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## Literacy and Race as Risk Factors to Low Rates of Advance Directives Among Older Adults

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### Abstract

**Background**—Advance directives are documented instructions by a patient to ensure their medical care preferences are fulfilled in the event they cannot communicate with clinicians or family members.

**Objectives**—The current study examined the relationship between literacy and other patient level factors on having an advance directive.

**Design**—Face-to-face structured interview.

**Setting**—Participants were recruited from either an academic general internal medicine clinic or one of four federally qualified health centers in Chicago.

**Participants**—784 adults ages 55 to 74.

**Measurements**—Assessment of participant literacy, sociodemographic factors, and having an advance directive for medical care.

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#### Author's Contribution

All of the authors cited contributed significantly to the study concept and design as well as manuscript preparation. Laura Curtis conducted the statistical analysis for this project.

#### Conflict of Interest

Three of the authors of this paper have conflicts of interest that should be mentioned. Michael Wolf has received grants and honoraria from Abbott Labs and McNeil. Michael Paasche-Orlow is a board member for a non-profit foundation called Nous Foundation, Inc., which promotes shared decision-making tools related to end of life decisions. See ACPdecisions.org (Advanced Care Planning Decisions.org). Elizabeth Wilson is a co-investigator on a grant funded by Abbott Labs.

**Results**—Having an advanced directive was reported by 12.4% of subjects with low literacy, 26.6% of those with marginal literacy, and 49.5% of those with adequate literacy ( $p < 0.001$ ). In multivariable analyses, both literacy and race were independently associated with a lower likelihood of having an advance directive. Specifically, people with limited literacy and African Americans were less likely to have an advance directive (RR, 0.45; 95% CI, 0.22–0.95; RR, 0.64; 95% CI: 0.47–0.88, respectively). Exploratory analyses exhibited that there was not a significant interaction between the effect of literacy and race.

**Conclusion**—Limited literacy and African American race were significant risk factors to not having an advance directive in this cohort of older patients. Literacy and race likely represent two separate but important causal pathways that need to be understood to improve how the health care system ascertains and protects patients' advanced care preferences.

### Keywords

Literacy; Advance Directive; End of Life Decisions; Race

## INTRODUCTION

High profile news events, such as the Terri Schiavo case and the rhetoric about “death panels” that surrounded the health care reform debate of 2009, have brought end-of-life decision making to the forefront of the American consciousness. Despite the attention, Americans have been slow to document their end-of-life preferences—less than one-third of American adults have advance directives (AD).[1–3] Indeed, even among patients with incurable cancer, only about 1 in 5 has documentation of advance directives with their clinicians.[4] With the rapidly expanding aging U.S. population and the growing use of life-sustaining technologies and therapies that increase the likelihood that end-of-life decision making will take place in the acute care setting, the need for ADs is ever more essential.

These findings are particularly troubling as there is strong evidence that there is an essential discordance between policy and preferences: the default practice in health care is to pursue aggressive treatment – but when surveyed, most people want to limit the aggressiveness of medical care at the end of their lives.[5–7] While details vary by state, the most prominent legal bulwarks to protect people's wishes and rights are health care proxy and advance directive statutes.

A variety of studies examining patient, provider, and institutional barriers have revealed low rates of AD adoption.[2, 3, 8] The likelihood of a patient having an AD in place has been linked to patient level factors such as race, education level, income, and health status.[3, 9, 10] However, patient's literacy skills have received little attention as a possible barrier to having an AD. In this study, we examined the role of literacy in the adoption of an AD among a cohort of older adults. We also conducted analyses to determine how literacy influences the association between other patient-level factors and AD adoption.

## METHODS

### Subjects

Adults between the ages of 55 and 74 who received care at one urban academic general internal medicine clinic or one of four federally qualified health centers in Chicago, Illinois were recruited to participate in a National Institute of Aging (NIA) - funded investigation of the relationship between literacy and cognitive function, known as the ‘LitCog’ Study (R01 AG030611). Subject enrollment took place between August 2008 and November 2010. Exclusion criteria included: severe visual or hearing impairments, non-English speaking, critically ill status, or moderate to severe cognitive impairment. The Northwestern

University Institutional Review Board approved the study and all subjects provided written informed consent prior to participation.

### Study Procedures and Data

Subjects completed a four-hour, structured cognitive interview, divided over two days with a trained interviewer. This included comprehensive assessments of literacy, cognitive function, physical and mental health status, and health-related behaviors. Documentation of having an AD was determined by self-report with the question: “do you have a living will, durable power of attorney for health care, or some other type of written statement about what you would want done in the event you could not speak for yourself?” Answers were first documented verbatim, then coded as a dichotomized variable (yes versus no) by the interviewer. For ambiguous responses, the verbatim response was reviewed by the study team and a decision for coding was made by consensus.

Literacy was measured using the Test of Functional Health Literacy in Adults (TOFHLA) [11]. The TOFHLA is a well-established literacy assessment comprised of two parts: a 10-item numeracy measure and a 50-item reading comprehension measure. Per the standard TOFHLA scoring protocol, scores on the numeracy portion were weighted and added to the raw score from the comprehension passage for a total score out of a possible 100 points and were classified as follows: inadequate (0–53), marginal (54–56), and adequate (67–100).[11] We also collected self-reported data on other variables previously shown to have an association with written documentation of end-of-life preferences, including race (African American vs. other), age, sex, and educational attainment.

### Analysis

We used chi-square and Wilcoxon Rank Sum tests to evaluate the bivariate associations between advance directives and independent variables of interest, including literacy level, age, sex, educational attainment, income level, and number of chronic conditions. The relationship between literacy and each of these factors was examined. We then constructed multivariable generalized linear models (GLM) with advance directives (yes/no) as the dependent variable. We specified a Poisson distribution and log link to estimate risk ratios (RR) rather than odds ratios (OR) for ease of data interpretation[12, 13] and because ORs tend to overestimate point estimates when the outcome is common (>10%).[14]

First, all independent variables mentioned above except literacy were modeled. Literacy was then added to the model to examine its independent association with advance directives as well as its effect on the estimates of other variables in the model. Finally, in a separate analysis, we tested an interaction term for race and literacy in a fully specified model of having an advance directive.

## RESULTS

803 study subjects were enrolled into the study between August of 2008 and November 2010. Of these, 784 (97.6%) responded to the AD item and were included in these analyses. The mean age of the sample was 63.1 years (SD = 5.4), two-thirds of participants were female (67.7%), 43.1% were African American, and 27.2% had a high school education or less. Nearly one-third of participants had limited literacy (28.9%; low = 12.7% and marginal = 16.2%). Literacy skills also differed significantly by race: 47.4% of African-Americans had adequate literacy compared with 88.8% of non-African Americans ( $p < 0.001$ ).

Overall, 41.2% of study subjects reported having documented their end-of-life preferences. Literacy skills were strongly associated with having an AD; 12.4% of subjects with low literacy, and 26.6% of those with marginal literacy reported having an AD, compared to

49.5% of those with adequate literacy ( $p < 0.001$ ; Table 1). In addition to literacy, race was also strongly associated with self-report of an AD. Less than half the portion of African American patients reported having an AD as compared to white participants (22.9% vs. 57.2%,  $p < 0.001$ ). Other factors significantly associated with having an AD included older age, higher education, higher income, part time employment, and fewer chronic conditions (Table 1).

In multivariable analysis excluding literacy, African American adults were found to be less likely to have an AD than adults of other races (RR, 0.58; 95% Confidence Interval (CI) 0.43–0.79). Younger age and less education also contributed to lower rates of having an AD. Introduction of literacy into the model reduced the influence of race, but African American race remained significantly associated (RR, 0.64; 95% CI, 0.47–0.88). The relationships between ADs and both education and age were reduced to a point of non-significance with the addition of literacy in model. In the full model, people with limited literacy were less likely to have an advanced directive (RR, 0.45; 95% CI, 0.22–0.95) (Table 2). Analysis for interaction showed that there was no significant interaction between literacy and race ( $p = 0.57$ , data not shown).

## DISCUSSION

In our sample of nearly 800 older adults, less than half had advance directives in place (41.2%). Through multivariable analysis, we found that participants with low literacy were less likely to have an AD. The effect of literacy was independent of the influence of race, income, education, and age. This finding should lead to renewed efforts to reduce the complexity of AD documentation and discussions and lead to broad implementation of interventions which can reduce literacy barriers relating to advanced care planning.

Race was also a significant factor: African Americans were approximately half as likely to have an AD as compared with participants of other races. This finding is consistent with previous research documenting lower rates of AD completion in African American populations.[15] Literacy mediated only a small portion of the race-AD relationship and both literacy and race remained significant independent predictors of having an AD in analyses that controlled for a range of factors, such as age, education, and co-morbidities. These results identify literacy and race as the lead independent predictors of having an AD. [16, 17]

In terms of literacy, these findings may represent inadequate knowledge about end-of-life care and disempowerment related to medical decision-making and advanced care planning. Clinicians frequently avoid end-of-life discussions, even though patients are more satisfied when the topic is discussed.[18] When the topic is broached, it may be particularly challenging for patients with inadequate literacy to understand;[19–21] tools such as video decision-aids are useful to ensure patient education about complex topics like advanced directives and can help facilitate clinician-patient communication.[21]

Several reports present additional evidence that lend evidence to the relationship we report between low literacy and having an AD. For example, Mueller et al.[22] conducted a nationwide assessment of the readability of AD forms and found that the majority of the documents exceeded the recommendations for writing patient education materials at a 5<sup>th</sup> grade level.[23] Sudore et al. evaluated the use of an AD redesigned to meet most adults' literacy needs (5<sup>th</sup> grade reading level with graphics) and found that the document was not only preferred by patients, but also resulted in higher completion rates of ADs in the study population.[24]

As for race, the finding that African Americans are less likely to have an AD has been previously observed, has been the focus of multiple studies, and has been challenging to explain.[25–27] For example, the low rate of AD among African Americans could reflect a cultural phenomenon such as wariness for discussing death or issues of distrust in the health care system that could instill wariness about any documentation that could be used to limit care. However, evidence about these theories is mixed.[10, 27, 28] Potentially, factors associated with race but not otherwise captured in our models, such as inadequate communication by providers with African American patients regarding advanced care planning and what is needed to protect patient preferences can explain our race-AD finding. [29, 30]

Some limitations of this study should be mentioned. First, having an AD was assessed by self-report and it is possible that some patients did not accurately recall if they had an AD at the time of their study interview. However, patient or family self-report of ADs is generally how this information is elicited in clinical practice in acute care settings. Second, we were unable to measure other factors that might have influenced adoption of an AD by the individuals in our study. For example, we do not have knowledge of whether a health care provider had ever discussed ADs with the study participant, or whether they were exposed to written or multimedia information about AD forms. Third, patients included in the analysis were predominantly Caucasian and African American. In future studies on this topic, greater effort needs to be made to ensure racial diversity in the sample population. Finally, the rate of having an AD in this study (40%) was higher than previously reported for U.S. adults. We feel that this was likely due to a higher average age for participants in this study in comparison to prior prevalence reports.

Our findings support the need to adjust the reading level of AD forms and provide easy to use and understand decision-aids, but also demonstrate that improving the understandability of the AD process is only part of the solution. Other types of psychosocial factors such as cultural beliefs, perceptions of trust in those suggesting an AD, and previous personal experiences with end-of-life care likely influence the adoption of an AD and are more difficult to measure than basic demographic or literacy metrics.

As Americans face increasingly complex advanced care planning decisions, educating adults about their options and documenting their preferences has become an important way to protect people's wishes and rights. The current report identifies both health literacy and race as significant independent factors associated with having an advanced directive. Interventions to ascertain and document patients' advanced care wishes - to empower patients - will need to manage both phenomena.

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**Table 1**

## Demographic Information

Characteristic	Total (N = 784) %	Percent with advanced directives	p-value
Age group			< 0.001
55–60	37.9	32.0	
61–65	28.4	43.1	
66–70	21.6	50.3	
71–74	12.1	49.5	
Sex			0.78
Female	67.7	40.9	
Male	32.3	41.9	
Race			< 0.001
African American	43.1	22.9	
Caucasian	50.0	57.2	
Other	6.9	38.9	
Health Literacy			< 0.001
Low	12.7	12.4	
Marginal	16.2	26.6	
Adequate	71.2	49.5	
Education			< 0.001
High school or less	27.2	18.3	
Some college	21.9	40.1	
College graduate	20.3	53.5	
Graduate degree	30.6	54.2	
Income			< 0.001
< \$10,000	12.1	16.7	
\$10,000 – \$24,999	19.1	25.4	
\$25,000 – \$49,999	15.3	38.6	
> \$50,000	53.4	54.4	
Work status			0.02
No work	64.9	40.6	
Part-time	14.9	52.1	
Full-time	20.2	35.4	
Number of Chronic Conditions			< 0.001
0–1	44.9	48.0	
2	28.8	40.7	
3 or more	26.3	41.2	



**Table 2**

Effect of Health Literacy on Relationships between Patient Level Characteristics and Advanced Directives

Characteristic	RR	95% CI	p-value
Health Literacy			
Low	0.45	0.22, 0.95	0.04
Marginal	0.81	0.53, 1.23	0.32
Adequate	---	--	
Age group			
55–60	0.69	0.47, 1.01	0.05
61–65	0.86	0.59, 1.25	0.43
66–70	1.04	0.71, 1.54	0.83
71–74	---	---	
Sex			
Female	0.98	0.77, 1.25	0.86
Male	---	---	
Race			
African American	0.64	0.47, 0.88	0.01
Non-African American	---	---	
Education			
High school or less	0.68	0.44, 1.07	0.09
Some college	1.14	0.81, 1.60	0.46
College graduate	1.08	0.81, 1.45	0.59
Graduate degree	---	---	
Income			
< \$10,000	0.62	0.35, 1.11	0.11
\$10,000 – \$24,999	0.72	0.48, 1.09	0.12
\$25,000 – \$49,999	0.89	0.62, 1.28	0.54
> \$50,000	---	---	
Number of Chronic Conditions			
0–1	---	---	
2	1.01	0.78, 1.32	0.93
3 or more	0.89	0.64, 1.23	0.49

RR = Risk Ratio

CI = Confidence Interval