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Incidence and Predictors of Advance Care Planning Among Persons with Cognitive Impairment

Linda Garand, PhD, GCNS-BC¹, Mary Amanda Dew, PhD^{2,3,4,5}, Jennifer H. Lingler, PhD, MA, FNP^{1,2,5}, and Steven T. DeKosky, MD^{2,4,5}

¹University of Pittsburgh Department of Health and Community Systems, Alzheimer Disease Research Center, Pittsburgh, PA

²University of Pittsburgh Department of Psychiatry, Alzheimer Disease Research Center, Pittsburgh, PA

³University of Pittsburgh Department of Psychology, Alzheimer Disease Research Center, Pittsburgh, PA

⁴University of Pittsburgh Department of Epidemiology, Alzheimer Disease Research Center, Pittsburgh, PA

⁵University of Pittsburgh Department of Biostatistics, Alzheimer Disease Research Center, Pittsburgh, PA

Abstract

Objective—Persons with mild cognitive impairment (MCI) and Alzheimer’s disease (AD) are at heightened risk for future decisional incapacity. We sought to characterize advance care planning (ACP) rates over time in individuals who had no advance directives (living will or durable power of attorney) in place when they initially presented for a cognitive evaluation.

Design—Retrospective analysis of data that had been prospectively collected.

Setting—Alzheimer’s Disease Research Center memory disorders clinic.

Participants—Persons (N=127) with a diagnosis of MCI or early AD (n = 72) or moderate to severe AD (n = 55) and no advance directives upon initial presentation for a cognitive evaluation.

Measurements—Extraction of responses to items pertaining to advance care planning assessed during annual semi-structured interviews.

Results—By 5 years of follow-up, 39% of the sample had initiated ACP, with little difference by baseline diagnosis. Younger subjects (under 65 years old) were significantly more likely to initiate advance directives (43%) than were older subjects (37%). This age effect was more pronounced in men than women as well as in married subjects, those with a family history of dementia, no depressive disorder, and subjects with moderate to severe AD (versus those with MCI or early AD) at baseline.

Corresponding author: Linda Garand, PhD, GCNS-BC, Assistant Professor of Nursing, University of Pittsburgh, 415 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261, Telephone: 412-383-7946, Fax: 412-383-7293, ligst4@pitt.edu.

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Conclusion—Only a minority of subjects initiated ACPs. The findings suggest the need for interventions aimed at enhancing ACP completion rates, particularly among older adults with cognitive impairment since these individuals may have a timed-limited opportunity to plan for future medical, financial, and other major life decisions.

Keywords

mild cognitive impairment; Alzheimer's disease; durable power of attorney; living will

Both the aging of the population and the growing numbers of people living with Alzheimer's disease (AD) and other forms of dementia have generated considerable interest in advance care planning among persons with and at risk for cognitive impairment. Persons with dementia progressively lose the capacity to make meaningful decisions about their current and future medical, financial, and other life affairs.^{1,2} Therefore, it is important for persons with early stage dementia and those at increased risk for dementia (e.g., persons with mild cognitive impairment or MCI) to consider, in advance, how they would like their important life decisions to be made under such circumstances.

Formal advance care planning (ACP) begins with conversations about the future. Such conversations may or may not lead to the completion of written advance directives. Living wills (LW) and durable powers of attorney (DPOA) are the most widely recognized examples of advance directives.³ Living wills specify personal preferences for future medical care and durable powers of attorney authorize another person to make health care decisions if the individual is unable to make their own decisions.

A number of personal factors are correlated with ACP completion rates. Studies of cognitively intact samples show that persons who have completed ACP tend to be older, married, female, white, well-educated,⁴⁻¹¹ and know someone with cognitive impairment.¹² Other factors found to be associated with ACP include poor physical health or recent hospitalization,^{5,9,11,13-17} a desire for control,^{16,18-21} positive relationships with significant others,²²⁻²⁴ religious affiliation,⁵ and various beliefs and attitudes about ACP.^{4,11,16,25-27}

Only one study to date has described the prevalence rates and sociodemographic correlates of ACP completion among individuals who have sought a research evaluation of cognitive complaints.²⁸ In this study, Lingler and associates found no significant differences in the likelihood of having already completed ACP among subjects who were newly diagnosed with MCI or AD (71% prior ACP completion) as compared to normal controls (69% prior ACP completion). Among those with cognitive impairment, severity of impairment (MCI and early AD versus moderate to severe AD) was unrelated to prior ACP completion. Similar to non-cognitively impaired samples, older age, white race, and higher education level were positively correlated with prior ACP completion rates.²⁸

It is possible that receiving a diagnosis of MCI or AD would trigger ACP completion and, in particular, that receiving a diagnosis that is less severe (e.g., MCI or early AD) might have a different impact on ACP completion than a more severe diagnosis. Yet, no studies have examined this question since earlier work has used cross-sectional/retrospective designs. Persons who learn that they have MCI or early AD are in a unique position to plan for a range of scenarios that can arise within the course of their potentially long illness trajectory. Thus, as follow-up to the Lingler et al. report,²⁸ we examined prospectively collected data on the ACP completion (designation of a DPOA or execution of a LW) patterns of individuals with no ACP at the time of their cognitive diagnosis. Patients were followed for

up to 5 years and we examined baseline sociodemographic and clinical variables that predicted ACP completion.

METHODS

Setting

Adults presenting to the University of Pittsburgh Alzheimer's Disease Research Center (ADRC) with complaints of memory or other cognitive impairment consent to and undergo standardized clinical research evaluations consisting of a medical and neurological history and examination, brain imaging, psychosocial assessment, psychiatric interview, and neuropsychological testing. All ADRC participants have an informant (e.g., spouse, child, sibling or friend) who has frequent interaction with them and can independently report on their functioning. Upon completion of the baseline research evaluation, data are reviewed by a multidisciplinary clinical research team to establish consensus regarding the participant's cognitive diagnosis (AD, MCI or no cognitive disorder) defined according to standardized criteria.^{29,30} After the cognitive diagnosis is established, an ADRC neurologist or geriatrician and social worker meet with the participant and their informant to discuss the cognitive diagnosis and available treatments. At this meeting, ADRC participants are asked to return to the ADRC (with an informant) for annual evaluations. As part of the initial and annual psychosocial evaluation, the participants' social worker inquires whether a LW or DPOA has been completed. If advance directives have not been completed, the social worker explains the purpose of advance directives, provides written education materials to support the verbal information given, and offers to provide a referral to an Elder Law Attorney in their community.

Sample

Participants in the current study included all individuals who consecutively presented at the ADRC Memory Disorders Clinic between January 1, 2000 and August 31, 2005, received a consensus diagnosis of AD or MCI, and reported no ACP at their initial ADRC visit (verified by the informant). Of the 661 individuals diagnosed with AD or MC during this period, 185 (28%) had not completed any ACP at baseline and were thus eligible for inclusion in the current study. The rate of advance care planning observed in our ADRC cohort (72%) falls within the range of rates reported among other older adult samples where rates of advance planning range from 10% to 85%.^{7,12,14,31-38}

Among the 185 subjects with no ACP at baseline, 58 (31.8%) never returned to the ADRC for follow-up evaluation. Based on notes in the ADRC records for these 58 individuals, 5 (8.6%) died, 4 (6.9%) declined further follow-up, 11 (19%) were too disabled to return for follow-up, and 38 subjects (65.5%) were lost to follow-up for unknown reasons. There were no significant differences between subjects lost to follow-up and those included in the present study on baseline demographic or clinical characteristics, except that a larger proportion of those lost to follow-up had major depression (44.8%) than those with follow-up data (22.8%; $\chi^2=7.82$, $df=1$, $p=.008$). A total of 127 subjects were included in the present analyses. We examined data from these individuals for up to five years after they received their initial ADRC diagnosis to identify sociodemographic and clinical factors that predicted ACP completion. Data collection ended on 2/10/10, at which time all study participants had reached a study end point.

Procedure

The University of Pittsburgh Institutional Review Board approved this retrospective analysis of data that had been prospectively collected during annual ADRC reassessments of

subjects. Date were extracted from the ADRC records by a trained research assistant and verified by the investigators.

Measures

Advance Care Planning Status—The subject's ACP status had been recorded as part of the standard psychosocial assessment that was conducted at the initial and annual follow-up ADRC visits by a Master's-level social worker. Semi-structured interview questions (recorded using a checklist format) ascertained if the subject had (a) designated a durable power of attorney (DPOA), or (b) completed a living will (LW). Item responses were determined based on both the informant's and participant's report. When neither of them knew the participant's ACP status, the item was coded as "no LW or DPOA."

Clinical Factors—We divided subjects into two groups: (a) those with a diagnosis of MCI or early AD (defined as a diagnosis of MCI or AD, 29-30 plus a score of 20 or higher on the Mini Mental State Exam, MMSE39), and (b) those with moderately to severely advanced AD (i.e., a diagnosis of probable or possible AD30 and MMSE scores of 19 or lower).

Sociodemographic and Background Characteristics—Sociodemographic variables that have been shown to be correlated with ACP completion in other samples were included in the current analysis.^{7,8,9,12,28} Sociodemographic information such as age, gender, race, marital status, and education level was systematically collected at the initial ADRC visit using a clinician-administered sociodemographic questionnaire. We included information regarding the participant's family history of AD in the analyses because having a family member with cognitive impairment can serve as a proxy for having witnessed first-hand an individual with progressively impaired decisional capacity and knowing someone with dementia has been found to be positively associated with ACP completion rates.¹² Family history of AD was documented as part of the standard psychosocial assessment described above.

Finally, since older adults with a Major Depressive Disorder (MDD) at the initial visit may lack the motivation to execute ACP in subsequent years (because they may experience ongoing or recurrent MDD episodes), we also extracted research record data regarding the patient's psychiatric diagnosis of MDD at the time of their initial ADRC evaluations. Mood assessments are conducted by a psychiatrist as a part of the standardized multi-disciplinary evaluations.

Analytic Approach

We first conducted descriptive analyses and then determined if there were significant differences between subjects in the two cognitive diagnostic groupings on other baseline characteristics using chi-square analyses. Since ACP was documented as present versus absent at annual follow-up assessments, we used survival analysis methods to determine the incidence of ACP completion during the follow-up period. Specifically, we employed life table analyses using the Kaplan Meier method because ACP status was documented at the annual visit but the precise date of ACP completion was not recorded. Within these analyses, we determined whether the likelihood of ACP completion over the five-year follow-up period varied as a function of baseline diagnostic status and sociodemographic and other background characteristics. Two-sided P-values of less than .05 indicated significant between-group differences.

RESULTS

Baseline Sample Characteristics

As shown in Table 1, most of the subjects were aged 65 or older, married, and European American. Men and women were almost equally represented. Slightly less than half the sample had a known family history of dementia and nearly one-quarter of the sample had a psychiatric diagnosis of MDD at baseline. Subjects with MCI or mild AD were more likely to be female and have an education beyond high school. There were no other baseline differences between the two groups.

Advance Care Planning

The cumulative incidence (actuarial rate, adjusted for censoring) of ACP over 5 years was 39%. Of those subjects completing advance directives, 15.1% completed a LW only, 39.4% completed a DPOA only, and 45.5% completed both a LW and DPOA. The pattern of ACP completion did not vary significantly by cognitive diagnostic grouping (see Figure 1a). In fact, the curves in the figure completely overlap until the fourth year of follow-up.

Among the baseline sociodemographic and background characteristics, age was the only factor that significantly predicted ACP completion rates during the five years after receiving an ADRC cognitive diagnosis (refer to Table 2). As illustrated in Figure 1b, younger subjects showed a significantly higher rate of ACP (43%) over five years of follow-up compared to older subjects (37%). Interestingly, all ACP completion in the younger group occurred within the first two years after diagnosis. In the older group, the incidence of completion slowly increased across all five years of follow-up. ACP completion rates did not vary significantly by subjects' gender, marital status, educational level, family history of AD, or MDD during the study period. (Race was not included in the analyses due to limited variability on this characteristic.)

To examine whether the age effect was more pronounced in some subgroups of the sample than in others, we conducted a series of two-factor survival analyses with age and each of the other sociodemographic or background variables entered into the model. Specifically, within the context of the Kaplan-Meier Survival Analysis models, the association of the age factor over time to ACP completion could then be tested within each stratum of a given sociodemographic or background characteristic. As shown in Table 3, age played a significant role among individuals with more severe cognitive impairment (among those with moderate to severe AD); younger subjects were more likely to complete ACPs (55%) than were older subjects (24%). In contrast, the rates of ACP completion among subjects with MCI or mild AD were more similar across younger and older subjects (29% and 41%, respectively). In addition, subjects' age was important in the men, but not women. Among men, 60% of those under age 65 completed ACPs while only 30% of older men did so. In women, the proportions of younger and older subjects who completed ACPs did not differ from each other (21% and 45% respectively). Similarly, younger subjects were more likely to complete ACPs if they had a family history of AD, if they were married, or if they did not have MDD at baseline. There was no age difference in ACP completion rates among subjects with no family history of AD, among unmarried subjects, or among those with MDD at baseline.

DISCUSSION

This is the first study examining prospectively recorded data on advance directive completion rates in persons at high risk for future decisional incapacity. In the large cross-sectional study by Lingler and associates, the majority of 661 persons (71%) with MCI or AD had completed advance directives before presenting to the ADRC for an evaluation of

their cognitive symptoms.²⁸ The current sample was limited to those individuals with MCI or AD who presented to the ADRC with no ACP in place and returned for follow-up (N = 127). Only a minority (39%) of these individuals went on to complete ACP within 5 years of learning their cognitive diagnosis, and the severity of their diagnosis showed little impact on likelihood of ACP completion.

Because ours was a secondary analysis, we could not question subjects directly regarding their reasons for not completing advance directives. While it is possible that some individuals made an informed decision not to complete healthcare advance directives after learning of their cognitive diagnosis, it is also possible that they have informational or counseling needs related to understanding their new diagnosis and the goal of advance directives. Their families may also play a key role in whether ACP take place and they may need additional information or counseling as well.

We examined a range of baseline sociodemographic and clinical characteristics in relation to subsequent ACP completion and found the most pronounced predictive effects for age. Younger subjects (under age 65) were significantly more likely than older subjects to complete ACP after learning they had MCI or AD. In contrast, earlier studies show that advanced age is associated with higher prevalence rates of ACP completion among elderly community, nursing home, and medical clinic samples^{7,8,9,12} and among those who complete planning prior to being diagnosed with MCI or AD.²⁸ For younger subjects, receiving a cognitive diagnosis may be their first occasion to consider ACP. In addition, our finding that the age effect was strongest in certain subjects within our sample suggests that other factors, such as being male, married, euthymic, having a first degree relative with AD, and having relatively advanced cognitive impairment (moderate to severe AD versus MCI or mild AD) may further motivate younger subjects to plan for future decisional incapacity.

Several limitations of the study must be borne in mind. In particular, we focused on individuals who sought an evaluation of their cognitive symptoms at a University-based research center. Individuals seeking an ADRC diagnosis of their cognitive symptoms may differ from or be more homogeneous than individuals who have not sought such a diagnosis. For example, a large proportion of the sample (89.8%) was European American, and the rate of ACP in the sample was at the upper end of the prevalence rates found in other older adult populations. Further, the retrospective nature of the study design did not allow us to determine the type of DPOAs completed (financial versus health care durable power of attorney), nor were we able to independently verify that advance directives were completed, aside from verification from a family informant. Additionally, individuals who did not return for follow-up at the ADRC could not be included in the present analyses. Because we found significant differences in annual follow-up rates among subjects based on a diagnosis of MDD, it is possible that ACP completion rates were different in these subjects. Lastly, because we relied on data extracted from ADRC clinical records, it is possible that information on ACP completion was missing or inaccurately recorded. However, because the ADRC focuses on acquisition of research data, the records on which we relied are more likely to be complete than are routine medical records. Nevertheless, prospective studies of ACP completion rates, in which subjects are questioned further regarding reasons they did or did not engage in such planning, are needed.

Results of this study contribute to our understanding of factors that influence ACP among a group of individuals at high risk for future decisional incapacity. Given the low rate of ACP completion over the 5 years of follow-up, results of this study suggest the need for investigations to examine modifiable factors that influence ACP completion in this segment of the population. Such work will help us to identify effective interventions designed specifically to promote awareness of advance directives in persons with dementia. While it

may not be feasible for a person to complete advance directives once they have moderate to severe AD, it should be a priority for older adults with MCI or early AD since these individuals may have a time-limited opportunity to plan for future medical care or designate a health care proxy.

With death rates from dementia steadily increasing,⁴⁰ there is a national imperative to recognize it as a terminal illness, to improve end-of-life care for affected individuals, and to promote optimal decision-making by their families.^{41,42} Toward this end, the American Association for Geriatric Psychiatry set forth a minimal set of care principles for patients with dementia and their caregivers that includes encouraging patients to complete advance directives for medical care and institutional placement and be educated about the potential adverse consequences of not doing so.⁴³

But what form should that education take? In meta-analytic reviews of interventions designed to promote ACP completion among older (generally cognitively intact) adults, interventions have been categorized as didactic or interactive.^{44,45} Didactic interventions are those that give information to participants either distributed by person through an educational program, clinical encounter or by a mailing. Interactive interventions are those that include person-to-person interaction where participants have the opportunity to ask questions and/or receive assistance completing advance directives. To date, interactive interventions appear to be more successful in promoting ACP completion.^{44,45} Such interventions will require modifications to be suitable for persons with early dementia and their family caregivers, with more education about the prognosis, clinical course and expected complications of dementia. Further, in cases where the window for meaningful advance planning has already passed, clinicians should educate or counsel family members about surrogate decision making in the absence of a written care and/or proxy directives.⁴⁶

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Figure 1a.
Cumulative Incidence of Advance Care Planning by Cognitive Status of Participants

Figure 1b.
Cumulative Incidence of Advance Care Planning by Age of Participants

Table 1

Participant Characteristics by Diagnostic Category (N = 127)

Characteristic at baseline, n (%)	Diagnostic Group, n (%)		χ^2 (df = 1)	P
	MCI or Early AD (n = 72)	Moderate or Severe AD (n = 55)		
Age, 65 years or older	61 (84.7)	43 (78.2)	.34	.362
Gender, female	36 (50.0)	37 (67.3)	.05	.070
Ethnicity, European American	64 (88.8)	50 (90.9)	.14	.775
Marital status, Married*	47 (65.3)	41 (74.5)	.81	.432
Education, beyond high school	31 (43.0)	13 (23.6)	5.19	.025
Positive family history of AD**	32 (44.4)	23 (41.8)	.16	.716
Current major depressive disorder***	13 (18.0)	16 (29.0)	2.08	.199

Note: MCI = mild cognitive impairment, AD = Alzheimer's Disease

* 2 cases of missing data, n = 125

** 6 cases of missing data, n = 121

*** 3 cases of missing data, n = 124

Table 2

Bivariate associations of baseline characteristics with rates of advance care planning by 5 years of follow-up, survival analyses (N = 127)

Variable		Actuarial Rate by 5 Years	Wilcoxon χ^2 (df = 1)	P value
Age,	≥ 65 years old	.37	4.854	.028 *
	< 65 years old	.43		
Gender,	female	.43	1.016	.313
	male	.37		
Marital status,	married	.36	.259	.611
	not married	.46		
Education,	≤ high school	.40	1.772	.183
	> high school	.37		
Family history of AD,	yes	.39	.304	.581
	no	.39		
MDD,	present	.10	3.214	.730
	absent	.48		

Note: MDD = Major Depressive Disorder

Associations of subject age with rates of advance care planning as a function of other baseline characteristics, survival analyses (N = 127)

Table 3

Variable	Label	Wilcoxon χ^2 (df=1)	P value	Proportion of subjects aged < 65 with ACP	Proportion of subjects $\geq$ 65 with ACP
Cognitive Diagnosis	MCI or Early AD (n = 72)	0.190	.663	.29	.41
	Moderate or Severe AD (n = 55)	7.341	.007 **	.55	.24
Marital Status	Not married (n = 37)	0.016	.898	.22	.48
	Married (n = 88)	5.748	.017 *	.48	.33
Gender	Male (n = 54)	7.264	.007 **	.60	.30
	Female (n = 73)	0.000	.991	.21	.45
Education	$\leq$ High school (n = 83)	2.096	.148	.37	.38
	> high school (n = 44)	2.117	.146	.48	.33
Family History of AD	No family history (n = 66)	0.001	.980	.24	.39
	Family history (n = 55)	5.572	.018 *	.51	.36
Major Depressive Disorder (MDD)	No MDD (n = 95)	6.915	.009 **	.58	.46
	MDD (n = 29)	0.149	.699	.14	.09

* Test statistic is significant beyond the 0.05 level (2-tailed)

** Test statistic is significant beyond the 0.01 level (2-tailed)