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Advance Directives in Patients Over 60 Years Old: Assessment of Perceived Value and Need For Education in the Outpatient Setting

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Abstract

Background: Advance directives have widely been regarded as playing a pivotal role in end-of-life care for patients. This study sought to evaluate the current value and perspective on advance directives in patients greater than 60 years of age visiting outpatient clinics.

Methods: A cross-sectional survey study was performed at four different departmental outpatient clinics at Texas Tech University Health Sciences Center in Amarillo, Texas for patients over the age of 60 years who presented during a three-month time frame. In addition to demographic data, the survey collected data on patients' perspective on and completion of advance directives.

Results: 314 patients completed the survey. Non-Hispanic white patients were significantly more likely than those of other racial or ethnic groups to have an advance directive in place (58.8% vs. 28.8%, $p < 0.001$). Married and widowed patients were more likely to have advance directive than those single or separated (57.2% and 63.1% vs. 30.8% and 35.5%, $p = 0.002$). Those with greater than 12 years of education were also more likely to have an advance directive in place than those with 12 or fewer years of education (59% vs. 48%, $p = 0.042$). Patients who received education from their primary care provider about advance directives were more likely to have an advance directive than those who had not received any education (64.7% vs. 44.9%, $p = 0.01$).

Conclusion: Education from physicians about the value of having an advance directive is a powerful intervention that can result in a significant increase in completion of advance directives. Specific demographic groups that could benefit from education about the value of advance directives include patients of different racial or ethnic backgrounds, patients who are single or divorced, and patients with limited education. We recommend that physicians work to

initiate discussions about end-of-life care with all patients over 60 years of age.

Keywords: Primary care; Patients; Patient self-determination act; Family medicine

Introduction

Engaging patients and their families in advance care planning may well be the single most important thing we can do as a society to improve the quality of end-of-life care [1-6]. In the absence of effective advance care planning, patients may receive unwanted and unnecessary care at the end of life at a significant cost to families and society. A key component of the advance care planning process is the completion of advance directives such as a living will and durable power of attorney for healthcare. These documents allow patients to communicate their values and wishes for future care preferences in the event that they become incapable of making decisions about next steps in treatment. In fact, patients who have prepared an advance directive are more likely to receive care that is aligned with their preferences [7-13]. Since the passing of the 1991 Patient Self-Determination Act, which requires Medicare/Medicaid reimbursed healthcare facilities to provide information to patients about advance directives upon admission, the percentage of American's who have completed an advance directive has increased from around 15% [14] to around 25% [15].

Completion rates improve with age [15,16] and declining health status [2] but close to 50% of those over the age of 65 still do not have an advance directive in place. Significant attention has been paid to demographic and socioeconomic factors that may explain non-completion. With few exceptions, studies have reported lower completion rates among black, Hispanic and other non-white groups [15-17]. These same studies also found that lower education and socioeconomic status were associated with lower completion rates.

Investigation into potential barriers to completion have revealed a number of patient and family related factors including a lack of knowledge about advance directives, mistrust of the healthcare system, religious, spiritual and cultural beliefs that may be inconsistent with advance directives, and language barriers [17,18]. On the physician side, a lack of formal training on communicating about end-of-life issues, a lack of time, limited prognostic capability, and uncertainty about how to communicate with patient from different racial, ethnic, or cultural backgrounds can contribute to a reluctance to initiate advance directive discussions [18].

Over the next few decades we will experience a tremendous growth in our aging population. It will become more racially and ethnically diverse (Census report 2012). This demographic shift combined with advances in medical care and life prolonging treatments bring with it a growing demand for advance care planning and advance directive discussions so we can provide care that is aligned with our patients' values and preferences.

This study sought to evaluate: 1) advance directive completion rates in patients 60 years or older visiting an outpatient clinic; 2) the association between socio-demographic factors and advance directive completion; 3) patient perspectives on advance directives; and 4) the impact of provider education on advance directive completion.

Methodology

Study design and sample

This study was conducted at four departmental outpatient clinics at Texas Tech University Health Sciences Center in Amarillo, Texas. The outpatient departments included Internal Medicine, Gynecology, Surgery, and Family Medicine. Over a three month period (December 2015-February 2015), all patients over the age of 60 were provided with a one-page survey at the time they presented to the front desk at participating clinics. They were encouraged to fill out this survey before departure from the clinic. All surveys were collected by members of the front desk staff at each outpatient clinic and placed into a designated box. Research team members retrieved all collected surveys on a daily basis. The study protocol was reviewed by the Institutional Review Board and determined to be exempt because the survey contained no identifying data.

Advance directives survey

We designed a brief one-page survey that could be completed in less than 5 minutes. The survey collected demographic

information regarding age, gender, race/ethnicity, marital status, and level of education. Patients were asked if they had an advance directive, living will, or durable power of attorney, and whether their primary care provider had ever educated them about the value of having an advance directive. Six questions assessed patients' personal perspectives on and desire for involvement in advance care planning. Response options included 'not important', 'neutral', 'important', and 'very important.' To avoid duplication, the survey included a question asking if the patient had previously completed the survey. Duplicates were excluded from the analysis.

Data analysis

Data were analyzed using descriptive statistics and Pearson Chi-square test of independence. Statistical analyses were conducted using IBM statistical package for the social sciences (SPSS) 22.0 version. A two-tailed p value of <0.05 was considered significant.

Results

Demographic variables and advance directive completion

The research team collected a total of 438 surveys. Of these, 124 were excluded due to duplication, incompleteness, or failure to meet the age criteria, resulting in a total of 314 surveys that were included in the final analysis. The largest number of completed surveys came from Family medicine (n=201, 64%), followed by Internal medicine (n=74, 23%), Surgery (n=31, 10%), and Gynecology (n=8, 3%). The majority of respondents were female (n=220, 70%), white (n=262, 83.4%), and married (n=159, 50.6%).

In this outpatient clinic population, 53.5% (n=168) of respondents reported having an advance directive in place at the time of the survey. **Table 1** shows the association of demographic variables to AD completion. There was no gender difference in completion rates. Non-Hispanic white patients were significantly more likely than those of other ethnic or racial groups to have completed an AD. Married and widowed patients were more likely to have an advance directive in place compared with either single or divorced/separated patients (57.2% and 63.1% vs. 30.8% and 35.6%, p=0.002). Education was significantly associated with advance directive completion with the largest difference seen in those with postgraduate education compared to those with an 8th grade education or less (73.2% vs. 25% respectively).

Table 1: Relationship of demographics to advance directives (AD) completion.

Variables	No AD N (%)	Completed AD N (%)	X ²	p-value
Gender				
Male	41 (43.6)	53 (56.4)	0.447	ns
Female	105 (47.7)	115 (52.3)		

Ethnicity/Race				
Non – Hispanic White	108 (41.2)	154 (58.8)	17.721	<0.001
Hispanic	20 (74.1)	7 (25.9)		
Others (African American/Asian)	18 (72.0)	7 (28.0)		
Marital Status				
Married	68 (42.8)	91 (57.2)	15.224	0.002
Widowed	31 (36.9)	53 (63.1)		
Single	18 (69.2)	8 (30.8)		
Divorced/Separated	29 (64.4)	16 (35.6)		
Education				
8 years or less	12 (75.0)	4 (25.0)	12.341	0.008
9-12 years (High school)	69 (50.0)	69 (50.0)		
13-16 years (College)	54 (45.4)	65 (54.6)		
More than 16 years (Post-graduate training)	11 (26.8)	30 (73.2)		
Primary Care Provider Education on ADs				
No	98 (55.1)	80 (44.9)	12.103	0.001
Yes	48 (35.3)	88 (64.7)		

Patients who reported receiving previous education from their primary care provider about the value of advance directives (n=136, 43.3%), were more likely to have an advance directive than those who indicated they had not received prior education (64.7% vs. 44.9%, p=0.001). Non-white patients were significantly more likely than patients of other ethnic and racial groups to report having received education from their primary care provider (45.8% vs. 30.8%, p=0.046). There was no clear association between the patient’s level of education and provider education about advance directives.

Perspective on advance directives

Data for the assessment of the perspective of ADs and desire for involvement in advance care planning and education are

displayed in **Table 2**. Most patients indicated it was either “important” or “very important” for them to learn about options for end-of-life services and care (n=217, 69.1%), to learn about implementing plans to ensure their wishes are honored (n=227, 72.3%), to learn how to voice decisions to family, friends and health care providers (n=236, 75.2%), and to engage in personal or community efforts to improve end-of-life care (n=183, 58.3%). Patients who felt that learning about options and implementing plans for end-of-life care was important were significantly more likely to have an AD in place. Slightly more patients with an AD in place endorsed the importance of voicing decisions to family and participating in community efforts but these associations did not reach significance.

Table 2: Relationship between beliefs about advance directives (AD) and advance directive completion.

Survey Questions	No AD N (%)	Completed AD N (%)	X ²	p-value
How important is:				
Learning about options for end-of-life services and care				
Not important/Neutral	55 (56.7)	42 (43.3)	5.875	0.015
Important/Very Important	91 (41.9)	126 (58.1)		
Learning about implementing plans to ensure my wishes are honored				
Not important/Neutral	51 (58.6)	36 (41.4)	7.111	0.008
Important/Very Important	95 (41.9)	132 (58.1)		
Learning how to voice decisions to family, friends and health care providers				

Not important/Neutral	40 (51.3)	38 (48.7)	0.955	0.328
Important/Very Important	106 (44.9)	130 (55.1)		
Engaging in personal or community efforts to improve end-of-life care				
Not important/Neutral	63 (48.1)	68 (51.9)	0.23	0.23
Important/Very Important	83 (45.4)	100 (54.6)		
In the event that you become incapable of communicating your wishes regarding end-of-life care, how important is:				
Having my wishes for end-of-life known				
Not important/Neutral	34 (56.7)	26 (43.3)	3.084	0.079
Important/Very Important	112 (44.1)	142 (55.9)		
Having my wishes for end-of-life honored				
Not important/Neutral	33 (55.0)	27 (45.0)	2.156	0.142
Important/Very Important	113 (44.5)	141 (55.5)		

The large majority of patients (n=254, 80.9%) indicated it was either "important" or "very important" for them to have their wishes for end-of-life care known and to have these wishes honored in the event that they become incapable of communicating your wishes regarding end-of-life care, and, while more patients with an AD in place rated these issues as important, this association also did not reach significance. The perspectives on advance directives were similar across racial/ethnic groups.

Discussion

We found that about half of participants had an advance directive in place at the time of the survey. Consistent with previous research, our data revealed strong associations between advance directive completion and racial/ethnic background, education, and marital status [15,16]. Being married or widowed was associated with advance directive possession, with widowed participants having the highest completion rate. The loss of a loved one may cause patients to be more conscious of their own preferences should they face a similar health situation and be unable to make decisions for themselves. Additionally, married couples may be more willing to prepare for adverse health events because they hope to decrease the burden that making end-of-life decisions will place on their spouse.

Compared to non-Hispanic whites, participants from different racial or ethnic backgrounds were about 50% less likely to have completed an advance directive. Although this is largely consistent with the existing literature on racial and ethnic disparities in advance care planning, it is important to note that compared to the local demographics of the study location, Hispanic older adults were somewhat underrepresented in this study. A limitation of our work is that the survey was only available in English. We suspect that older patients for whom Spanish is their primary language are even less likely to have advance directives in place than their English-speaking counterparts. Our overall sample of non-white patients was relatively small which also did not allow us to tease apart any

differences between these minority groups. Interestingly, perspectives on advance directives did not appear to vary much across racial/ethnic groups.

Our study found a significant relationship between physician education on advance directives and completion of such documents. Of note is the finding that non-white patients were significantly less likely to have received physician education, a finding that was not explained by differences in level of education. Yet, the large majority of our study participants, regardless of background, were interested in learning about advance directives and expressed that they wanted their wishes known and adhered to.

Previous research has shown that patients prefer end-of-life care discussions to be initiated by their physicians [19], and that lack of physician initiative is one of the biggest barriers to advance care planning [20,21]. Differences between the physician and patient likely contribute to this barrier. There is considerable research showing that when there are discordances between healthcare provider and patient characteristics (e.g., age, socioeconomic status, education, racial or ethnic minority status), there is less effective communication [22]. Due to the brief nature of our survey, we were not able to explore what specific aspects of the patient-provider relationship fostered or hampered advance directive discussions but this is a key area for future research.

It is important for physicians in the outpatient setting to initiate discussions about advance care planning and assess the presence of advance directives. One study reported that less than 20% of patients who had completed an advance directive told their primary care physician and less than half of those patients had the documentation in their medical record [23]. Another found that only 30% of patients who had discussed their wishes had done so with their family physician [1]. More concerning, this study also reported that the agreement between patients' expressed preferences for end-of-life care and documentation in the medical record was only 30%. Clearly more time is needed for such conversations. With recent changes in Medicare reimbursement for advance care planning

discussions physicians now have greater incentives to talk to their older patients about advance directives and properly document these discussions in the medical record [24].

Conclusion

In conclusion, this study sheds further light on certain subgroups of patients with the greatest need for advance directive discussions—patients with lower education, those who are single or divorced, and those belonging to a racial or ethnic minority group. It also underscores the critical role of the healthcare provider in such discussions. Understanding our patients' values will help us provide care that is aligned with their preferences. Given the increasing racial and ethnic diversity among our aging population, we encourage healthcare providers to seek out additional training on cross-cultural communication in the context of advance care planning to help reduce the disparities that still exist.

References

- Heyland DK, Barwich D, Pichora D, Dodek P, Lamontagne F, et al. (2013) Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Intern Med* 173: 778-787.
- Sinuff T, Dodek P, You JJ, Barwich D, Tayler C, et al. (2015) Improving end-of-life communication and decision making: the development of a conceptual framework and quality indicators. *J Pain Symptom Manage* 49: 1070-1080.
- Allison TA, Sudore RL (2013) Disregard of patients' preferences is a medical error: Comment on "Failure to engage hospitalized elderly patients and their families in advance care planning". *JAMA Intern Med* 173: 787-787.
- You JJ, Downar J, Fowler RA, Lamontagne F, Ma IW, et al. (2015) Barriers to goals of care discussions with seriously ill hospitalized patients and their families: A multicenter survey of clinicians. *JAMA Intern Med* 175: 549-556.
- Heyland DK, Cook DJ, Rocker GM, Dodek PM, Kutsogiannis DJ, et al. (2010) Defining priorities for improving end-of-life care in Canada. *CMAJ* 182: E747-E752.
- Sudore RL, Fried. (2010) Redefining the "planning" in advance care planning: Preparing for end-of-life decision making. *Ann Intern Med* 153: 256-261.
- Silveira MJ, Kim SY, Langa KM (2010) Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 362: 1211-1218.
- Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T (2007) Association between advance directives and quality of end-of-life care: A national study. *J Am Geriatr Soc* 55: 189-194.
- Karen M D, Hancock AD, Reade CM, Silvester W (2010) The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *BMJ* 340: c1345.
- Nicholas LH, Langa MK, Iwashyna TJ, Weir DR (2011) Regional variation in the association between advance directives and end-of-life Medicare expenditures. *JAMA* 306: 1447-1453.
- Fagerlin A, Schneider CE (2004) Enough: The failure of the living will. *Hastings Cent Rep* 34: 30-42.
- Shalowitz DI, Garrett-Mayer E, Wendler D (2006) The accuracy of surrogate decision makers: A systematic review. *Arch Intern Med* 166: 493-497.
- Wright AA, Zhang B, Ray A, Mack JW, Trice E, et al. (2008) Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 300: 1665-1673.
- Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ (1991) Advance directives for medical care- a case for greater use. *N Engl J Med* 324: 889-895.
- Rao JK, Anderson LA, Lin FC, Laux JP (2014) Completion of advance directives among U.S. consumers. *Am J Prev Med* 46: 65-70.
- Huang IA, Neuhaus JM, Chiong W (2016) Racial and ethnic differences in advance directive possession: Role of demographic factors, religious affiliation, and personal health values in a national survey of older adults. *J Palliat Med* 19: 149-156.
- Kwak J, Haley WE (2005) Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontol* 45: 634-641.
- U.S. Department of Health and Human Services (2008) advance directives and advance care planning: Report to congress.
- Davison SN (2006) Facilitating advance care planning for patients with end-stage renal disease: The patient perspective. *Clin J Am Soc Nephrol* 1: 1023-1028.
- Diaz-Montes TP, Johnson MK, Giuntoli RL II, Brown AJ (2013) Importance and timing of end-of-life care discussions among gynecologic oncology patients. *Am J Hosp Palliat Care* 30: 59-67.
- Sahm S, Will R, Hommel G (2005) What are cancer patients' preferences about treatment at the end of life, and who should start talking about it? A comparison with healthy people and medical staff. *Support Care Cancer* 13: 206-214.
- Smedley BD, Stith AY, Nelson AR (2003) Unequal treatment: Confronting racial and ethnic disparities in health care. Washington (DC): National Academies Press (US).
- Landry FJ, Kroenke K, Lucas C, Reeder J (1997) Increasing the use of advance directives in medical outpatients. *J Gen Intern Med* 12: 412-415.
- U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services (2016) Advance care planning (ACP) as an optional element of an annual wellness visit (AWV).