

Patient and caregiver characteristics related to completion of advance directives in terminally ill patients

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ABSTRACT

Objective: There is a growing body of literature describing the characteristics of patients who plan for the end of life, but little research has examined how caregivers influence patients' advance care planning (ACP). The purpose of this study was to examine how patient and caregiver characteristics are associated with advance directive (AD) completion among patients diagnosed with a terminal illness. We defined AD completion as having completed a living will and/or identified a healthcare power of attorney.

Method: A convenience sample of 206 caregiver–patient dyads was included in the study. All patients were diagnosed with an advanced life-limiting illness. Trained research nurses administered surveys to collect information on patient and caregiver demographics (i.e., age, sex, race, education, marital status, and individual annual income) and patients' diagnoses and completion of AD. Multivariate logistic regression was employed to model predictors for patients' AD completion.

Results: Over half of our patient sample (59%) completed an AD. Patients who were older, diagnosed with amyotrophic lateral sclerosis, and with a caregiver who was Caucasian or declined to report an income level were more likely to have an AD in place.

Significance of results: Our results suggest that both patient and caregiver characteristics may influence patients' decisions to complete an AD at the end of life. When possible, caregivers should be included in advance care planning for patients who are terminally ill.

KEYWORDS: Advance directives, Advance care planning, Caregiver, Terminally ill patients

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INTRODUCTION

Advance care planning (ACP) at the end of life is beneficial for patients, as well as for their caregivers and health providers. Previous studies have shown that ACP, including the completion of an advance directive (AD), is related to greater patient satisfaction and hospice use, fewer communication concerns with healthcare providers about end-of-life decision making, and better mental health outcomes among surviving caregivers (Detering et al., 2010; Teno et al., 2007; Tierney et al., 2001; Garrido & Prigerson, 2014; Garrido et al., 2014). However, nearly 20 years of research have continued to show suboptimal ACP rates among patients with progressive life-limiting diseases. In particular, the reported rates of AD completion among these patients vary widely, ranging from 17 to 40% (Astrow et al., 2008; Emanuel et al., 1991; Halpern et al., 2011; Holley et al., 1999; Kumar et al., 2010; Morhaim & Pollack, 2013; Tajouri et al., 2012; Wilkinson et al., 2007).

There is a growing body of literature describing the characteristics of patients who plan for the end of life. For example, studies have consistently shown that patients with minority racial or ethnic backgrounds are less likely to engage in ACP (Johnson et al., 2008; Kwak & Haley, 2005; Rao et al., 2014; Triplett et al., 2008). In addition, some findings suggest that AD completion is more likely among male patients (Bravo et al., 2003) and in those with higher socioeconomic status (Rao et al., 2014), higher educational level (Hirschman et al., 2012; MacIver et al., 2008; Rosnick & Reynolds, 2003), of older age (Bravo et al., 2003; Rosnick & Reynolds, 2003; Triplett et al., 2008), or with a regular source of healthcare (Rao et al., 2014). Although there is an established body of literature describing important patient characteristics associated with ACP and AD completion, little research has examined caregiver characteristics associated with AD completion among patients who are terminally ill.

The Institute of Medicine defines caregivers as those who play a significant role in providing care and who assist with the crucial activities of daily living (Institute of Medicine, 2014). Caregiver participation is important in end-of-life care and decision making (Rabow et al., 2004), and patients with life-threatening illnesses often express a preference for involving their caregivers in making decisions about their healthcare (Sulmasy et al., 2007). However, the majority of existing caregiver research primarily focuses on caregivers' experience (e.g., caregiver burden, care satisfaction, and end-of-life care) and communication preferences (Parker et al., 2007), and few studies have examined how different caregivers (e.g., based on their race/ethnicity, age, education,

or income) may influence objective end-of-life care planning or decision-making outcomes (e.g., completion of AD) among the patients they care for. Understanding the demographic correlates of AD completion, including those of patients as well as their caregivers, will help palliative care professionals target their efforts to promote AD completion in underrepresented groups. Further, understanding these associations is imperative to the design, implementation, and evaluation of interventions developed to improve family-centered ACP.

The purpose of this study was to understand the factors that may influence AD completion among terminally ill patients by examining both patient and caregiver characteristics that are associated with a patient's completion of AD. We defined AD completion as a patient having completed a living will and/or identified a healthcare power of attorney.

METHODS

This cross-sectional analysis examined baseline data from a larger, prospective five-year randomized controlled trial to evaluate the efficacy of the TAILORED (Trial of Ascertain Individual preferences for Loved Ones' Role in End-of-life Decision) nurse-led guided discussion intervention on patient and family healthcare decision-making outcomes. The intervention was designed to prepare caregivers for the proxy decision-making role and to initiate or promote advance care planning discussions between patients and their caregivers.

Between 2010 and 2014, a convenience sample of patient-caregiver dyads was enrolled from Johns Hopkins medical institutions (Baltimore, MD) and the University of Chicago Hospital (Chicago, IL). The eligibility criteria for patient enrollment were: (1) a diagnosis of amyotrophic lateral sclerosis (ALS), stage III/IV gastrointestinal/pancreatic cancer, or New York Heart Association class III/IV congestive heart failure (CHF) with an internal cardioverter-defibrillator; (2) at least 18 years of age; (3) English-speaking; (4) able to identify a caregiver who is involved in healthcare decision making; and (5) a willingness of the identified caregiver to participate in the research study. The three disease groups were chosen to obtain a sample of patients in the terminal phase of illness, as evidenced by a prognosis of at least 50% 2-year mortality (American Joint Committee on Cancer, 2002; del Aguila et al., 2003; de Vita et al., 2001). The three groups were also chosen because they reflect different end-of-life disease trajectories during the advanced stage of illness near death (i.e., ALS patients exhibit gradual decline in health status, advanced cancer patients exhibit a rapid decline, and CHF patients exhibit fluctuating

changes in health status at the end of life). The eligibility criteria for caregiver enrollment were: (1) is at least 18 years of age; (2) speaks and reads English; and (3) identified by the patient as someone with whom the patient makes healthcare decisions. All patients and caregivers over 80 years of age completed the Short Portable Mental Status Questionnaire (Pfeiffer, 1975), and those who made five or more errors (indicative of moderate cognitive impairment) were excluded. The study was approved by the institutional review boards at both institutions.

In the parent study, trained research nurses consented and administered a self-report paper-and-pencil survey battery to all participants at study baseline. All patients and caregivers completed the instruments independently. The data employed in this analysis were abstracted from participants' background forms. The variables included in the analysis included patients' and caregivers' demographic information (i.e., age, sex, race/ethnicity, education level, marital status, and individual annual income). Patients' diagnoses and reports of their AD completion were also recorded. Patient AD completion was assessed by their response to the following questions: (1) Have you completed a living will? and (2) Have you chosen a healthcare agent (durable power of attorney for healthcare)? Patients were considered to have completed an AD if they responded yes to either or both of these questions. Data collected from dyads in both treatment groups in the parent study (i.e., intervention and control) were analyzed as an aggregate. The final sample for this analysis consisted of 206 patient–caregiver dyads (i.e., 412 individual participants).

Statistical Analysis

Analyses were performed using Stata 13[®] software (StataCorp, 2013). Descriptive statistics were used to describe patient and caregiver characteristics. Bivariate analyses (i.e., *t* and chi-square tests) were employed to determine whether patient or caregiver characteristics differed between patients with and without AD. Multivariate logistic regression was utilized to assess which patient and caregiver variables were associated with a patient's completion of an AD. Stepwise logistic regression was conducted by entering candidate predictor variables one by one into the model and choosing the “best” or the most parsimonious model based on the lowest Akaike information criterion (AIC). This model selection procedure was run using the “swaic” command. A value of alpha of 0.05 was used for all statistical tests. Model accuracy has been assessed using threefold cross-validated area under the ROC curve (Picard & Cook, 1984).

RESULTS

The patient and caregiver characteristics of the full sample (206 patient–caregiver dyads) are listed in Table 1. Patients reported a mean age of 60.91 years ($SD = 11.95$). Most patients were male (59.71%), non-Hispanic Caucasian (62.62%), married (72.82%), and had obtained a college or higher degree (57.28%). The distribution of patients with ALS, cancer, and heart failure was 31.07, 45.63, and 23.30, respectively. Over half of the patients (61.65%) reported earning an individual income of \$40,000 or more in the previous year.

The majority of caregivers were female (73.30%) and reported being the patient's spouse or significant other (66.02%). The mean age of caregivers was 55.52 years ($SD = 12.76$). Similar to the demographic characteristics of the patients, the caregivers were primarily non-Hispanic Caucasian (64.08%), married (81.55%), and had obtained a college or higher degree (61.17%). More than half of the caregivers (66.99%)

Table 1. Patient and caregiver demographic characteristics (N = 206)

Demographic characteristics	Patient	Caregiver
Mean age in years (<i>SD</i>)	60.91 (11.95)	55.52 (12.76)
Male (<i>n</i> , %)	123 (59.71)	55 (26.70)
Disease group (<i>n</i> , %)		
Amyotrophic lateral sclerosis	64 (31.07)	–
GI/pancreatic cancer	94 (45.63)	–
Congestive heart failure	48 (23.30)	–
Race (<i>n</i> , %)		
Caucasian (non-Hispanic)	129 (62.62)	132 (64.08)
African American (non-Hispanic)	48 (23.30)	47 (22.82)
Other	29 (14.08)	27 (13.10)
Highest education level (<i>n</i> , %)		
High school or below	88 (42.72)	80 (38.83)
Some college or above	118 (57.28)	126 (61.17)
Marital status (<i>n</i> , %)		
Married	150 (72.82)	168 (81.55)
Not married	56 (27.18)	38 (18.45)
Individual annual income (<i>n</i> , %)		
\$0–40 K	51 (24.76)	39 (18.93)
>\$40–80 K	61 (29.61)	55 (26.70)
>\$80 K	66 (32.04)	83 (40.29)
Don't know/decline to answer	28 (13.59)	29 (14.08)
Relationship with patient (<i>n</i> , %)		
Spouse/significant other	–	136 (66.02)
Child	–	22 (10.68)
Parent	–	20 (9.71)
Sibling	–	12 (5.82)
Other	–	16 (7.77)

also reported earning an individual annual income of \$40,000 or more in the previous year.

Patient Characteristics Related to AD Completion

Of the 206 patients enrolled in the study, 122 (59.22%) reported having completed a living will and/or identified a healthcare power of attorney. Those who completed an AD were significantly more likely to be older ($t(204) = 3.57, p < 0.01$), non-Hispanic Caucasian ($\chi^2(df = 2) = 12.66, p < 0.01$), have ALS ($\chi^2(df = 2) = 7.82, p = 0.02$), or have a higher annual income ($\chi^2(df = 3) = 9.41, p = 0.02$). Patient sex or marital status was not related to patient completion of AD in bivariate analyses. Patients' demographic characteristics by AD completion are presented in Table 2.

Caregiver Characteristics Related to Patient's AD Completion

Certain caregiver characteristics were associated with patients' completion of an AD. In our sample, patients were significantly more likely to have an AD in place if the caregiver was older ($p < 0.01$), non-Hispanic Caucasian ($\chi^2(df = 2) = 24.90, p < 0.01$), married ($\chi^2(df = 1) = 7.53, p < 0.01$), or reported a higher annual income ($\chi^2(df = 3) = 11.25, p = 0.01$). Caregiver sex, level of education, and relationship

to the patient were not related to patient AD completion in the bivariate analyses. Comparisons of caregiver demographic characteristics by patient AD completion are presented in Table 3.

Model for AD Completion

After deletion of 5 cases with missing values, data from 201 dyads were used for multivariate logistic regression analysis to construct a predictive model for AD completion. Based on the forward-selection procedure, the model associated with the smallest AIC (i.e., the most parsimonious model) included patient age, patient disease group, caregiver race/ethnicity, and caregiver annual income (Table 4). The multivariate model had acceptable out-of-sample discrimination between patients who did and did not have an AD; the cross-validated area under the ROC curve was 0.72 ($CI_{95\%} = 0.65-0.80$).

In terms of patient characteristics, the odds of completing an AD were 5% higher ($p < 0.01$, $CI_{95\%} = 1.02-1.07$) per year increase in patient age after adjustment for patient's diagnosis, and caregiver annual income and race. On the other hand, the odds of completing an AD were 58% lower among those with cancer compared to those with ALS after adjustment for patient age and caregiver race and annual income ($p = 0.03$, $CI_{95\%} = 0.19-0.93$); the odds of AD completion did not significantly differ between those with CHF and ALS.

Table 2. Patient characteristics and completion of an advance directive (AD)

Patient characteristics	With AD ($n = 122$)	Without AD ($n = 84$)	Statistic	p value
Mean Age in Years (SD)	63.31 (11.87)	57.43 (11.24)	$t = 3.57$	<0.01
Sex ($n, \%$)			$\chi^2 = 2.22$	0.136
Male	78 (63.41)	45 (36.59)		
Female	44 (53.01)	39 (46.99)		
Disease group ($n, \%$)			$\chi^2 = 7.82$	0.020
Amyotrophic lateral sclerosis	47 (73.44)	17 (26.56)		
GI/pancreatic cancer	49 (52.13)	45 (47.87)		
Heart failure with ICD	26 (54.17)	22 (45.83)		
Race ($n, \%$)			$\chi^2 = 12.66$	<0.01
Caucasian (non-Hispanic)	88 (68.22)	41 (31.78)		
African American (non-Hispanic)	19 (39.58)	29 (60.42)		
Other	15 (51.72)	14 (48.28)		
Highest education level ($n, \%$)			$\chi^2 = 4.16$	0.041
High school or below	45 (51.14)	43 (48.86)		
College or above	77 (65.25)	41 (34.75)		
Marital status ($n, \%$)			$\chi^2 = 0.07$	0.790
Married	88 (58.67)	62 (41.33)		
Not married	34 (60.71)	22 (39.29)		
Individual annual income ($n, \%$)			$\chi^2 = 9.41$	0.024
\$0–40 K	22 (43.14)	29 (56.86)		
>\$40–80 K	35 (57.38)	26 (42.62)		
>\$80 K	46 (69.70)	20 (30.30)		
Don't know/decline to answer	19 (67.86)	9 (32.14)		

Table 3. Caregiver characteristics and patient completion of an advance directive (AD)

Caregiver characteristics	With AD (<i>n</i> = 122)	Without AD (<i>n</i> = 84)	Statistic	<i>p</i> value
Mean age in years (<i>SD</i>)	58.09 (11.63)	51.78 (13.46)	<i>t</i> = 3.54	<0.01
Sex (<i>n</i> , %)			$\chi^2 = 2.15$	0.143
Male	28 (50.91)	27 (49.09)		
Female	94 (62.25)	57 (37.75)		
Race (<i>n</i> , %)			$\chi^2 = 24.90$	<0.01
Caucasian (non-Hispanic)	95 (71.97)	37 (28.03)		
African American (non-Hispanic)	18 (38.30)	29 (61.70)		
Other	9 (33.33)	18 (66.67)		
Highest education level (<i>n</i> , %)			$\chi^2 = 1.62$	0.203
High school or below	43 (53.75)	37 (46.25)		
College or above	79 (62.70)	47 (37.30)		
Marital status (<i>n</i> , %)			$\chi^2 = 7.53$	<0.01
Married	107 (63.69)	61 (36.31)		
Not married	15 (39.47)	23 (60.53)		
Individual annual income (<i>n</i> , %)			$\chi^2 = 11.25$	0.01
\$0–40 K	14 (35.90)	25 (64.10)		
>\$40–80 K	34 (61.82)	21 (38.18)		
>\$80 K	54 (63.53)	29 (36.47)		
Don't know/decline to answer	20 (68.97)	9 (31.03)		
Relationship with patient (<i>n</i> , %)			$\chi^2 = 5.78$	0.22
Spouse/significant other	83 (61.03)	53 (38.97)		
Child	9 (40.91)	13 (59.09)		
Parent	15 (75.00)	5 (25.00)		
Sibling	6 (50.00)	6 (50.00)		
Other	9 (56.25)	7 (43.75)		

Two caregiver characteristics were included in the model: caregiver race/ethnicity and reported individual annual income. Caregiver race was associated with patient AD completion in the multivariate logistic regression model ($\chi^2(df = 2) = 6.46$, $p = 0.04$). The odds of patient completion of AD were 66% lower ($p < 0.01$, $CI_{95\%} = 15-0.74$) among those with non-Hispanic African-American caregivers and 70% ($p = 0.01$, $CI_{95\%} = 0.11-0.78$) lower among those with caregivers who self-identified as belonging to another racial/ethnic group as compared to those

with non-Hispanic Caucasian caregivers after adjustment for patient age, diagnosis, and caregiver annual income. Patients' adjusted odds of completing an AD were 3.37 times higher among those whose caregivers reported "don't know" or "decline to answer" for individual annual income ($p = 0.04$, $CI_{95\%} = 1.05-10.81$) compared to those whose caregivers reported earning less than \$40,000. Since no differences in the odds of patient AD completion was found between other caregiver annual income groups in this model, characteristics were compared

Table 4. Predictors of advance directive (AD) completion based on the most parsimonious model

Predictors	<i>n</i>	Adjusted odds ratio	$CI_{95\%}$	<i>p</i> value
Patient age per 1-year increment	201	1.05	1.02–1.07	<0.01
Patient disease group				
Amyotrophic lateral sclerosis	62	Reference		
GI/pancreatic cancer	91	0.42	0.19–0.93	0.03
Congestive heart failure	48	0.64	0.25–1.61	0.34
Caregiver race/ethnicity				
Caucasian (non-Hispanic)	129	Reference		
African American (non-Hispanic)	45	0.34	0.15–0.74	<0.01
Other	27	0.30	0.11–0.78	0.01
Caregiver individual income				
0–40 K	36	Reference		
40–80 K	55	2.05	0.76–5.53	0.16
80 K+	81	2.12	0.84–5.37	0.11
Don't know/decline to answer	29	3.37	1.05–10.81	0.04

between caregivers who reported an actual annual income level and those who did not report an income level (i.e., “don’t know” or “decline to answer”). In this post-hoc analysis, caregivers who did not report an individual annual income level were significantly older ($p < 0.01$) compared to those who reported an annual income level. No other differences were found based on caregiver sex, education level, marital status, or relationship to the patient.

DISCUSSION

The present analysis examined patient and caregiver characteristics associated with completion of an advance directive (AD) in terminally ill patients. Similar associations between patient characteristics and AD completion have been reported in the literature (see Wilkinson et al., 2007). However, to our knowledge, ours is the first dyadic study to include caregiver characteristics as predictors for patient completion of AD. We aimed to develop the “best” model using patient- and caregiver-specific characteristics as candidate predictors of AD completion. For this purpose, an automatic forward-selection procedure was employed to select the most parsimonious list of predictors, and the final multivariate logistic regression model included patient age, patient disease group, caregiver race/ethnicity, and caregiver annual income. Our findings support the need to increase efforts in counseling patients and their caregivers from underrepresented groups to promote AD completion. Additionally, continued exploration into the social determinants of health and other factors that may explain discrepant AD completion tendencies among different patient groups at the end of life are warranted.

More than half of our patients reported having completed an AD at study baseline. Consistent with prior research, patients were more likely to have completed a living will and/or identified a durable healthcare power of attorney as they got older. It is plausible that older adults are more likely to complete an AD because they have had more illness experiences or more opportunities to come into contact with ACP advocates in their healthcare. Therefore, our findings suggest a need for targeted counseling to promote AD completion among younger patients who are diagnosed with a life-limiting disease.

Patients with ALS were also more likely to have completed an AD compared to patients with cancer. This finding may be related to the differences in disease trajectory—that is, compared to patients with cancer, patients with ALS may be more likely to believe that their health decline and the likelihood of losing decision-making capacity are imminent as the disease progresses. It is also possible that AD completion rate in our sample of patients with ALS

was comparatively high because we recruited these patients from a clinic where providers strongly subscribe to the ACP model and integrate it into the care of their patients upon diagnosis. Nonetheless, it has been suggested that patients with advanced cancer may be less likely to have documented ACP compared to patients with ALS despite having worse survival outcomes due to the hopefulness and optimism commonly encouraged among patients with cancer (Astrow et al., 2008). Because different diseases present different trajectories and illness experiences, qualitative research in this area is needed to fully understand ACP preferences and practices among patients with different diseases and at different stages of their disease progression.

Our results suggest that caregiver characteristics play a role in AD completion among terminally ill patients. Since we expected a strong correlation between patient and caregiver race/ethnicity and income, we avoided including both patients’ and caregivers’ race/ethnicity or income variables in the same model. Instead, we allowed the automatic selection procedure to select the best set of predictors, which included caregiver, rather than patient, race/ethnicity and income. These findings point to the importance of including caregivers in ACP discussions, particularly for patients with caregivers in underrepresented groups. Furthermore, more dyadic studies including both patients and their caregivers are needed to understand caregiver influence on patient AD completion and use, and how caregivers can best be included in ACP for patients at the end of life.

The findings from previous studies primarily point to differences in AD completion based on patient race (i.e., nonwhite patients are less likely to have an AD in place; Zaide et al., 2013), yet we found that caregiver race/ethnicity was a strong predictor for patient AD completion, and that AD completion was significantly lower among patients with caregivers who were not Caucasian. These findings suggest that palliative care professionals should actively engage minority caregivers in end-of-life discussions to improve ACP among terminally ill patients.

We also found that the odds of AD completion among patients whose caregiver did not report an income level were more than three times higher compared to patients with caregivers who reported an actual income level. We offer two possible explanations for this finding. First, our post-hoc analysis suggests that this may be related to caregiver age—that is, those who declined to report their income tended to be older and, possibly, retired, so that they did not know what their income was. Another possibility is that those who declined to report their income have an inherently stronger desire to control how their private or health information will be used and, in turn,

influenced the patient to complete an AD to assure their ability to assert control over their healthcare preferences at the end of life.

Our study revealed important patient and caregiver characteristics associated with patient AD completion. However, AD completion only serves as a surrogate quality outcome of advance care planning. Therefore, palliative care professionals must continue their efforts in communicating, documenting, and implementing AD, and include caregivers in these important discussions to assure that patients' wishes are honored at times of decisional incapacity.

Three limitations of our study should be noted. First, we used a convenience sample of patient–caregiver dyads, thereby limiting the generalizability of our results. However, we recruited patients in multiple disease categories and from two geographically distinct locations to improve sample variability. Second, this analysis was limited to the variables employed in the parent study, and it is possible that other patient or caregiver characteristics essential to a patient's decision for AD completion were not included. For example, previous studies have suggested differences in ACP based on a patient's source of healthcare, comorbidities, and recent changes in health status (Hirschman et al., 2012; Rao et al., 2014). However, much of our findings corroborate the existing knowledge of patient characteristics related to AD completion, and they generate new insight into caregiver characteristics in relation to patient AD completion at the end of life.

Finally, our best model was developed using one dataset. The model has not been tested on another dataset that would assess the external accuracy of our model. To address this concern, we attempted to control model overfitting by using a limited set of variables and by employing explicit model selection criteria. In addition, we also report threefold cross-validated area under the curve to assess model performance accuracy.

CONCLUSIONS

Both patient and caregiver characteristics may influence a patient's completion of an advance directive at the end of life. When possible, caregivers should be included in advance care planning for patients who are terminally ill. Our findings call for the need to further explore characteristics related to patient use of an AD, and how caregivers may influence patients' decisions to exercise ACP and to complete an AD. A holistic understanding of these relationships will help palliative care professionals target their efforts to promote AD completion and inform the design, implementation, and evaluation of interventions so as to improve family-centered ACP.

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