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Awareness of diagnosis predicts changes in quality of life in individuals with mild cognitive impairment and mild stage dementia

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Abstract

Background and Objective: This observational study examined how awareness of diagnosis predicted changes in cognition and quality of life (QOL) 1 year later in older adults with normal cognition and dementia diagnoses.

Research Design and Methods: Older adults ($n = 259$) with normal cognition, mild cognitive impairment (MCI), or mild stage Alzheimer's disease (AD) completed measures of diagnostic awareness, cognition, and multiple domains of QOL. We compared 1-year change in cognition and QOL by diagnostic group and diagnostic awareness.

Results: Patients who were unaware of their diagnosis at baseline showed average decreases in both satisfaction with daily life (QOL-AD; paired mean difference (PMD) = −0.9, $p < 0.05$) and physical functioning (SF-12 PCS; PMD = −2.5, $p < 0.05$). In contrast, patients aware of their diagnosis at baseline showed no statistically discernable changes in most QOL domains (all $p > 0.05$). Of patients aware of their diagnosis at baseline ($n = 111$), those who were still aware ($n = 84$) showed a decrease in mental functioning at follow up ($n = 27$; SF-12 MCS). Change in MoCA scores in patients unaware of their diagnosis was similar to that in patients aware of their diagnosis, −1.4 points (95% CI −2.6 to −0.6) and −1.7 points (95% CI −2.4 to −1.1) respectively.

Discussion and Implications: Awareness of one's diagnosis of MCI or AD, not the severity of cognitive impairment, may predict changes in patients' mental functioning, expectations of their memory, satisfaction with daily life, and physical functioning. The findings may help clinicians

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CONFLICT OF INTEREST STATEMENT

The authors have no conflict of interest to report.

HUMAN PARTICIPANT PROTECTION

The Institutional Review Board of the University of Pennsylvania approved all procedures involving human subjects.

anticipate the types of threats to wellbeing that a patient might encounter and identify key domains for monitoring.

Keywords

cognitive decline; cognitive impairment; cognitive performance; diagnosis awareness; self-reported symptoms

1 | INTRODUCTION

Alzheimer's disease (AD) dementia is a leading cause of death and disability. The premise of efforts to discover treatments for AD is that early detection—even before the onset of symptoms—will aid opportunities to prevent or slow dementia through both novel targeted pharmaceutical treatments and lifestyle changes.[1] If dementia can be slowed down or postponed indefinitely, individuals' healthy life expectancy may be extended.

The prospect of millions of people living with mild stage dementia symptoms, or even no dementia symptoms means clinicians need to understand the patient experience of these conditions. In dementia, wellbeing is often operationalized as quality of life (QOL): a subjective, multidimensional construct typically evaluated across several areas of a person's life. The conceptual framework for QOL in dementia often integrates cognitive functioning, physical functioning, social interactions, mental functioning, and mood.[2] Studies often have relied on the premise that the relationship between QOL and cognitive decline centers on whether, and to what degree, the patient is aware of their cognitive impairments.[3–5]

In a prior cross-sectional study, we found that patients who were aware of their diagnosis–either MCI or mild stage dementia—and its prognosis report lower QOL than those unaware of these facts about themselves.[6] These relationships appeared independent of the severity of cognitive impairment as measured by cognitive testing. The finding was notable as it was one of only a few to have studied persons along a spectrum from normal cognition to mild stage dementia, allowing conclusions about QOL in persons along a spectrum of cognitive function.[7–10] This approach is essential in light of advances in diagnosis and treatment as it may help to anticipate the treatment needs of patients.

The purpose of this observational study was to examine how baseline diagnostic category and diagnostic awareness predict 1-year change in QOL and cognition in individuals with MCI or mild stage dementia. This is an exploratory study intended to be hypothesis generating. Based on our previous cross-sectional study,[6] we expected subjective knowledge of a MCI or mild stage dementia diagnosis would predict change in QOL. Specifically, persons who were aware of their diagnosis at baseline would show declines in psychological domains of QOL—including mood, stress, satisfaction, and mental wellbeing—while both those aware and unaware of their diagnosis at baseline would show declines in physical domains of QOL—instrumental and basic activities of functioning, physical well-being, and cognitive performance, and normal controls who had no dementia diagnosis would demonstrate age-related declines in physical domains of QOL. Thus, the design of the study allowed for us to assess the effects of dementia (no cognitive impairment vs. mild stage cognitive impairment) and diagnostic awareness (no diagnosis vs. aware of diagnosis vs.

unaware of diagnosis). The results of this study may offer insight into the challenges of early diagnosis as well as ways to anticipate challenges to QOL for individuals who are diagnosed early.

2 | METHOD

2.1 | Design

This was a secondary analysis of an existing data set from an observational study of older adults (n = 259) with normal cognition (NC), mild cognitive impairment (MCI), or mild stage Alzheimer's disease dementia (AD) who completed measures of diagnostic awareness, cognition, and multiple domains of QOL. We compared 1-year change in cognition and QOL by diagnostic group and diagnostic awareness group. Data were collected between 2013 and 2017.

2.2 | Eligibility

Eligibility criteria were: age ≥65, native English speaker, ≥sixth grade education, mini-mental state exam (MMSE) score of ≥20, able to read from a handheld visual acuity card, and able to hear conversational speech. Because interviews were conducted in participants' homes, participants were required to live within one-hour drive of the Penn Memory Center. Participants with AD dementia and MCI were required to participate with a study partner (knowledgeable informant). If, at 1 year follow up, individuals no longer met the eligibility, they were considered no longer eligible and no further data were collected from them.

2.3 | Recruitment

The sample included 259 individuals recruited from the PMC cohort study. This was a convenience sample of PMC controls and patients. Individuals with normal cognition or mild stage dementia were identified by searching the inclusion criteria in the integrated neurodegenerative disease database, a registry of patients and caregivers who consent to contact about research studies.[11] Potentially eligible candidates were approached in no particular order. Flow from recruitment through analysis is shown in Figure 1.

Candidate participants were called by a research assistant who explained the study and assessed interest in participating. Individuals with NC were contacted directly. Candidates with MCI or AD were contacted via their study partner. All participants gave written informed consent or, for those not capable, assent while their study partners gave written informed consent. Participants received a $20 gift card after each study interview.

2.4 | Participant interviews

Face-to-face interviews were conducted by trained research assistants at participants' homes, unless they requested to meet at the PMC. To establish a baseline, two 1–1.5 h interviews were conducted within 3 months of a participant's most recent PMC cohort assessment. A pair of follow-up interviews were conducted about 1 year after the baseline interviews.

2.5 | Diagnostic groups

The sample included 259 individuals recruited from the PMC cohort study from three clinical diagnostic groups: mild stage AD dementia (n = 68), MCI (n = 92), and NC (n = 99). The diagnoses were assigned during the routine annual neurological assessments using the criteria from the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA)[12] and Peterson criteria[13] to define AD and MCI, respectively. Participants with NC had neuro-psychological testing commensurate with similarly aged and educated peers and did not meet criteria for either dementia or MCI.

2.6 | Measures

2.6.1 | Cognitive testing—An assessment battery was used to assess cognitive functioning and QOL. Global cognition assessed with the MMSE[14] and montreal cognitive assessment (MoCA).[15] Verbal and non-verbal memory were assessed with the Philadelphia verbal learning task (PVLT)[16] and Biber Figure Learning Task (BFLT).[17] Executive function was measured with the graphic pattern generation (GPG) test.[18] Premorbid cognitive ability was assessed via the Wechsler test of adult reading (WTAR)[19] and Wechsler Adult Intelligence Scale third edition (WAIS-III) Information subtest.[20]

2.6.2 | QOL measures—Self-report measures assessed five QOL domains: cognitive problems, mental functioning, mood, physical functioning, and satisfaction with daily life and health-related QOL.[2] Cognitive problems were assessed by the Cognitive Difficulties Scale (CDS).[21,22] Higher scores reflect more problems. Distress due to these problems was assessed with an adapted GDI.[23] Higher scores reflect more symptom distress. An item from the Geriatric Depression Scale (GDS) asked respondents (yes/no) whether they experience "more memory problems than most others."[24] Mental functioning was assessed with the Perceived Stress Scale (PSS),[25] where higher score reflect more stress, and Short Form Health Survey (SF-12) Mental Composite Scale (MCS),[26] where higher scores reflect better mental functioning. Mood was assessed using the GDS[24] and Beck Anxiety Inventory (BAI).[27] Higher scores reflect more mood symptoms. Physical functioning was assessed with three measures. Basic daily activities and those instrumental to personal independence were assessed via the Lawton-Brody Basic and Instrumental Activities of Daily Living scales (B/IADLs).[28] General physical functioning was assessed with the SF-12 Physical Composite Scale (PCS).[26] Higher scores on these measures indicate better physical functioning. Satisfaction and health-related QOL: Satisfaction with physical health, living situation, family, marriage, self, and money were assessed with the QOL-AD.[29] Health-related QOL linked to mobility, self-care, usual activity, pain, and anxiety were measured by the Euro-QOL (EQ-5D), which also included a visual analog scale to assess overall "health state" (EQ-VAS).[30] Difficulty in daily life related to health, well-being, cognitive functioning, social relationships, daily activities, and self-concept was measured by the DEM-QOL.[31] Higher scores indicate better QOL.

2.6.3 | Awareness of diagnosis, prognosis, and cognitive problems—To assess awareness of diagnosis and beliefs about prognosis, we administered the AD Insight Questionnaire to participants in the MCI and dementia groups.[32] The questionnaire asked

about cognitive problems ("Do you have problems with your memory or thinking?") and, if initial question was negative, "Do you have some mild problems with your memory or thinking?" A separate question asked about prognosis ("Do you think your memory or thinking problems will get worse?") and diagnosis. For diagnosis, participants were first asked whether they had "Mild Cognitive Impairment" and then "Alzheimer's disease." If patients responded "no" to the AD diagnosis question, the interviewer followed with the question, "What about a little bit of Alzheimer's disease?" If patients responded "no," the interviewer followed with the question, "Do you have dementia?" Participants who responded affirmatively to any of the diagnosis-related items were entered into analyses as being "aware" of their diagnosis whereas all others were coded "unaware." If, for example, an individual had a documented diagnosis of MCI but affirmed that they had dementia, they were entered into the analysis in the "aware" group. The single item assessing prognosis was also analyzed independently.

2.6.4 | Standard demographics—Age, gender, race, ethnicity, years of education, and handedness were collected directly from NC participants and from study partners of dementia and MCI participants.

All procedures involving human subjects were approved by the local Institutional Review Board (University of Pennsylvania, "Quality of Life Study", IRB protocol #807342).

2.7 | Statistical analysis

Bivariate analyses (paired *t*-tests) were used to compare scores at baseline (Time 1) to subsequent assessments 1 year later (Time 2). In these analyses, participants served as their own controls. Categorical variables used chi-square tests, and rank variables utilized Kruskal–Wallis test followed by Dunn's test for multiple comparisons.[33,34] All statistical tests were two sided. A 95% confidence interval (CI) that includes zero indicates a lack of statistical significance ($p > 0.05$).

To minimize the influence of floor and ceiling effects and measurement error, we created a composite score to assess performance-based memory.[35] The Cognitive Composite Score (CCS) was calculated as the average of the z-scores from the PVLT immediate memory, PVLT long-term memory, BFLT immediate memory, and BFLT long-term memory. This score was standardized to the NC group so that this group had an average of zero and standard deviation of 1.0. The Cronbach alpha for the CCS was 0.95.

Data were missing for participants who did not have data at follow up ($n = 37$) because they withdrew ($n = 13$), were ineligible to continue ($n = 12$), or were lost to follow up ($n = 12$; Figure 1). In these instances, they were entered into the analyses assuming no change over time in their scores, which was a statistically conservative approach given our study sought to identify change. All 95% confidence intervals are bias corrected and accelerated estimates based on 1000 bootstrap samples. We do not adjust for multiple testing given this is an exploratory study. Given 3 groups and 14 variables in each set of analyses, two comparisons could reach statistical significance by chance alone. All analyses were conducted in Stata version 14.0.

3 | RESULTS

3.1 | Baseline participant characteristics

The three diagnostic groups did not differ on age, race, handedness, or the percentage of college graduates (all $p > 0.05$, Table 1). The MCI group had fewer women (46%) than both the NC (73%) and dementia (63%) groups. On all but two measures (WTAR IQ and BFLT-Perseverations), the average cognitive performance of the three groups differed consistently with the NC group performing relatively strongest, the mild-stage dementia group performing weakest, and the MCI group's performance falling between the two (all $p < 0.01$). Baseline diagnostic status of those who discontinued between baseline and follow up were ($n = 37$; dementia [$n = 18$], MCI [$n = 16$], NC [$n = 3$]).

3.2 | Change in diagnosis and cognitive measures by baseline diagnostic group

At 1-year follow up, the majority of individuals were in the same clinical diagnostic group as they were at baseline (Table 2). The measures of composite memory and executive function also appeared fairly stable over time in each of the three diagnostic groups (all $p > 0.05$). A few of the domain-level measures of memory, premorbid intelligence, and crystalized intelligence showed statistically but not clinically significant changes from baseline to 1-year follow up.

The MCI group showed a decline on the MoCA (paired mean difference [PMD] = −0.63, 95% CI −1.25 to −0.03; $p < 0.05$). On average, global impairment worsened in the dementia group as measured by both the MMSE and MoCA (both $p < 0.05$). A similar magnitude difference but in the direction of improved scores was observed on the MoCA in the cognitively normal group (PMD = 3.0, 95% CI −3.89 to −2.24; $p < 0.05$).

3.3 | Change in cognitive problems, mood, mental functioning, physical functioning, and QOL by diagnostic group

The NC group showed, on average, showed decreases in health-related QOL (DEM-QOL, PMD = −1.0, 95% CI −1.9 to −0.1, Table 3), anxiety symptoms (BAI, PMD = −1.0, 95% CI −1.9 to −0.2), and physical wellbeing (SF-12 PCS, PMD = −1.5, 95% CI −2.8 to −0.2). The MCI group demonstrated a similar pattern with, on average, an increase in impairment in instrumental activities of daily life (IADLs, PMD = 0.7, 95% CI 0.02–1.2) along decreases in overall health rating (EQ-VAS, PMD = −3.6, 95% CI −6.5 to −0.8) and physical functioning (SF-12 PCS, PMD = −2.4, 95% CI −4.1 to −1.0).

The dementia group showed an increase in impairment in instrumental activities of daily life (IADLs, PMD = 0.8, 95% CI 0.02–1.6). In addition, about 11.8% fewer believed their memory would worsen over time (95% CI −23.2 to −2.2). No other statistically significant changes from baseline to follow up were observed (all $p > 0.05$).

3.4 | Change in cognitive measures by baseline awareness of diagnostic label

Change in global cognition as measured by the MoCA in patients unaware of their diagnosis was similar to the change in patients aware of their diagnosis, −1.4 (95% CI −2.6 to −0.6) and −1.7 (95% CI −2.4 to −1.1) respectively (Table 4). Change in the composite measure

of memory was also statistically similar in patients unaware of their diagnosis and patients aware of their diagnosis, −0.2 (95% CI −0.4 to 0) and −0.2 (95% CI −0.3 to −0.03) respectively.

3.5 | Change in mental and physical functioning by baseline awareness of diagnostic label

Patients aware of their diagnosis at baseline showed a decrease in mental functioning from baseline to one year follow up (SF-12 MCS; PMD = −1.4, 95% CI −2.4 to −0.2; Table 4). In the group unaware of their diagnosis at baseline, patients showed on average a decrease in physical functioning from baseline to one year follow up (SF-12 PCS; PMD = −2.5, 95% CI −4.1 to −1.10), which was statistically similar to that in the normal control group (SF-12 PCS; PMD = −1.5, 95% CI −2.8 to −0.9). They also showed a decrease in satisfaction with daily life (QOL-AD; PMD = −0.9, 95% CI −1.9 to −0.2). Neither those aware or unaware of their diagnosis at baseline showed changes in their reports of cognitive symptoms over time ($p > 0.05$).

3.6 | Change in mental and physical functioning by change in baseline awareness of diagnostic label

At baseline, most ($n = 111$, 69.4%) patients diagnosed with either MCI or mild stage dementia were aware that they had one of these diagnoses. Some ($n = 49$, 30.6%) were unaware. At one year, most ($n = 103$, 64.4%) maintained these initial responses, either aware ($n = 84$) or unaware ($n = 19$). Some ($n = 27$, 16.9%) were no longer aware they had a diagnosis of MCI or dementia. Others ($n = 30$, 18.8%) were now aware that they had one of these diagnoses (data not shown in tables).

Neither change or consistency in diagnosis awareness appeared to affect mental functioning (SF-12 MCS) or physical functioning (SF-12 PCS) (Figure 2). In addition, neither change or consistency in diagnosis awareness appeared to affect satisfaction in daily life (QOL-AD) or depression (GDS) (all $p > 0.05$).

Report of cognitive symptoms was not statistically different between baseline and follow-up for those who were initially aware (CDS, −0.4, 95% CI −3.1–2.3) and unaware (0.7, 95% CI −1.8–3.2), respectively (Table 4). In a subanalysis examining change in diagnostic awareness (data not shown in tables), those who became aware of their diagnosis at follow-up reported similar cognitive symptoms (0.8, 95% CI −2.0–3.6) as those who were no longer aware at follow-up (0.8, 95% CI −2.7 to 4.3). Awareness of memory problems, as measured by asking individuals whether they believed that they experienced more memory problems than others, showed a similar pattern of responding.

About 78% of those aware of their diagnosis at baseline expected their memory problems to worsen over time. At 1 year, 66.3% of this group still expected their memory problems to worsen for a decrease of −11.7% (95% CI −23.2 to −2.3). In comparison, among those unaware of diagnosis at baseline about 47% expected their memory problems to worsen over time at baseline. At 1 year, 41.6% of this group still expected their memory problems to worsen for a decrease of −5.4% (95% CI −14.4 to 3.3).

In a subanalysis that examined findings by change in awareness, from baseline to follow up 13.3% (95% CI −2.3 to 29.0) more of those who became aware of their diagnosis at follow-up expected their memory problems to worsen over time. This was statistically similar to the change in the group who was no longer aware of their diagnosis at follow-up (−11.1%, 95% CI −27.2 to 5.0).

4 | DISCUSSION

The purpose of this observational study was to examine how diagnostic category and awareness of that diagnosis predict change in QOL and cognition over time in a sample of 259 older adults with MCI, mild stage dementia, and normal cognition. It is the only study we know of to examine longitudinal change in quality of life based on dementia diagnosis and diagnostic awareness. Thus, a major goal of this study was hypothesis generation.

We set out to conduct our study expecting subjective knowledge of a MCI or dementia diagnosis to predict change in QOL. We expected that persons who were aware of their diagnosis at baseline would show declines in psychological domains of QOL while both those aware and unaware of their diagnosis at baseline and those with normal cognition would show declines in physical domains of QOL. Our findings suggest associations between awareness of diagnosis and QOL are more nuanced. We discuss these gradations in relation to each of our key findings in this section.

Our findings are consistent with those from other studies of comparable duration that have shown declines in QOL do not uniformly coincide with cognitive and functional declines related to AD.[8,37–41] From baseline to 1-year, we found persons aware of their diagnosis experience a decline in mental functioning. In contrast, those unaware of their diagnosis experience decreases in satisfaction with daily life, and physical functioning.

The associations in this study indicate that it may be helpful to discern whether a patient is or is not aware of their diagnosis. Individuals who are living with this knowledge may benefit from clinicians talking with them about their perceptions related to that diagnostic status, such as those related to stereotype threat and distress from cognitive problems. Moreover, our findings may help guide interventions by helping clinicians anticipate the types of threats to wellbeing that a patient might encounter.

Our findings also raise a question about whether awareness of diagnosis would extend to awareness of AD risk information. Lineweaver et al.[42] found, for example, that older adults who know they are an ApoE4 carrier, a gene associated with lifetime risk of late-onset AD, report more cognitive symptoms and perform worse on memory measures than adults who are ApoE4 carriers but do not know this information. While specific results from our study that evaluates change in patients with MCI and mild stage AD may not generalize to cognitively normal individuals who are informed about their future risk of developing dementia, our findings identify longitudinal correlates of diagnostic information that raise questions that warrant future investigation. It would be useful to know whether and how awareness of diagnostic data, such as an AD biomarker result, might affect a cognitively normal person’s wellbeing.

Awareness of diagnosis was fairly stable over 1-year. At 1 year, most patients with either MCI or mild stage AD maintained their baseline awareness, either aware ($n = 84$) or unaware ($n = 19$). Neither awareness of diagnosis or change in diagnostic awareness were associated with progression of disease as measured by neuro-psychological testing or cognitive and functional impairments, which is consistent with prior studies.[35,37,40,41,43,44] Reports of cognitive symptoms also did not differ by diagnostic awareness or change in diagnostic awareness. However, individuals aware of their diagnosis were more likely to expect their memory to worsen at baseline and continued to expect their memory to worsen at follow-up than those who were unaware of their diagnosis.

Other longitudinal studies have found that lower awareness is associated with better QOL.[45–49] These findings are in contrast to what we observed in our study. This is likely due to the fact that prior studies of "awareness" have focused on anosognosia—a neuropsychiatric symptom related to AD that confers an inability to be aware of one's circumstance. The presence of this symptom increases as dementia severity increases and is not exceedingly common in MCI or mild stage dementia.[45,48] The contrast in findings between the current study and these prior studies underscores the need for future investigations to understand the nuances in how pathophysiology alters QOL.[5,50]

While our study did not investigate how individuals became aware of their diagnosis or why they were unaware of their diagnosis, our findings suggest that within similar stages and severities of disease—defined by disease staging and cognitive test scores—there is heterogeneity in diagnosis awareness that differentially corresponds to patient outcomes. If these differences in awareness are, even partially, explained by anosognosia, it raises substantive questions about how a patient's perception of their condition early in disease may be informed pathophysiological processes. The extension of AD diagnosis into earlier —preclinical—stages of disease may add further complexity as diagnosis at this very early stage tends to be heavily reliant on a person's report of their experiences, including cognitive and functional symptoms.

Our study has limitations. This study was carried out at a single site in a convenience sample. Results may not generalize to populations with other characteristics. Moreover, this is a correlational study. Thus, it's not possible to make causal inferences about the results. In addition, we report paired mean differences, which control for all time-invariant factors but may not reflect individual-level change. This approach to analysis is equivalent to using the follow-up score as the dependent variable for estimating the mean difference when the groups being compared are similar on characteristics that may be potential confounders. In our study, the aware and unaware groups were balanced on all but one sociodemographic characteristic (all $p > 0.80$) and all cognitive tests (all $p > 0.49$) and diagnosis MCI versus AD ($p > 0.68$). The one feature on which the awareness groups differed was mean age; the mean age in the unaware group was 80.7 and the mean age in the aware group was 77.0 years. The change score provides a more precise estimate than the follow-up score if the correlation between baseline and follow-up is high, which was the case for most variables in this study. Lastly, it is possible that there may be some differences between study groups that we did not identify given limitations of sample size.

Awareness of one's diagnosis of MCI or dementia predicts changes in patients' mental functioning, satisfaction with daily life, and physical functioning. These associations appeared independent of changes in cognition, which were similar between those aware and unaware of their diagnosis. More follow-up data points would provide insight into the trajectory of these changes. Future research is needed to understand how, if at all, these findings may apply to cognitively unimpaired persons who learn AD biomarker results.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Key points

- Older adults aware of their diagnosis of Alzheimer's disease (AD) or mild cognitive impairment were more likely to expect their memory to worsen at baseline and continued to expect their memory to worsen at 1-year follow-up than those who were unaware of their diagnosis.
- From baseline to 1-year, persons aware of their diagnosis experienced a decline in mental functioning. In contrast, those unaware of their diagnosis experienced decreases in satisfaction with daily life and physical functioning.
- We discuss our findings in terms of their applicability to help clinicians monitor patient wellbeing and whether they might extend to awareness of other AD diagnostic data beyond clinical diagnosis such as AD gene and biomarker test results.

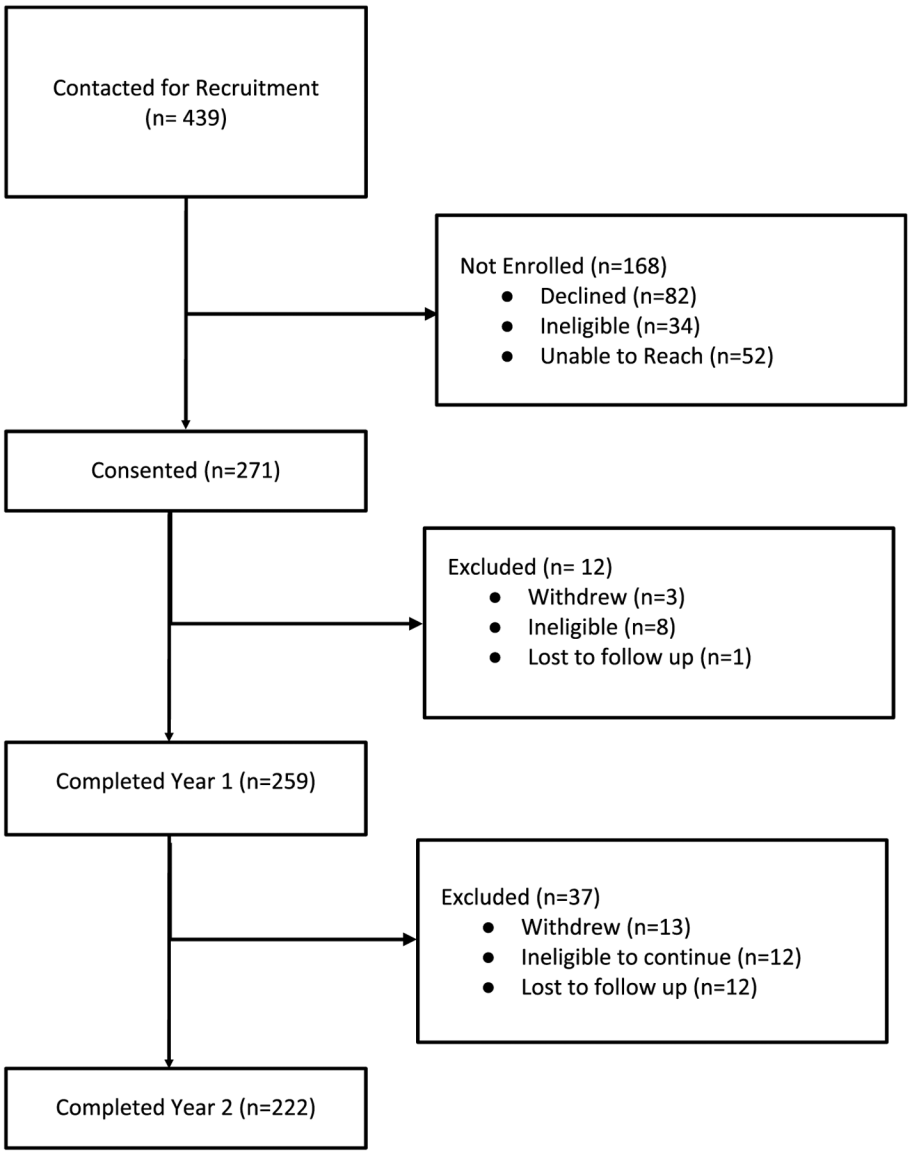

FIGURE 1.
Flow from recruitment through analysis.

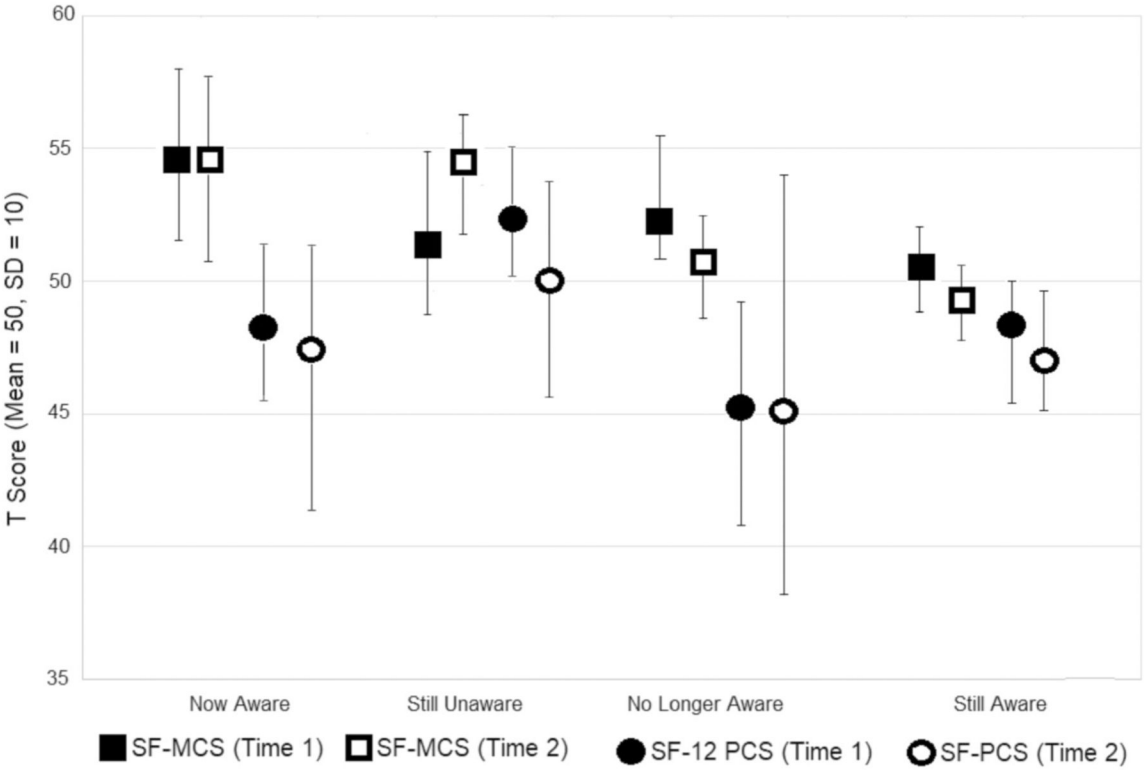

FIGURE 2.

Mean Mental Functioning (SF-12 MCS) and Physical Functioning (SF-12 PCS) by Diagnostic Awareness Group. Older adults with a diagnosis of MCI[13,36] or dementia[12] completed the AD Insight Questionnaire.[32] Participants who responded affirmatively to any of the diagnosis-related items on the AD Insight Questionnaire were entered into our analyses as being "aware" of their diagnosis whereas all others were coded "unaware". *Now Aware* (n = 30) = Unaware of diagnosis at the first assessment but aware at the second. *Still Unaware* (n = 19) = Unaware of diagnosis at both assessments. *No Longer Aware* (n = 27) = Aware of diagnosis at first assessment and unaware at second. *Still Aware* (n = 84) = Aware of diagnosis at both assessments.

TABLE 1

Baseline participant characteristics and cognitive measures by diagnostic group.

	Variable	Normal control (*n* = 99)	Mild cognitive impairment (*n* = 92)	Alzheimer's disease (*n* = 68)	P value[a]
Demographics	Age (years), mean (SD)	79.2 (7.1)	78.1 (6.4)	78.2 (6.5)	0.44
	Female, *n* (%)	72 (72.7)	42 (45.6)	43 (63.2)	<0.001
	African american, *n* (%)	9 (9.1)	8 (8.7)	4 (5.9)	0.73
	College graduate, *n* (%)	66 (66.7)	55 (59.8)	38 (55.9)	0.34
	Right handed, *n* (%)	94 (95.0)	82 (89.1)	64 (94.1)	0.48
Memory	Cognitive composite score, mean (SD)	0.0 (1.0)	−2.4 (1.5)	−4.1 (1.1)	0.001
	PVLT-immediate memory, mean (SD)	39.2 (4.2)	29.5 (6.7)	23.2 (6.3)	0.001
	PVLT-long delay, mean (SD)	7.5 (2.0)	4.0 (2.9)	1.1 (1.9)	0.001
	PVLT-intrusions, mean (SD)	1.6 (3.1)	6.1 (6.0)	8.3 (7.8)	<0.001
	PVLT- perseverations, mean (SD)	0.9 (1.7)	1.6 (2.0)	1.0 (1.7)	0.01
	BFLT-immediate memory, mean (SD)	93.5 (22.1)	53.4 (28.6)	22.7 (19.7)	<0.001
	BFLT-long delay, mean (SD)	21.4 (5.4)	11.2 (7.4)	3.2 (5.4)	0.001
	BFLT-intrusions, mean (SD)	0.1 (0.5)	0.2 (0.5)	1.0 (2.9)	<0.001
	BFLT-perseverations, mean (SD)	0.1 (0.4)	0.1 (0.4)	0.1 (0.3)	0.91
Global cognition	MMSE, mean (SD)	29.2 (1.0)	27.3 (2.2)	24.4 (2.7)	0.001
	MoCA, mean (SD)	26.8 (2.3)	22.0 (3.2)	18.6 (3.7)	0.001
Cognitive reserve	WTAR IQ, mean (SD)	114.1 (9.2)	110.6 (11.0)	110.8 (11.0)	0.06
	WAIS-III IS, mean (SD)	14.6 (2.5)	12.0 (2.9)	9.5 (2.2)	<0.001
Executive function	GPG unique designs, mean (SD)	16.2 (2.5)	13.8 (3.3)	11.7 (4.2)	<0.001
	GPG generation rule violations, mean (SD)	0.7 (1.3)	1.7 (3.0)	2.9 (3.7)	<0.001

Abbreviations: AD, Alzheimer's disease; BFLT, Biber Figure Learning Task; GPG, graphic pattern generation; IQ, intelligence quotient; MCI, mild cognitive impairment; MMSE, mini mental state exam; MoCA, montreal cognitive assessment; PVLT, Philadelphia verbal learning task; WAIS-III IS, Wechsler Adult Intelligence Scale third edition Information subtest; WTAR, Wechsler test of adult reading.

[a]Chi-square test with 2 degrees of freedom for categorical variables. For remaining rank variables, Kruskal–Wallis test with correction for ties.

TABLE 2

One-year change in diagnosis and cognitive measures by baseline diagnostic group.

	Variable	Normal control (*n* = 99) Change[a] (95% CI)	Mild cognitive impairment (*n* = 92) Change[a] (95% CI)	Mild stage dementia (*n* = 68) Change[a] (95% CI)
Diagnosis time 2	Normal control	99.0% (92.7–99.9)	3.9% (1.2−11.8)	>0%
	Mild cognitive impairment	1.0% (0.1−7.3)	92.1% (83.3−96.5)	>2.0% (0.3−13.4)
	Alzheimer's disease	0%	3.9% (1.2−11.8)	>98.0% (86.6−99.7)
Memory	Cognitive composite score	0.05 (−0.1 to 0.16)	−0.21 (−0.35 to 0.06)	>−0.10 (−0.30 to 0.04)
	PVLT-immediate memory	0.08 (−0.96 to 0.47)	−0.44 (−1.75 to 0.09)	>−0.18 (−1.91 to 0.40)
	PVLT-long delay	0.08 (−0.18 to 0.37)	−0.44 (−0.85 to −0.04)	>−0.18 (−0.56 to 0.11)
	PVLT-intrusions	0.13 (−0.53 to 0.78)	−0.05 (−1.11 to 0.99)	>0.98 (−0.32 to 2.43)
	PVLT- perseverations	0.43 (0.02−0.88)	0.41 (−0.04 to 0.89)	>0.10 (−0.53 to 0.51)
	BFLT-immediate memory	2.93 (0.62−5.34)	−2.13 (−4.78 to 0.64)	>−0.84 (−4.87 to 1.94)
	BFLT-long delay	0.20 (−0.56 to 0.96)	−0.70 (−1.62 to 0.02)	>−0.36 (−1.67 to 0.54)
	BFLT-intrusions	−0.08 (−0.30 to 0.02)	−0.05 (−0.19 to 0.04)	>−0.22 (−0.45 to −0.09)
	BFLT-perseverations	−0.01 (−0.10 to 0.06)	−0.03 (−0.14 to 0.06)	>0 (−0.05 to 0.21)
Global cognition	MMSE	−0.12 (−0.42 to 0.13)	−0.43 (−0.87 to 0.05)	>−1.50 (−2.30 to −0.94)
	MoCA	3.80 (3.31−4.27)	−0.63 (−1.25 to −0.03)	>−3.0 (−3.89 to −2.24)
Cognitive reserve	WTAR IQ	−0.40 (−1.10 to 0.34)	−1.90 (−3.90 to 0.12)	>−0.55 (−1.70 to 0.60)
	WAIS-III information subtest	−0.05 (−0.30 to 0.20)	−0.36 (−0.65 to −0.07)	>−0.66 (−1.10 to −0.26)
Executive function	GPG unique designs	0.17 (−0.30 to 0.64)	−0.29 (−1.13 to 0.40)	>−0.22 (−1.11 to 0.63)
	GPG generation rule violations	0.06 (−0.24 to 0.45)	0.29 (−0.34 to 1.03)	>−0.06 (−1.10 to 0.67)

Note: 95% CI = 95% confidence interval. 95% CIs that do not include zero are significant at $p < 0.05$.

Abbreviations: BFLT, Biber Figure Learning Task; GPG, graphic pattern generation; IQ, intelligence quotient; MMSE, mini mental state exam; MoCA, montreal cognitive assessment; PVLT, Philadelphia verbal learning task; WAIS-III, Wechsler Adult Intelligence Scale third Ed.; WTAR, Wechsler test of adult reading.

[a]Paired mean difference (PMD) from baseline to 1-year follow-up.

Table 3

Baseline and 1-year change in self-reported cognitive problems, quality of life, mood, mental functioning, and physical functioning by diagnostic group ($N = 259$).

		Normal control (n = 99)		Mild cognitive impairment (n = 92)		Mild stage dementia (n = 68)	
Outcome		**Baseline mean**	**Change[a] (95% CI)**	**Baseline mean**	**Change[a] (95% CI)**	**Baseline mean**	**Change[a] (95% CI)**
Cognitive problems	CDS	33.0	1.3 (−0.6 to 3.1)	30.4	1.2 (−1.2 to 4.0)	44.7	−1.8 (−5.0 to 1.5)
	More memory problems than most others[b]	6.0[c]	1 (−3.8 to 5.9)	28.8[c]	−3.3 (−11.9 to 6.3)	48.0[c]	6.0 (−1.5 to 15.9)
	Expects memory to worsen	N/A	1 (0−6.9)	47.0[c]	−5.4 (−14.4 to 3.3)	78.0[c]	−11.8 (−23.2 to −2.2)
Satisfaction and health related QOL	EQ-5D	0.86	−0.01 (−0.0 to 0.0)	0.91	0.01 (−0.0 to 0.0)	0.8	−0.01 (−0.0 to 0.0)
	EQ-VAS	81.9	−1.0 (−3.2 to 1.6)	86.5	−3.6 (−6.5 to −0.8)	79.8	−0.7 (−3.7 to 2.1)
	QOL-AD	42.2	−0.4 (−0.9 to 0.2)	42.5	−0.7 (−1.4 to 0.1)	39.2	0.1 (−0.6 to 0.9)
	DEM-QOL	98.9	−1.0 (−1.9 to −0.1)	98.0	−0.1 (−1.5 to 1.5)	89.4	0.8 (−1.0 to 2.9)
Mental functioning and wellbeing	GDS	3.9	0.3 (−0.2 to 0.8)	4.5	0.4 (−0.5 to 1.2)	7.1	0.2 (−0.4 to 1.1)
	BAI	5.3	−1.0 (−1.9 to −0.2)	4.4	0.3 (−0.6 to 1.4)	8.0	−0.5 (−1.4 to 0.2)
	PSS	9.8	0.7 (−0.2 to 1.7)	9.1	0.6 (−0.3 to 1.5)	13.7	−0.5 (−1.6 to 0.6)
	SF-12 MCS	55.7	−0.7 (−2.2 to 0.7)	54.2	−0.7 (−2.0 to 0.6)	51.4	−0.07 (−1.9 to 0.5)
Physical functioning and wellbeing	lADLs	8.9	0.3 (−0.1 to 0.6)	10.7	0.7 (0.2−1.2)	11.0	0.8 (0.02–1.6)
	BADLs	0.5	0.2 (−0.0 to 0.3)	0.5	0.1 (−0.0 to 0.6)	1.0	0.2 (−0 to 0.5)
	SF-12 PCS	46.1	−1.5 (−2.8 to −0.2)	51.0	−2.4 (−4.1 to −1.0)	47.0	0.3 (−1.0 to 1.8)

Note: 95% CI = 95% confidence interval. Confidence Intervals that do not include zero are statistically significant at $p > 0.05$.

Abbreviations: AD, Alzheimer's disease; BADLs, Basic Activities of Daily Living Scale; BAI, beck anxiety inventory; CDS, Cognitive Difficulties Scale; EQ, Euro-QOL; GDS, Geriatric Depression Scale; IADLs, Instrumental Activities of Daily Living Scale; MCI, mild cognitive impairment; MCS, Mental Composite Scale; N/A, non-applicable; PCS, Physical Component Scale; PMD, paired mean difference; PSS, Perceived Stress Scale; QOL, quality of life; SD, standard deviation; SF-12, Short Form Health Survey; VAS, Visual Analog Scale.

[a] Paired mean difference (PMD) from baseline to 1-year follow-up.

[b] Single item from Geriatric Depression Scale.

[c] Mean of a dichotomous variable, expressed as percentage affirmatively endorsed.

TABLE 4

Baseline and 1-year change in cognitive measures, self-reported cognitive problems, quality of life, mood, mental functioning, and physical functioning by diagnostic group and baseline awareness of diagnosis ($N = 259$).

		Normal control ($n = 99$)		Patients unaware of diagnosis ($n = 49$)		Patients aware of diagnosis ($n = 111$)	
Outcome		**Baseline mean**	**Change[a] (95% CI)**	**Baseline mean**	**Change[a] (95% CI)**	**Baseline mean**	**Change[a] (95% CI)**
Cognitive performance	MoCA	26.8	3.8 (3.3−4.3)	20.2	−1.4 (−2.6 to −0.6)	20.8	−1.7 (−2.4 to −1.1)
	CCS	0.0	0.1 (−0.1 to 0.2)	−3.4	−0.2 (−0.4 to 0)	−3.0	−0.2 (−0.3 to −0.03)
Cognitive problems	CDS	33.0	1.3 (−0.5 to 3.1)	30.4	0.7 (−1.8 to 3.2)	44.7	−0.4 (−3.1 to 2.3)
	More memory problems than most others[b]	6.0[c]	1.0 (−3.8 to 5.9)	28.8[c]	−3.3 (−11.9 to 6.3)	48.0[c]	6.0 (−1.5 to 15.9)
	Expects memory to worsen	N/A	1.0 (0−6.9)	47.0[c]	−5.4 (−14.4 to 3.3)	78.0[c]	−11.7 (−23.2 to −2.3)
Satisfaction and health related QOL	EQ-5D	0.86	−0.01 (−0 to 0)	0.9	0.0 (−0 to 0)	0.82	0 (−0 to 0)
	EQ-VAS	81.9	−1.0 (−3.2 to 1.5)	86.5	−2.7 (−6.2 to 0.5)	79.8	−2.2 (−5.1 to 0.3)
	QOL-AD	42.2	−0.4 (−1.0 to 0.2)	42.5	−0.9 (−1.9 to −0.2)	39.2	−0.1 (−0.7 to 0.7)
	DEM-QOL	98.9	−1.0 (−1.9 to −0.1)	98.0	−0.3 (−2.1 to 1.5)	89.4	0.6 (−0.9 to 2.1)
Mental functioning and wellbeing	GDS	3.9	0.3 (−0.2 to 0.8)	4.5	−0.1 (−1.1 to 0.8)	7.1	0.5 (−0.1 to 1.2)
	BAI	5.3	−1.0 (−1.9 to −0.2)	4.4	−0.3 (−1.1 to 0.4)	8.0	0.1 (−0.7 to 1.0)
	PSS	9.8	0.7 (−0.2 to 1.7)	9.1	1.2 (0−2.4)	13.7	−0.3 (−1.2 to 0.5)
	SF-12 MCS	55.7	−0.7 (−2.2 to 0.7)	54.2	0.7 (−0.9 to 2.4)	51.4	−1.4 (−2.4 to −0.2)
Physical functioning and wellbeing	IADLs	8.9	0.3 (−0.1 to 0.6)	10.7	0.4 (−0.1 to 1.0)	11.0	0.8 (0.2−1.5)
	BADLs	0.5	0.2 (0–0.3)	0.5	0.1 (−0.1 to 0.4)	1.0	0.2 (−0.1 to 0.5)
	SF-12 PCS	46.1	−1.5 (−2.8 to −0.2)	51.0	−2.5 (−4.1 to −1.1)	47.0	−0.7 (−2.1 to 0.7)

Note: 95% CI = 95% confidence interval. 95% CIs that do not include zero are significant at $p < 0.05$.

Abbreviations: BADLs, Basic Activities of Daily Living Scale; BAI, Beck Anxiety Inventory; CCS, Cognitive Composite Score; CDS, Cognitive Difficulties Scale; EQ, Euro-QOL; GDS, Geriatric Depression Scale; IADLs, Instrumental Activities of Daily Living Scale; MCS, Mental Composite Scale; MoCA, montreal cognitive assessment; N/A, non-applicable; PCS, Physical Component Scale; PPS, Perceived Stress Scale; QOL, quality of life; SF-12, Short Form Health Survey; VAS, Visual Analog Scale.

[a] Paired mean difference (PMD) from baseline to 1-year follow-up.

[b] Single item from Geriatric Depression Scale.

[c] Mean of a dichotomous variable, expressed as percentage affirmatively endorsed.