts, Clare, & Woods, 2009).

PwMCI are at high risk for decreased physical function (Okonkwo, Waldley, Griffith, Ball, & Marion, 2006; Wadley et al., 2009), emotional distress, depressive symptoms (Laketsos et al., 2002), falls (Boripuntakul, 2014; Delbaere et al., 2012; Montero-Odasso, Muir, & Speechley, 2012), and mortality (Yaffe, Petersen, Lindquist, Kramer, & Miller, 2006). They also experience many difficulties that affect their quality of life, including significant conflicts in dyadic communication and reduced functional performance (Bàrrios et al., 2013; Ready, Ott, & Grace, 2004; Teng, Tassniyom, & Lu, 2012; Wadley et al., 2009). MCI involves functional decline that may include decrements in engagement in meaningful activities and sense of mastery (Blieszner, Roberto, Wilcox, Barham, & Winston, 2007), and it is associated with depressive symptoms (Apostolova & Cummings, 2008; Panza et al., 2010). Research findings have shown that caregivers of persons with AD are relatively much more likely to become ill and to die earlier (Schulz et al., 2004). Providing early non-pharmacological interventions during this valuable window of time offers an opportunity to prepare PwMCI and their family caregivers for the future and for coping with the inevitable changes and possible behavioral disturbances over time.

Awareness of Cognitive Changes, Meaning of Diagnosis

Subjective cognitive complaints are one of the major diagnostic criteria for MCI and require self-assessment of cognitive functioning. Thus, having self-awareness or the ability to accurately assess one’s own situation, performance, or function is essential for the process of early diagnosis of MCI. From a methodological standpoint, the operationalization of awareness in MCI tends to fall into two main classifications: (a) clinician’s rating of awareness and (b) incongruity in ratings between patients and their caregivers (Farias, Mungas, & Jagust, 2005; Frank, Lenderking, Howard, & Cantillon, 2011; Frank et al., 2006; McIlvane, Popa, Robinson, Houseweart, & Haley, 2008; Snow et al., 2004). Several studies have shown that PwMCI have more awareness of their cognitive impairment and functional performance deficits than those with mild or late-stage dementia (Clare, 2004; Roberts & Clare, 2013; Roberts et al., 2009; Snow et al., 2004; Vogel et al., 2004).

Awareness of cognitive changes over time can be related to internal perceptions such as symptoms or to external stimuli including failure at certain familiar tasks or interactions with persons who inform the PwMCI of these changes. Some researchers have argued that the complex, dynamic, and multifaceted nature of awareness is associated with psychogenic and psychosocial factors (Roberts & Clare, 2013; Roberts et al., 2009). Understanding PwMCI’s awareness of cognitive changes and of the meaning of their diagnosis is crucial to understanding the social and psychological effects of MCI and how these influence the ability to cope with cognitive impairment.