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Original Article

Advance Care Planning in Community-Dwelling Patients With Dementia



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Abstract

Context. Little is known about advance care planning (ACP) among community-dwelling patients with dementia.

Objectives. To describe aspects of ACP among patients with dementia and examine the association between ACP and health care proxy (HCP) acceptance of patients' illness.

Methods. Cross-sectional observational survey of 62 HCPs of patients with dementia ($N = 14$ mild, $N = 48$ moderate/severe), from seven outpatient geriatric and memory disorder clinics in Boston. Aspects of ACP included HCP's report of patients' preferences for level of future care, communication with HCP and physician regarding care preferences, and proxy preparedness for shared decision making. The association between ACP and HCP acceptance with patients' illness was examined using the Peace, Equanimity, and Acceptance subscale of the Cancer Experience Scale.

Results. Eleven percent of proxies believed that the patient would want life-prolonging treatment, 31% a time-limited trial of curative treatment, and 47% comfort-focused care. Thirty-one percent reported that the patient had communicated with their physician regarding preferences for care, and 77% had communicated with the HCP. Forty-four percent of HCPs wanted more discussion with the patient regarding care preferences. The HCP having discussed care preferences with the patient was associated with greater acceptance of the patient's illness ($P = 0.004$).

Conclusion. Our findings support need for greater ACP discussions between patients and proxies. Discussions regarding goals of care are likely to benefit patients through delivery of care congruent with their wishes and HCPs in terms of greater acceptance of patients' illness. *J Pain Symptom Manage* 2018;55:1105–1112. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Dementia, advance care planning, health care proxy

Introduction

Over 5 million Americans have Alzheimer's disease, a number expected to reach 13 million by 2050.¹ Persons with dementia are frequent users of the medical system; the total Medicare and Medicaid payments

for patients with dementia are approximately three times those of age-matched controls.² An accumulation of evidence now supports that dementia is a terminal illness with a predictable trajectory of decline.³

The concept of advance care planning (ACP) has evolved from a one-time intervention to that of a

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health behavior involving ongoing communication between patients, providers, and proxy decision makers, encompassing broad goals of care and specific treatment choices.⁴ This model fits well with dementia, due to the deteriorating course during which common complications and decisions can be anticipated.^{3,5}

ACP is the most consistent modifiable factor associated with better palliative care outcomes in advanced dementia^{3,6–11} including lower levels of stress, anxiety, and depression among family members.¹² However, physicians, patients, and families may avoid ACP owing to concern that it may cause psychological distress.^{13,14} Family caregivers, likely to become surrogate decision makers, may be unprepared for their role^{15,16} owing to inadequate knowledge of patients' wishes for future care. Among patients with early dementia, family caregivers have been found to have low-to-moderate agreement with patients regarding wishes for future care.¹⁷ Currently, there is little understanding of the prevalence and timing of ACP discussions over the course of dementia.

The objectives of this study were to describe ACP among community-dwelling patients with dementia at various stages of illness and to examine the association between elements of ACP and proxy acceptance of the patient's illness. The goal is to provide information to optimize the timely transfer of medical decision-making responsibility from patient to proxy to promote care consistent with patient's wishes.

Methods

Recruitment and Study Population

HCPs of patients were recruited from outpatient settings: 1) three primary care practices of Hebrew SeniorLife (HSL) community housing sites, 2) neurology referral memory disorders clinics (Brigham and Women's Hospital and Massachusetts General Hospital), and 3) academic primary care geriatric practices (Beth Israel Deaconess Medical Center and Boston Medical Center).

At HSL, Beth Israel Deaconess Medical Center, and Boston Medical Center, the electronic medical record was queried to identify patients meeting initial criteria, including a diagnosis of dementia; being 60 years of age or older; and seen in the clinic practice in the past year. At the memory disorders clinics, potential patients were identified by providers at weekly meetings attended by the clinicians in those clinics. At all sites, either the designated HCP or the emergency contact person in the medical record was identified as the proxy. Patients' physicians were asked to categorize the patients' dementia stage as mild, moderate, or severe based on their clinical judgment. Consent was

obtained verbally by telephone for all participants. The HSL institutional review board approved the study's conduct, non-HSL sites ceded review to HSL.

Data Collection and Elements

HCPs participated in a 40-minute telephone interview conducted by a trained research assistant.

Patient and Proxy Characteristics

Patient demographic information including age, gender, race (white, black/African-American, Asian, other), and ethnicity (Hispanic, non-Hispanic) was obtained from medical record review or proxy interview. Dementia stage (mild, moderate, or severe) was obtained from the referring physician. Proxy characteristics obtained at interview included age, gender, race, ethnicity, education, relationship to patient, frequency of caregiving (\geq once weekly vs. $<$ once weekly) and years involved in the patient's care (≥ 3 or < 3).

Care Preferences

Proxies were asked whether the patient had a written living will and had formally designated an HCP. Proxies were asked whether the patient had expressed a preference regarding the following treatments should the need arise: resuscitation, mechanical ventilation, hospitalization, and tube feeding. For those who had expressed a preference, the nature of that preference was also solicited. Proxies were asked to choose which of the following levels of care best represented patients' preferences for future medical care: 1) treatments to live as long as possible even if that resulted in discomfort, inability to care for self, or reliance on machines to live, 2) a time-limited trial of treatments, which would be stopped if they were not helping or caused suffering, or 3) treatments designed to focus on quality of life and comfort even if that meant a shorter life.

Communication

Proxies were asked whether patients had discussed the following with their physicians: health care proxy designation, preference for specific treatments (e.g., resuscitation, mechanical ventilation, hospitalization, tube feeding), and preferences for broad level of medical care. Proxies were asked whether they had discussed these topics with the patient and if they desired more communication about the patient's wishes.

Proxy Preparedness

Proxies were asked whether they believed the patient would be capable of participating in decision making in one and five years (response options dichotomized to "fully, mostly, or somewhat" capable vs. "not at all" capable). Proxies were asked to rate their

confidence in knowledge of the type of medical care the patient would want at the end of life; their ability to make medical decisions for the patient; and their knowledge about dementia needed to make medical decisions. Likert scale response options were analyzed as “fairly” or “extremely” confident vs. “somewhat,” “a little,” or “not at all” confident.

The Alzheimer’s Disease Knowledge Scale¹⁸ (range 0–30, higher scores indicate greater knowledge) was used to measure proxy understanding of dementia. Because knowledge of the disease process is important for decision making, proxies were asked the degree to which they were interested in learning more about end-stage dementia, with response options of “very interested,” somewhat interested,” or “not at all interested;” dichotomized for analysis as “very interested” vs. “other.” We inquired about the proxies’ opinion regarding the best time to educate patients and families about the late stages of illness, with response options of “when the patient is first given the diagnosis,” “about a year after the patient has had the diagnosis,” “after the patient has had the diagnosis for a few years,” “when the patient enters the end stage of the disease,” or “never.” For analysis purposes, the response of “when the patient is first given the diagnosis” was compared to the other response options combined.

Proxy acceptance of the patient’s illness was measured using an adapted version of the Peace, Equanimity, and Acceptance in the Cancer Experience [PEACE] Scale.¹⁹ This scale, originally developed for patients with advanced cancer, measures peaceful acceptance of the patient’s terminal illness, and we used the five-item Peaceful Acceptance subscale (range 5–20, higher scores indicate greater acceptance). Caregiver burden was measured using the 12-item version of the Zarit Burden Interview²⁰ (range 12–60, higher scores indicate greater burden).

Statistical Analysis

Descriptive statistics including means with SDs for continuous measures and proportions were calculated for discrete measures. Variables were compared across the three clinic types and stage of dementia (mild vs. moderate/severe) using ANOVA for continuous variables and chi-square tests for discrete variables. A *P*-value of 0.05 or less was used to determine statistical significance.

Linear regression was used to evaluate the association between elements of ACP (independent variables) and the peaceful acceptance of illness subscale from the PEACE Scale (outcome). Covariates included patient and proxy characteristics. Independent variables found to be associated with these outcomes at a *P* value of <0.1 in unadjusted analyses were included in the multivariable models.

All statistical analyses were performed using STATA SE version 12.0 (STATA Corporation, College Station, TX).

Results

Participant Recruitment

We identified 163 potentially eligible patient/proxy dyads. We were able to contact 113 (69%) of these proxies of whom 62 (55%) agreed to participate; 19 (31%) from HSL clinics, 23 (37%) from memory disorders clinics, and 20 (32%) from academic primary care geriatric clinics.

The most commonly cited reasons that proxies (*n* = 51) refused to participate were lack of interest (*n* = 20), too burdensome (*n* = 12), and privacy concerns (*n* = 10). Demographic data were obtained from only 34 proxies who refused participation. Their mean age (62 years) and gender (62% female) were similar to participants; however, a relatively larger proportion of participants were nonwhite (33% vs. 16%).

Participant Characteristics

Participant characteristics are presented in [Table 1](#). The mean age of patients was 84 years (SD, eight years). Patients in the memory disorders clinics had a younger mean age (79) than those in the community housing clinics (89) or academic geriatric clinics (85), *P* < 0.001. Overall, 38 patients (61%) were female, with a lower percentage (39%) in the memory disorders clinics than in community housing (79%), or academic geriatric clinics (70%), *P* = 0.02. The majority of patients were white (89%), with a significantly lower proportion in the academic geriatric clinic (65%) compared to the other two clinical settings (100%), *P* < 0.01. Physicians classified the patients’ stage of dementia as follows: mild, *n* = 14 (23%); moderate, *n* = 30 (48%); severe, *n* = 14 (23%); and moderate to severe (not classified further), *n* = 4 (6%).

The mean age of proxies was 62 years (SD 11.5 years) and 44 (71%) were female. Overall, 52 (84%) were white, with higher percentages from community housing clinics (95%) and memory disorder clinics (96%), than the academic geriatric clinics (60%), *P* < 0.01. Overall 40 (65%) proxies were a child of the patient, although this percentage was lower in the memory disorder clinics (30%), compared to the community housing (84%) or academic geriatric clinics (85%), *P* < 0.001. Forty-seven (76%) proxies provided care to the patient at least weekly, and 32 (55%) had provided care for three years or longer. The mean Zarit Burden score was 28.6 (SD 7.7) (range 12–60).

Table 1
 Characteristics of Patients With Dementia and Their Proxies

Characteristic	All	Setting			Dementia Stage	
	<i>N</i> = 62, <i>n</i> (%)	Community Housing Primary Care <i>N</i> = 19, <i>n</i> (%)	Memory Disorders Clinic <i>N</i> = 23, <i>n</i> (%)	Academic Geriatric Primary Care <i>N</i> = 20, <i>n</i> (%)	Mild <i>N</i> = 14, <i>n</i> (%)	Moderate or Severe <i>N</i> = 48, <i>n</i> (%)
Patient characteristics						
Age in yrs, mean (SD)	84 (8.2)	89 (5.3) ^a	79 (8.8) ^a	85 (6.1) ^a	81 (8.5)	84 (8.0)
Female	38 (61)	15 (79) ^b	9 (39) ^b	14 (70) ^b	8 (57)	30 (63)
Race						
White	55 (89)	19 (100) ^a	23 (100) ^a	13 (65) ^a	13 (93)	42 (88)
African American	4 (6)	0	0	4 (20)	1 (7)	3 (6)
Other/refused	3 (5)	0	0	3 (15)	0	3 (6)
Hispanic ethnicity	2 (3)	0	1 (4)	1 (5)	0	2 (4)
Proxy characteristics						
Age in yrs, mean (SD)	62 (11.5)	62 (10.9)	65 (12.7)	58 (9.7)	61 (10.3)	62 (11.9)
Female	44 (71)	10 (53)	18 (78)	16 (80)	8 (57)	36 (75)
Race						
White	52 (84)	18 (95) ^a	22 (96) ^a	12 (60) ^a	39 (81)	13 (93)
African American	6 (10)	0	0	6 (30)	5 (10)	1 (7)
Other	4 (6)	1 (5)	1 (4)	2 (10)	4 (8)	0
Hispanic ethnicity	3 (5)	1 (5)	1 (4)	1 (5)	3 (6)	0
College education or greater	47 (76)	17 (89)	16 (70)	14 (70)	12 (86)	35 (73)
Child of patient	40 (65)	16 (84) ^a	7 (30) ^a	17 (85) ^a	8 (57)	32 (67)
Caregiver burden						
Provides care at least weekly	47 (76)	11 (58)	19 (83)	17 (85)	11 (79)	36 (75)
Proxy involved in care three years or more	32 (55)	8 (47)	12 (57)	12 (60)	6 (46)	26 (58)
Zarit Burden Scale ^c	28.6 (7.7)	28.3 (5.7)	30.9 (9.4)	26.3 (6.8)	28.7 (7.7)	28.6 (7.8)

^a*P* < 0.01.

^b*P* < 0.05.

^cTwelve-item version of the Zarit Burden Interview (range 12–60, higher scores indicate greater burden).

Care Preferences

Overall, 56% of proxies reported the patient had a living will. This proportion was higher in the HSL community (74%) and memory disorders clinics (70%) than the geriatric clinics (25%), *P* = 0.003. HCP designation was high (92%). Sixty-eight percent of proxies reported that patients had expressed a preference regarding resuscitation, 67% mechanical ventilation, 60% hospitalization, and 61% tube feeding. Of these patients who expressed preferences (results not in table), 45% did not want to be resuscitated, 56% did not want mechanical ventilation, 8% did not want to be hospitalized, and 71% did not want to be tube-fed under any circumstances. Preferences for level of care were as follows: 11% of proxies reported the patient would want treatments designed to prolong life; 31% a time-limited trial of treatment; and 47% would want treatments focused on comfort (Table 2). Of those who wanted to focus on comfort (results not in table), 55% did not want resuscitation, 65% did not want mechanical ventilation, and 5% did not want hospitalization.

Communication

Overall, 68% of proxies reported that the patient had communicated with their physician about HCP designation, and this was higher in geriatric primary

care practices (90%) compared to memory disorders clinics (61%) or community practices (53%), *P* = 0.03. Proxy report of patient communication with their physician regarding preferences for level of care was 31% and for specific treatment preferences was as follows: resuscitation (35%), mechanical ventilation (26%), hospitalization (31%), and tube feeding (19%). While 77% of proxies stated they had discussed preferences for the level of care with the patient, 44% felt they would like to have more discussion.

Proxy Preparedness

Approximately half of proxies felt that the patient would be unable to participate in medical decision making in one year, and 84% of proxies felt that the patient would be unable to participate in medical decision making in five years. Overall, 84% of proxies were fairly or extremely confident in knowing what the patient would want at the end of life, and 97% of proxies were fairly or extremely confident in being able to make medical decisions on their behalf. A slightly lower percentage of proxies (80%) were fairly or extremely confident that they had the knowledge of dementia needed to make decisions.

Although the proxies' knowledge of dementia was high, with a mean score of 25 (range 0–30) on the

Table 2
Proxy Perceptions About Advance Care Planning in Dementia

Proxy Perception	All	Setting			Dementia Stage	
	N = 62, n (%)	Community Housing Primary Care N = 19, n (%)	Memory Disorders Clinic N = 23, n (%)	Academic Geriatric Primary Care N = 20, n (%)	Mild N = 14, n (%)	Moderate or Severe N = 48, n (%)
Care preferences						
Patient has a living will	35 (56)	14 (74) ^a	16 (70) ^a	5 (25) ^a	10 (71)	25 (52)
Patient has designated a health care proxy	57 (92)	18 (95)	22 (96)	17 (85)	12 (86)	45 (94)
Patient has expressed a preference regarding						
Resuscitation	42 (68)	14 (74)	14 (61)	14 (70)	11 (79)	31 (65)
Mechanical ventilation	41 (67)	11 (58)	13 (57)	17 (85)	11 (79)	30 (63)
Hospitalization	37 (60)	11 (58)	12 (52)	14 (70)	6 (43)	31 (65)
Tube feeding	38 (61)	10 (53)	14 (61)	14 (70)	9 (64)	29 (60)
Preference for level of care						
Life-prolonging treatment	7 (11)	2 (11)	1 (4)	4 (20)	1 (7)	6 (31)
Limited treatment trial	19 (31)	6 (32)	7 (30)	6 (30)	3 (21)	16 (33)
Comfort treatment only	29 (47)	8 (42)	13 (57)	8 (40)	9 (64)	20 (42)
Not ready to answer/unsure	7 (11)	3 (16)	2 (9)	2 (10)	1 (7)	6 (31)
Communication						
Patient has discussed with their physician						
Health care proxy designation	42 (68)	10 (53) ^b	14 (61) ^b	18 (90) ^b	10 (71)	32 (67)
Goals of care	19 (31)	6 (32)	7 (30)	6 (30)	4 (29)	15 (31)
Resuscitation	22 (35)	8 (42)	7 (30)	7 (35)	5 (36)	17 (35)
Mechanical ventilation	16 (26)	4 (21)	6 (26)	6 (30)	4 (29)	12 (25)
Hospitalization	19 (31)	7 (37)	5 (22)	7 (35)	4 (29)	15 (31)
Tube feeding	12 (19)	3 (16)	6 (26)	3 (15)	3 (21)	9 (19)
Proxy discussed preferred level of care with patient	48 (77)	12 (63)	17 (74)	19 (95)	12 (86)	26 (54)
Proxy wants to discuss preferred level of care more with patient	27 (44)	7 (37)	11 (48)	9 (45)	9 (64)	18 (38)
Proxy preparedness						
Believes patient will be incapable of decision making in one year	32 (52)	13 (68)	10 (43)	9 (45)	2 (14) ^a	30 (63) ^a
Believes patient will be incapable of decision making in five years	52 (84)	18 (95)	18 (78)	16 (80)	7 (50) ^a	45 (94) ^a
“Extremely or fairly” confident in						
Knowledge of what the patient wants at the end of life	52 (84)	15 (80)	19 (83)	17 (85)	10 (71)	42 (86)
Ability to make medical decisions for the patient	60 (97)	19 (100)	22 (96)	19 (95)	14 (100)	46 (96)
Knowledge of dementia needed to make decisions	49 (80)	14 (74)	17 (74)	18 (90)	10 (71)	39 (81)
Very interested in learning more about end-stage dementia	40 (66)	13 (68)	16 (70)	11 (55)	9 (64)	31 (65)
Patient should be educated about end-stage disease at diagnosis	31 (50)	8 (42)	10 (43)	13 (65)	8 (57)	23 (48)
Family should be educated about end-stage disease at diagnosis	36 (58)	10 (53)	13 (57)	13 (65)	7 (50)	29 (60)
Proxy knowledge of dementia, ^c mean (SD)	25 (3)	25.4 (2.9)	25.7 (2.1)	24.4 (4.2)	26.5 (2.2)	24.8 (3.3)
Acceptance of illness, ^d mean (SD)	16.7 (2.5)	16.3 (2.3)	16.8 (2.5)	17.1 (2.6)	16.5 (2.7)	16.8 (2.4)
Struggle with illness ^e mean (SD)	14.7 (4.4)	14.4 (4.0)	16.1 (4.5)	13.6 (4.3)	14.0 (5.1)	15.0 (4.2)

^aP < 0.01.

^bP < 0.05.

^cAlzheimer's Disease Knowledge Scale, range 0–30, higher scores indicate greater knowledge.

^dPeace, Equanimity, and Acceptance in the Cancer Experience Scale, Acceptance of Illness subscale, range 5–20, higher scores indicate greater acceptance.

^ePeace, Equanimity, and Acceptance in the Cancer Experience [PEACE] Scale. Struggle with Illness subscale, range 7–28, higher scores indicate greater struggle.

Alzheimer's Disease Knowledge Scale, 66% stated they were “very interested” in learning more about the disease. When asked the best time to educate patients about end-stage dementia, 50% responded at the time of diagnosis, 11% one year after the diagnosis, and 18% felt patients should never receive this education. A total of 58% believed families should be educated about end-stage dementia at the time of

diagnosis and 21% felt that one year after diagnosis was the best time.

Association Between ACP Elements and Proxy Acceptance of Dementia

Proxy scores on the Peaceful Acceptance subscale (mean, 16.7 [SD = .31]) reflected general proxy acceptance of the patient's dementia. Table 3 presents

Table 3
Factors Associated With Higher Proxy Peaceful Acceptance Scores (N = 62)^a

Characteristic	Unadjusted Analysis		Adjusted Analysis	
	Pvalue	Beta Coefficient (95% CI)	Pvalue	Beta Coefficient (95% CI)
Greater patient age	0.013	0.09 (0.02, 0.17)	0.146	0.06 (−0.02, 0.14)
Proxy is child of patient	0.044	1.13 (0.04, 2.59)	0.435	0.53 (−0.82, 1.88)
Greater proxy confidence in being able to make medical decisions for the patient	0.012	1.45 (0.33, 2.56)	0.271	0.61 (−0.49, 1.72)
Proxy has discussed preferences for levels of care with patient	<0.001	2.67 (1.33, 4.01)	0.004	2.18 (0.72, 3.64)
Proxy believes patient has discussed levels of care with their doctor	0.093	1.06 (−0.18, 2.30)	0.906	0.07 (−1.12, 1.26)

^aPeace, Equanimity, and Acceptance in the Cancer Experience Scale, Acceptance of Illness subscale, range 5–20, higher scores indicate greater acceptance.

linear regression analyses examining ACP elements associated with the Peaceful Acceptance subscale. Independent variables associated with higher scores (greater acceptance) in the unadjusted analysis at a $P = 0.10$ level included the following: greater patient age, proxy is patient's child, greater proxy confidence in being able to make medical decisions for the patient, proxies having discussed preferences for the level of care with the patient, and the proxy believing that the patient has discussed levels of care with their doctor. In the adjusted analysis, proxy having discussed preferences for level for care with the patient remained significant, $P = 0.004$.

Discussion

In this sample of patients with dementia from diverse outpatient settings, we found that the proxy having had a discussion with the patient regarding goals of care was associated with greater proxy acceptance of the dementia diagnosis. Although HCP designation was common, detailed knowledge of patients' wishes for future care was less common. Among those who stated preferences, a large percentage did not want to be resuscitated or placed on mechanical ventilation and had comfort as the goal of care, even in the early stage of disease. We found that HCPs were interested in learning more about the disease process and many wanted information about the end stage of disease at the time of diagnosis, which counters concerns that such early discussion may be disturbing to families. Our findings demonstrated a need for greater communication between patients and their physicians regarding both goals of care and specific treatment preferences.

In our sample, rates of HCP designation were high, but only 56% of proxies reported that the patient had a living will, and two-thirds reported that the patient had expressed a preference regarding specific interventions. Ideally, patients with dementia should discuss their health care values and preferences during the early stages of illness, when they are best

able to comprehend the significance of future medical decisions and best able to communicate their wishes. Our rates of HCP designation are higher than other studies but similar in terms of living will documentation. For example, in a mixed sample of community-dwelling patients with early cognitive impairment and normal subjects, 65% had a medical durable power of attorney designation and 56% had a living will.²¹ Ours is one of the only studies to document how often the most common predictable decisions for patients with dementia (institutionalization, hospitalization, tube feeding) are discussed in ACP.

We found inconsistencies between broad goals of care and preferences for specific interventions, similar to results from the CASCADE study where 95% of HCPs reported a desire for comfort care, but a large proportion of patients received invasive treatments.³ More detailed ACP discussion and education about common clinical scenarios can likely address such inconsistencies and allow for patient's wishes to be articulated with more specificity.

Although the majority of proxies stated they believed the patient had communicated with their physician about HCP designation, only approximately one-third believed the patient had communicated with their physician regarding preferences for level of care or for specific treatments. Thus, it seems there is room for increased discussion of ACP in the medical office setting. In addition, although discussions between HCP and patients regarding preferences for level of care had occurred in the majority of cases, 44% of proxies felt they would like to have further discussions.

Discussions between patients and proxies have the potential to impact future patient care through more informed surrogate decision making but also have the potential to affect proxies. In our analysis, discussions between proxies and patients regarding preferences for level of care were significantly associated with the greater proxy acceptance of illness. Our findings are in concert with those from terminal cancer patients, where evidence is now mounting that end-of-life discussions among families of

terminally ill patients not only fail to cause patient distress but also are associated with better caregiver bereavement outcomes.²² It is likely that acceptance of illness drives ACP discussion but also possible that ACP discussion helps to increase acceptance. Our results suggest that further study of this relationship may be fruitful. Interestingly, qualitative data from patients with dementia and their caregivers document a link between acceptance of illness and participation in ACP.²³

HCPs in our study had confidence in their ability to participate in shared decision making. However, although proxies' knowledge of dementia was high, 66% stated they were "very interested" in learning more about the disease. Interest in educating families and patients early about the disease process was also high. These findings support early and continued education for patients and families over the course of illness, to inform ACP regarding goals of care and specific treatments, and will hopefully encourage more research in which patients with dementia participate directly, to better understand their preferences.

Our study has certain limitations. Our relatively small sample was drawn from the Boston area and may not represent other U.S. regions or international locales. Our sample is highly educated and underrepresents racial and ethnic minorities. Finally, our findings are based on interviews with health care proxies rather than patients.

This study provides information regarding whether patients with dementia have communicated detailed wishes for future care and documents an interest on the part of both patients and proxies for early education regarding the course of illness. In addition, our findings note an association between discussions regarding patients' wishes for future treatment, and greater acceptance of illness on the part of health care proxies. In summary, our findings support early education of patients and families about the disease course and discussions regarding advance care planning among patients with dementia.

Disclosures and Acknowledgments

Everyone who has contributed significantly to this work has been listed as an author.

No authors report any conflict of interest.

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