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Caregiver support service needs for patients with mild cognitive impairment and Alzheimer's disease

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Abstract

Little is known about the service needs for persons caring for individuals with Mild Cognitive Impairment (MCI). In this study, the level of support service need for caregivers of individuals diagnosed with Alzheimer's Disease (AD; N=55) and MCI (N=25) was compared to normal controls (NC; N=44). Study partners (i.e., caregivers) completed questionnaires about their service needs and participants' neurobehavioral symptoms, functional abilities, and frailty. Total, social, and mental health service needs were significantly different among the three groups ($p < .0001$), with MCI and AD caregivers reporting more need for services as compared to the NC group. There was no significant difference between MCI and AD groups for total and social service need. In the MCI group, caregiver's service need was related to neurobehavioral symptoms and frailty, whereas service need among the AD caregivers was related to functional disability and frailty. Caregivers of individuals with MCI are already experiencing a need for increased services comparable to that of individuals caring for AD patients, though the pattern of patient-related factors is different between the two patient groups. These findings suggest possible areas of intervention that could be considered at the earliest stages of memory loss.

Key words/phrases

mild cognitive impairment; Alzheimer's disease; service need; support services; caregiver

The term Mild Cognitive Impairment (MCI) has been used to describe the transitional phase between normal functioning and Alzheimer's disease (AD)¹. According to Petersen and colleagues' 1 original criterion, amnesic MCI is diagnosed when there is a subjective memory complaint as well as evidence of objective memory impairment in the context of intact activities of daily living and general intellectual abilities. Peterson² later broadened the criterion to include two primary subtypes of MCI: amnesic and nonamnesic MCI. The broader definition of MCI acknowledges the possibility of other cognitive complaints or deficits in other areas besides memory. Many studies indicate that MCI progresses to AD at a relatively high rate, from 13–48% over 12–60 months^{3–5}. The cognitive and functional changes associated with the progression to AD as well as the potential for a longer disease course among individuals with MCI likely pose a unique set of challenges for caregivers or family members who provide assistance to or care for these patients. There is extensive literature on care burden by family

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members of patients with AD⁶⁻¹¹, especially the physical, emotional, and financial costs incurred as a result of increased caregiving responsibilities. As a result, many forms of support services have been developed to alleviate or reduce these costs, such as respite care¹⁷. However, little research has examined the need for help or support services among family members of patients with MCI.

Although no research exists on what formal support services family members of patients with MCI use, there is some evidence to suggest that spouses of patients with MCI are experiencing increased caregiver burden¹³⁻¹⁴. Garand and her colleagues¹⁴ reported that MCI spouses/caregivers endorsed an increase in caregiving responsibilities such as greater frequency of errands, more coordination of transportation, and greater management of business affairs and medications. Lifestyle constraints and increase in household responsibilities were related to subjective caregiver burden as well as caregiver anxiety. Although this study was one of the first studies to report the level and nature of caregiver burden among individuals with MCI, it was limited in that it did not include patient-related characteristics, such as, neurobehavioral symptoms or neuropsychological status nor did it provide any comparison groups.

Bruce et al.¹³ investigated the relationship between caregiver burden and patients' neuropsychological, behavioral, and emotional symptoms among patients diagnosed with MCI. The authors reported that more than 30% of the spousal or child caregivers endorsed clinically significant caregiver burden. The level of caregiver burden was significantly associated with several patient-related factors, such as increased behavioral problems, depression, memory impairments, and longer course of symptoms, though not related to overall neuropsychological status. Although there was no comparison group, the pattern of findings are similar to that found in the dementia literature, but the level of burden among the MCI caregivers appeared to be lower than that found in dementia caregivers.

Among the many symptoms associated with dementia, the presence of neurobehavioral symptoms has been found to be one of the significant predictors of caregiver burden and service need among caregivers of patients with Alzheimer's disease¹⁵⁻¹⁷. Recent studies have identified neurobehavioral symptoms as more common among patients with MCI compared to normal populations¹⁸⁻²², although at a lower rate than found in patients diagnosed with dementia^{10, 13}. Patients with MCI who have neurobehavioral difficulties have been found to have significantly greater cognitive and functional impairments than MCI patients with no neuropsychiatric symptoms, suggesting that the presence of neuropsychiatric symptoms is a marker for MCI severity¹⁹, and neurobehavioral dysfunction may exert its same effect on the family system as it does among AD patients. Less is known about the influence of MCI patients' neurobehavioral symptoms on caregiver or spousal distress, despite these symptoms being commonly found in this population.

It is unknown whether these MCI family members or caregivers require assistance adjusting to or providing care to the patient with mild cognitive problems, despite some research suggesting that they are at increased risk for distress. Identification of what factors relate to caregiver need for support services should provide an opportunity to intervene and possibly reduce their level of burden at the very earliest stages of a possible dementing condition, as well as potentially having important implications on the long-term economic challenges of the disorder as it progresses. The purpose of this study was to contrast the number and type of formal support services reported as a need by caregivers of persons with MCI and of persons with probable AD, and to compare these results to those from spouses and close support persons of healthy individuals. Given that neurobehavioral symptoms are common in patients with MCI, and these same symptoms are a predictor of caregiver burden and service need in AD, it was expected that such symptoms would be positively related to number of support services needed among MCI caregivers.

Method

Participants

One hundred and twenty four participants and their study partners enrolled in the longitudinal cohort (University of Michigan – Memory and Aging Project; UM-MAP) of the University of Michigan Alzheimer’s Disease Research Center (MADRC) were recruited for this study. The participants were recruited from the Cognitive Disorders Clinic in the Department of Neurology, the Neuropsychology Section at the University of Michigan, or from the community via newspaper advertisements, community outreach programs, the MADRC website, or word of mouth (62.9% recruited from a University clinic; 37.1% recruited from community). Once they were screened, they were enrolled in the MADRC as part of the UM-MAP, which also includes designation of a study partner. Participants were evaluated by a neurologist and underwent neuropsychological testing with a trained technician. Caregivers completed measures of functional ability and neurobehavioral symptoms with a trained staff member (e.g., study coordinator) and they completed a packet of questionnaires containing the other measures on their own. Both the participant and caregiver data were collected during the same research visit. UM-MAP has been approved by the Institutional Human Use Review Board of the University of Michigan Health System.

Of the 124 participants (*Mean* age = 71.2; *SD* = 9.06), 44 were healthy volunteers (normal controls; NC), 25 were designated with MCI, and 55 were diagnosed with probable AD. Diagnosis of the participants was done at a consensus meeting consisting of at least one neuropsychologist and two neurologists, as well as other support staff. Normal controls were in good health and demonstrated a normal neurological examination, had no history of central nervous system disease, and had no memory-related complaints or cognitive impairments on neuropsychological testing. Participants were diagnosed with MCI according to revised criteria published by Petersen ², and participants were diagnosed with probable AD according to NINCDS-ADRDA criteria²³

Study partners were identified as a spouse, family member, or close friend who knew the participant well and could rate the participants’ functioning. For those participants who were designated as MCI or AD, study partners also were identified as those individuals who provided care to the participant. Due to inclusion of healthy control participants with no cognitive impairment or those participants with minimal cognitive impairment, not all participants were in need of a caregiver, but the term “caregiver” is used to describe the study partners throughout this project. Caregivers were 79 women and 45 men, and they ranged in age from 32 to 90 years (*M* = 63.3, *SD* = 11.9). The majority (95.2%) of the caregivers identified themselves as white, 4 (3.2%) as African American, and 2 (1.6%) as another race. The relationship between the caregiver and the participants included 93 (75%) spouses, 26 (21%) children, 2 (1.6%) siblings, and 2 (1.6%) friends. The majority of the participant pairs (78.2%) were living together at the time of the study. Most (71 %) of the caregivers reported that they had daily contact with the participant, 5.6% indicated that they had contact 3–4 days per week, 2.8% had contact 2 days per week, and 7.5% had contact fewer than 2 days per week.

Measures

Caregiver measures

Service Utilization: The caregivers were asked to rate what kind of services they used in “caring for the person they were with today”²⁴. For each of the 18 services, there were three possible responses: 0 = “no the service is not needed,” 1 = “yes, it is used,” and 2= “not used, but the service is needed.” In order to create a “service need” variable which reflects the need for service, responses to the questions were dichotomized into 0 = service was not needed and 1 = if the service was needed regardless if it was fulfilled or not. Scores were summed to create

a total service need variable as well as individual service need subscales (medical, social and community, mental health, and other). The internal consistency reliability (Cronbach's alpha) of this measure in the present study was .76. For the subscales, the internal consistency was adequate for social service, mental health, and other service need subscales ($r_s = .52, .49, \& .58$, respectively), but low for the medical subscale ($r = .32$). The medical need subscale was not used in future analyses.

Neuropsychiatric Inventory Questionnaire (NPI-Q): The NPI-Q²⁵ assesses psychopathology commonly found in dementia patients through a semi-structured interview with a caregiver. The version used comprised of 12 behavioral domains: delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behavior, night-time behavior disturbances, and appetite and eating abnormalities. Individuals symptoms were scored as 0 (absent) or 1 (present), and if present, a severity rating was obtained: 1 (mild), 2 (moderate), 3 (severe). The range for the severity scale was 0–36. Caregivers completed the NPI-Q with a trained staff member (e.g., study coordinator).

Nagi motor items: The Nagi motor items are ratings of physical functioning taken from Established Populations for the Epidemiologic Study of the Elderly (EPESE) questionnaire²⁶, which includes 5 questions about the patient's difficulty performing basic movements. The questions asked "how much difficulty does the patient have..." in pulling/pushing objects, stooping, kneeling, carrying weights, and extending arms above shoulder level. Each item is rated on a 4-point scale of 0 (no difficulty at all) to 4 (just unable to do).

Functional Activities Questionnaire (FAQ): The FAQ²⁷ is comprised of 10 items developed to assess IADL activities over the past 4 weeks (e.g., writing checks, shopping, preparing a meal, paying attention, etc). Responses range from 0 (normal) to 3 (Dependent) with higher scores indicating more impairment (range 0–30). Caregivers completed the FAQ with a trained staff member.

Participant Variables

Neuropsychological assessment: All participants were administered a battery of neuropsychological tests taken from the Unified Data Set (UDS) test battery²⁸. The test battery assesses a broad domain of cognitive functions within a short time frame and includes the Mini Mental Status Examination²⁹, Boston Naming Test (30 item-odd numbered)³⁰, Animal fluency³¹, Logical Memory from the Wechsler Memory Scale-Revised³², Trail Making Test³³, and the Geriatric Depression Scale³⁴. A study team neurologist completed the Clinical Dementia Rating Scale (CDR)³⁵, a measure of dementia severity.

Statistical Analyses—We examined summary and average scores for caregiver ratings and participant assessment variables of the different groups (NC, MCI, AD). One-way analyses of variance (ANOVAs) were employed to examine age and education differences between groups and Chi-square significance tests were used to examine gender differences between groups as well as diagnostic group differences between medical comorbidities. Multivariate analysis of variance (MANOVA) was completed to examine the mean differences in service need scores between groups and we reported partial eta squared for effect size. Post hoc comparisons were completed using a Scheffe F-test. We report Cohen's d statistic for all comparisons that were significant as a measure of the strength of the statistical relationship. Effect sizes close to 0.5 are considered moderate, with 0.8 considered large³⁶. Product-moment correlation coefficients (Pearson's r and Spearman ρ) were computed to determine the association among sociodemographic variables, service need variables, and other predictor variables.

All variables were screened for violations of assumptions associated with univariate and multivariate tests. Variables with non-normal distributions that may inflate alpha were transformed to improve normality and linearity³⁷. Results of this evaluation led to the square root transformation of total service need and two of the need subscales (social and mental health). The untransformed values are included in the tables for ease of interpretation; however, the transformed variables are used in the statistical analyses and are noted where applicable.

Results

Demographic analyses

There were no significant differences among groups (NC, MCI, and AD) with respect to gender, age, or educational level for either of the participants or the caregivers (Table 1). As might be expected based upon selection criteria for the three groups, there was a significant difference between participant groups on the CDR, MMSE, and all of the neuropsychological variables. The AD group was found to have significantly greater impairments on all neuropsychological measures as compared to the two other groups, with the MCI participants falling between the AD and NC participants. The groups did not significantly differ from one another on the GDS. Table 1 lists the demographic information, and the means and standard deviations for each group (NC, MCI, AD) for the MMSE, CDR, and neuropsychological test variables, as well as the results of the ANOVAs and Chi-square tests. There were no significant differences between diagnostic groups with respect to presence or absence of medical conditions as collected through the UDS (e.g., cardiovascular, cerebrovascular, metabolic conditions) using a chi-square test with the exception of diabetes. However, this significance difference is likely due to the small difference in cell sizes: only one NL participant (2.3% of the sample) had diabetes, which violates one of the assumptions of the chi-square test and group comparisons could not be accurately calculated. Examination of individual percentages show that 25% of the MCI participants had diabetes and 12.7% of the AD participants had diabetes, a chi-square analyses indicated that MCI participants were not significantly more likely to have diabetes than were AD participants, ($p = .205$).

Multivariate Analyses

Multivariate analyses of (MANOVA) revealed statistically significant differences among NC, MCI, and AD groups for the total service need score, social service need subscale, and mental health service need subscale scores, $F(6, 228) = 13.60, p = .000, \eta_p^2 = .264$ (Table 2), although the effect size was small to modest. Posthoc analyses revealed a significant difference between the NC and both the MCI and AD groups ($p < .000; d = -1.20$ and -1.52 , respectively for total need; $d = -1.49$ and -1.49 , respectively for social need) for the total service need and social service need, but no significant difference between the MCI and AD group ($ps = .16$ and $.97$, respectively). Caregivers in the MCI and AD groups reported needing more outside services than caregivers of the NC. Caregivers in the AD group reported more mental health need than those in the NC and MCI groups ($p < .000, d = 1.3$ and 0.40 , respectively), but the MCI group was not significantly different from the NC or the AD group ($ps = .08$ and $.10$). Table 2 lists the mean ratings standard deviations for each of these variables by group as well as the results of the MANOVAs.

There were significant group differences among the NC, MCI, and AD groups on the FAQ, NPI-Q, and Nagi. Examination of the post-hoc analyses revealed that for the NPI-Q, caregivers reported fewer neuropsychiatric symptoms in the NC participants as compared to MCI and AD participants, but neuropsychiatric symptom did not differ between the MCI and AD participants. For the Nagi, caregivers reported better bodily strength in the NC and MCI group as compared to the AD group. As expected, AD participants had more functional disabilities than the MCI participants, who in turn had more functional disabilities than the NC group.

Relationship of caregiver ratings to participant and caregiver variables

In the total sample, higher participant education level was associated with lower total service need and social service need ($r_s = -.20$ and $.22$; $p_s = .04$ and $.03$) whereas greater participant age was associated with greater total service need, social service need, and mental health service need ($r_s = -.20$, $.25$ and $.1$; $p_s = .02$, $.01$ and $.05$). Caregiver educational level and age were not related to any of the service need variables in the total sample and or any of the diagnostic groups (NC, MCI, AD). ANOVAs indicated that caregiver gender was not associated with significant differences on any of the service need variables for the entire sample and among the separate groups (NC, MCI, AD). For the entire sample and within the separate diagnostic groups, participant gender was not associated with any differences between in total service need or social service need variables, but there was a significant difference between participants' gender for the mental health service need variable in the total sample, $F(1, 119) = 5.34$, $p = .023$. Caregivers of male participants reported needing more mental health needs. In terms of the caregivers' relationship to the participant, child caregivers reported significantly more social service needs as compared to spousal, other relative, or close friend caregivers, $F(1, 117) = 4.60$, $p = .004$. There were no significant differences between caregiver relationship (e.g., spouse/partner, child, other relative, close friend) and service need among the caregivers in the NC group, but there was a significant difference between caregiver relationship and service need among the MCI and AD groups. Among the MCI caregivers, child caregivers reported more need for social services as opposed to caregivers with other relationships. Among the AD caregivers, child caregivers reported more total service need and social service need as compared to the other relationships. Those caregivers who did not live with the participant reported greater social service need than those that did live with the participant, $F(1, 119) = 4.12$, $p = .045$. Among MCI caregivers, caregivers who did not live with the participant reported greater total service need than those caregivers who lived with the participant, $F(1, 22) = 5.3$, $p = .030$. Among the AD caregivers, those who did not live with the participant reported greater social service need $F(1, 52) = 6.52$, $p = .014$.

In the entire sample, total service need was strongly correlated with total neuropsychiatric symptoms and severity of neuropsychiatric symptoms. However, when examined by diagnostic group, higher total service and social service need were related to increased problems as noted on the NPI-Q and the Nagi only among the NC and MCI groups ($r_s = .44$ and $.43$; $p_s = .03$ and $.04$). No service need variables correlated with the FAQ ($r_s = .04$ and $.21$) in the NC and MCI groups. Caregivers of NC and MCI participants reported needing more global and social services as the number of neuropsychiatric symptoms increased and the more difficulties the participants had with bodily movement. In the AD group, total service need was positively related to NPI-Q ($r = .31$, $p = .03$), Nagi ($r = .39$, $p = .00$) and FAQ ($r = .54$, $p = .00$), and social service need was positively related to the Nagi ($r = .40$, $p = .00$) and FAQ ($r = .47$, $p = .00$). Neuropsychiatric symptoms were unrelated to social service needs among caregivers of the AD participants ($r = .19$, $p = .18$).

Discussion

The present findings indicate that caregivers of individuals with MCI are already experiencing a need for increased support services, particularly in social areas. This need for support services is greater than what the study partners of healthy controls are reporting and at a similar level as that reported by caregivers of patients with AD. These findings are particularly striking given that by definition, the MCI patients have less severe cognitive impairments and significantly less functional impairments than the AD patients. There were no differences among the three diagnostic groups with respect to medical comorbidities that could explain differential needs for support services by the caregivers. Prior research indicates that caregivers who require extra assistance when caring for patients experience significant distress or burden

38–41. Among dementia caregivers, need for services is directly related to caregiver burden 42–43. Despite no difference between the total number of support services and social support services needed among the MCI and AD caregivers, the factors underlying need for such services between the groups of caregivers are different. Patients' neurobehavioral symptoms and frailty are related to more need of social support services among the MCI caregivers, a pattern also found among the healthy controls. In contrast, increased frailty and worse functional abilities are related to increased social support services among AD caregivers. In the present study, neurobehavioral symptoms are prevalent in participants with MCI, consistent with previous studies^{18, 21}. Although the severity is lower than that reported in AD participants, the MCI neurobehavioral symptoms show an important relationship to overall total and social service needs among the MCI caregivers.

This study provides a new perspective on evaluating patients with MCI, as the findings suggest that their family members or caregivers are experiencing an increased need for support, especially as the patient's level of neurobehavioral dysfunction increases. Future research is necessary to demonstrate that providing MCI caregivers with realistic education and availability of resources related to psychiatric and behavioral difficulties may significantly reduce caregiver burden and inefficient service utilization. Providing caregivers or family members with access to support groups and lists of potential resources might help fulfill this need, which may in turn increase well-being and assist in buffering against the stresses related to caregiving.

There are limitations to this study that could impact interpretation and generalization of the results, such as small sample size as in the small number of MCI participants. There is large literature regarding the racial and ethnic differences in caregiver service need and utilization. Our sample included primarily Caucasian participants; therefore, the ability to generalize from the present study would be enhanced by replication with a more ethnically diverse patient and caregiver population. Data were not collected on whether the participants required use of a caregiver and for how long they may have provided such care. Certainly, duration of care and amount of informal care provided by the caregiver would have an impact on overall service need. In addition, recruitment of participants from mostly treatment clinics (63%) also may limit generalizability of the findings. It is unclear whether similar support service need would be found in an exclusively community-based sample. Furthermore, it has been suggested that there may be a different clinical pattern of neurobehavioral and psychiatric symptoms between amnesic MCI and nonamnesic MCI patients⁴⁴. Although not specifically addressed in this study, this remains an important question for further investigation. Although our study examined the type of support services needed among MCI caregivers, it did not address the frequency or actual confirmed use of those services. Future studies should investigate the direct relationship between support service need and caregiver well-being or burden as this is the first study to our knowledge that reports that caregivers of individuals with MCI are already experiencing a need for increased services comparable to that of individuals caring for AD patients.

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Table 1

Descriptive statistics and ANOVAs for participant and caregiver demographic variables.

Variables	NC (n = 44)	MCI (n =25)	AD (n = 55)	F	p	
Patient						
Age (years)	68.6 (8.6)	71.8 (8.4)	72.9 (9.4)	2.90	.059	
Education (years)	16.1 (2.6)	15.2 (3.3)	14.6 (3.4)	2.49	.087	
Gender (% Female) ^f	61.4	44.0	40.0	4.70	.095	
CDR	.11 (.21)	.58 (.19)	.88 (.47)	59.28	.000	NC<MCI<AD ^{a,b}
MMSE	28.9 (1.2)	26.9 (2.0)	20.2 (4.1)	112.36	.000	NC>MCI>AD ^a
Logical Memory I	18.9 (3.0)	11.0 (5.9)	5.4 (4.3)	101.25	.000	NC>MCI>AD ^a
Logical Memory II	18.0 (3.5)	10.0 (6.4)	3.5 (4.3)	101.52	.000	NC>MCI>AD ^a
TMT, Part A	30.4 (18.4)	41.9 (22.3)	69.2 (39.6)	20.80	.000	NC<MCI<AD ^{a,c,d}
TMT, Part B	73.3 (28.3)	124.4 (67.3)	227.8 (82.4)	62.93	.000	NC<MCI<AD ^{a,e}
Boston Naming	27.2 (4.6)	25.7 (3.3)	22.7 (5.4)	9.29	.000	NC<AD ^f
Animal Fluency	20.6 (5.2)	15.0 (3.8)	11.8 (6.8)	28.17	.000	NC>MCI>AD ^{a,g}
GDS	1.91 (2.6)	3.2 (2.6)	2.2 (2.6)	1.95	.146	
Caregiver/Informant						
Age (years)	61.8 (11.7)	64.2 (12.5)	64.1 (11.9)	0.57	.569	
Education (years)	15.9 (2.8)	15.6 (2.5)	15.3 (2.7)	0.57	.566	
Gender (% Female) ^f	54.5	64.0	70.9	2.80	.243	

^f Chi-square

^a Cohen's d > 1.0 for significant relationship unless otherwise noted;

^b Cohen's d = .83 for NC<AD;

^c Cohen's d = .57 for NC<MCI;

^d Cohen's d = .85 for MCI<AD;

^e Cohen's d = .99 for NC<MCI;

^f Cohen's d = .90 for NC<AD;

^g Cohen's $d = .58$ for MC<AD

Note. NC = Normal Controls; MCI = Mild Cognitive Impairment; AD = Alzheimer's disease; CDR = Clinical Dementia Rating Scale; MMSE = Mini Mental Status Examination, TMT = Trail Making Test

Table 2

Means, standard deviations and MANOVA results for participant and caregiver variables.

	NC (n = 44)	MCI (n =25)	AD (n = 55)	F	p	
Total service need ^f (0–17)	0.2 (0.7)	2.0 (2.0)	2.9 (2.4)	41.59	.000	NC<MCI=AD ^a
Social service need ^f (0–6)	0.1 (0.3)	1.1 (0.9)	1.2 (1.0)	37.77	.000	NC<MCI=AD ^a
Mental health need ^f (0–4)	0.1 (0.3)	0.5 (0.8)	0.8 (0.7)	18.90	.000	AD>NC ^a
FAQ (0–30)	0.7 (1.3)	5.5 (4.7)	13.1 (8.7)	49.79	.000	NC>MCI>AD ^a
NPI-Q total symptoms (0–12)	0.3 (0.6)	2.1 (2.3)	3.2 (2.5)	26.14	.000	NC<MCI=AD ^a
NPI-Q total severity (0–36)	0.4 (0.8)	3.6 (4.8)	5.0 (4.2)	20.84	.000	NC<MCI=AD ^{a,b}
Nagi total (0–20)	1.3 (2.3)	2.6 (2.9)	3.5 (4.4)	5.07	.003	AD>NC ^c

^fTransformed variables used in parametric analyses.

^aCohen's *d* > 1.0 for significant relationship unless otherwise noted;

^bCohen's *d* = .93 for NC<MCI;

^cCohen's *d* = .63 for AD>NC

Note. NC = Normal Controls; MCI = Mild Cognitive Impairment; AD = Alzheimer's disease; FAQ = Functional Activities Questionnaire; NPI-Q = Neuropsychiatric Inventory Questionnaire