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Literacy and Race as Risk Factors for Low Rates of Advance Directives in Older Adults

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OBJECTIVES: To examine the effect of the relationship between literacy and other individual-level factors on having an advance directive (AD).

DESIGN: Face-to-face structured interview.

SETTING: Participants were recruited from an academic general internal medicine clinic and one of four federally qualified health centers in Chicago.

PARTICIPANTS: Seven hundred eighty-four adults aged 55 to 74.

MEASUREMENTS: Assessment of participant literacy, sociodemographic factors, and having an AD for medical care.

RESULTS: One-eighth (12.4%) of participants with low literacy, 26.6% of those with marginal literacy, and 49.5% of those with adequate literacy reported having an AD ($P < .001$). In multivariable analyses, literacy and race were independently associated with less likelihood of having an AD. Specifically, participants with limited literacy (risk ratio (RR) = 0.45, 95% confidence interval (CI) = 0.22–0.95) and African Americans (RR = 0.64, 95% CI = 0.47–0.88) were less likely to have an AD. Exploratory analyses showed 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 for not having an AD in this cohort of older adults. Literacy and race probably represent two separate but important causal pathways that need to be understood to improve how the healthcare system ascertains and protects individuals' advance care preferences. *J Am Geriatr Soc* 61:403–406, 2013.

Key words: literacy; advance directive; end-of-life decisions; race

High-profile news events, such as the Terri Schiavo case and the rhetoric about “death panels” that surrounded the healthcare 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—fewer than one-third of American adults have advance directives (ADs).^{1–3} Even in individuals with incurable cancer, only approximately 20% have documentation of ADs 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 because 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} Although details vary according to state, the most-prominent legal bulwarks to protect people's wishes and rights are healthcare proxies and AD statutes.

A variety of studies examining individual, provider, and institutional barriers have revealed low rates of AD adoption.^{2,3,8} The likelihood of an individual having an AD in place has been linked to factors such as race, education,

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income, and health status,^{3,9,10} but literacy skills have received little attention as a possible barrier to having an AD. This study examined the role of literacy in the adoption of an AD in a cohort of older adults. Analyses were also conducted to determine how literacy influences the association between other individual-level factors and AD adoption.

METHODS

Participants

Adults aged 55 to 74 who received care at an urban academic general internal medicine clinic or one of four federally qualified health centers in Chicago, Illinois, were recruited to participate in the Health Literacy and Cognitive Function Among Older Adults Study, a National Institute of Aging (NIA)-funded investigation of the relationship between literacy and cognitive function (R01 AG030611). Enrollment took place between August 2008 and November 2010. Exclusion criteria were severe visual or hearing impairments, non-English speaking, critically ill, or moderate to severe cognitive impairment. The Northwestern University institutional review board approved the study, and all participants provided written informed consent before participation.

Study Procedures and Data

Participants completed a 4-hour, structured cognitive interview, divided over 2 days, with a trained interviewer. It included comprehensive assessments of literacy, cognitive function, physical and mental health, and health-related behaviors. Documentation of having an AD was determined according to self-report using 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?" The interviewer first documented answers verbatim and then coded them as a dichotomized variable (yes–no). For ambiguous responses, the study team reviewed the verbatim response and made a decision for coding by consensus.

Literacy was measured using the Test of Functional Health Literacy in Adults (TOFHLA),¹¹ a well-established literacy assessment comprising two parts: a 10-item numeracy measure and a 50-item reading comprehension measure. According to 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 classified as inadequate (0–53), marginal (54–56), and adequate (67–100).¹¹ Self-reported data were also collected 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

Chi-square and Wilcoxon rank sum tests were used to evaluate the bivariate associations between ADs and independent variables of interest, including literacy, age, sex,

education, income, and number of chronic conditions. The relationship between literacy and each of these factors was examined. Multivariable generalized linear models were then constructed with ADs (yes or no) as the dependent variable. A Poisson distribution and log link were specified to estimate risk ratios (RRs) rather than odds ratios (ORs) for ease of data interpretation^{12,13} and because ORs tend to overestimate point estimates when the outcome is common (>10%).¹⁴

All independent variables mentioned above except literacy were modeled. Literacy was then added to the model to examine its independent association with ADs, as well as its effect on the estimates of other variables in the model. In a separate analysis, an interaction term for race and literacy was tested in a fully specified model of having an AD.

RESULTS

Eight hundred three study participants were enrolled into the study between August 2008 and November 2010; 784 of these (97.6%) responded to the AD item and were included in these analyses. The mean age of the sample was 63.1 ± 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%; marginal, 16.2%). Literacy skills differed significantly according to race; 47.4% of African Americans had adequate literacy, compared with 88.8% of non-African Americans ($P < .001$).

Overall, 41.2% of study participants reported having documented their end-of-life preferences. Literacy skills were strongly associated with having an AD; 12.4% of participants with low literacy, 26.6% with marginal literacy, and 49.5% with adequate literacy reported having an AD ($P < .001$; Table 1). Race was also strongly associated with self-report of an AD (African American, 22.9%; whites, 57.2%, $P < .001$). Other factors significantly associated with having an AD were older age, higher education, higher income, part-time employment, and fewer chronic conditions (Table 1).

In multivariable analysis excluding literacy, African-American participants were 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 education and between ADs and age were nonsignificant with the addition of literacy in the model. In the full model, participants with limited literacy were less likely to have an AD (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 ($P = .57$, data not shown).

DISCUSSION

Fewer than half of a sample of 784 older adults had an AD in place (41.2%). Through multivariable analysis, it

Table 1. Demographic Information (n = 784)

| Characteristic | Total % | With Advance Directive | P-Value |
|------------------------------|---------|------------------------|---------|
| Age | | | < .001 |
| 55-60 | 37.9 | 32.0 | |
| 61-65 | 28.4 | 43.1 | |
| 66-70 | 21.6 | 5.3 | |
| 71-74 | 12.1 | 49.5 | |
| Sex | | | .78 |
| Female | 67.7 | 4.9 | |
| Male | 32.3 | 41.9 | |
| Race | | | < .001 |
| African American | 43.1 | 22.9 | |
| Caucasian | 50.0 | 57.2 | |
| Other | 6.9 | 38.9 | |
| Health literacy | | | < .001 |
| Low | 12.7 | 12.4 | |
| Marginal | 16.2 | 26.6 | |
| Adequate | 71.2 | 49.5 | |
| Education | | | < .001 |
| ≤ High school | 27.2 | 18.3 | |
| Some college | 21.9 | 4.1 | |
| College graduate | 20.3 | 53.5 | |
| Graduate degree | 30.6 | 54.2 | |
| Income, \$ | | | < .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 | | | .02 |
| No work | 64.9 | 4.6 | |
| Part time | 14.9 | 52.1 | |
| Full time | 20.2 | 35.4 | |
| Number of chronic conditions | | | < .001 |
| 0-1 | 44.9 | 48.0 | |
| 2 | 28.8 | 40.7 | |
| ≥ 3 | 26.3 | 41.2 | |

Table 2. Effect of Health Literacy on Relationships Between Individual-Level Characteristics and Advance Directives

| Characteristic | Risk Ratio (95% Confidence Interval) | P-Value |
|----------------------------------------------|--------------------------------------|---------|
| Health literacy (reference adequate) | | |
| Low | 0.45 (0.22-0.95) | .04 |
| Marginal | 0.81 (0.53-1.23) | .32 |
| Age (reference 71-74) | | |
| 55-60 | 0.69 (0.47-1.01) | .05 |
| 61-65 | 0.86 (0.59-1.25) | .43 |
| 66-70 | 1.04 (0.71-1.54) | .83 |
| Female | 0.98 (0.77-1.25) | .86 |
| African American | 0.64 (0.47-0.88) | .01 |
| Education (reference graduate degree) | | |
| High school or less | 0.68 (0.44-1.07) | .09 |
| Some college | 1.14 (0.81-1.60) | .46 |
| College graduate | 1.08 (0.81-1.45) | .59 |
| Income, \$ (reference > \$50,000) | | |
| <10,000 | 0.62 (0.35-1.11) | .11 |
| 10,000-24,999 | 0.72 (0.48-1.09) | .12 |
| 25,000-49,999 | 0.89 (0.62-1.28) | .54 |
| Number of chronic conditions (reference 0-1) | | |
| 2 | 1.01 (0.78-1.32) | .93 |
| ≥ 3 | 0.89 (0.64-1.23) | .49 |

was 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 to broad implementation of interventions that can reduce literacy barriers relating to advance care planning.

Race was also a significant factor; African Americans were approximately half as likely to have an AD as 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 relationship between race and having an AD, and 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 comorbidities. 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 advance care planning. Clinicians frequently avoid end-of-life discussions, even though people are more satisfied when the topic is discussed.¹⁸ When the topic is broached, it may be particularly challenging for individuals with inadequate literacy to understand¹⁹⁻²¹; tools such as video decision-aids are useful to ensure that education about complex topics such as ADs takes place and can help facilitate clinician-patient communication.²¹

Several reports have presented additional evidence that support the relationship between low literacy and having an AD. For example, a nationwide assessment of the readability of AD forms found that the majority of the documents exceeded the recommendations for writing patient education materials at a fifth-grade level.^{22,23} An evaluation of the use of an AD redesigned to meet most adults' literacy needs (fifth-grade reading level with graphics) found that, not only did people prefer the document, but that it also resulted in higher completion rates of ADs in the study population.²⁴

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 use by African Americans could reflect a cultural phenomenon such as wariness regarding discussing death or distrust of the healthcare system that could instill wariness about any documentation that could be used to limit care, but evidence about these theories is mixed.^{10,27,28} Factors associated with race but not otherwise captured in the models, such as inadequate communication by providers with African Americans regarding advance care planning and what is needed to protect individual preferences, might explain the association between race and having an AD.^{29,30}

Some limitations of this study should be mentioned. First, having an AD was assessed according to self-report, and it is possible that some participants did not accurately recall whether they had an AD at the time of their study interview, but self- or family report of ADs is generally how this information is elicited in clinical practice in acute care settings. Second, it was not possible to measure other factors that might have influenced adoption of an AD. For

example, it was not known whether a healthcare provider had ever discussed ADs with the study participants or whether they were exposed to written or multimedia information about AD forms. Third, participants 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. It is likely that a higher average age of participants in this study than in prior prevalence reports caused this.

These 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 probably influence the adoption of an AD and are more difficult to measure than basic demographic and literacy metrics.

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

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REFERENCES

- Pollack KM, Morhaim D, Williams MA. The public's perspectives on advance directives: Implications for state legislative and regulatory policy. *Health Policy* 2010;96:57–63.
- Gilligan MA, Jensen N. Use of advance directives: A survey in three clinics. *Wis Med J* 1995;94:239–243.
- Hanson LC, Rodgman E. The use of living wills at the end of life: A national study. *Arch Intern Med* 1996;156:1018–1022.
- Temel JS, Greer JA, Admane S et al. Code status documentation in the outpatient electronic medical records of patients with metastatic cancer. *J Gen Intern Med* 2010;25:150–153.
- Yung VY, Walling AM, Min L et al. Documentation of advance care planning for community-dwelling elders. *J Palliat Med* 2010;13:861–867.
- Fromme EK, Zive D, Schmidt TA et al. POLST registry do-not-resuscitate orders and other patient treatment preferences. *JAMA* 2012;307:34–35.
- McCarthy EP, Pencina MJ, Kelly-Hayes M et al. Advance care planning and health care preferences of community-dwelling elders: The Framingham Heart Study. *J Gerontol A Biol Sci Med Sci* 2008;63A:951–959.
- Barondess L. Helping patients make their health care wishes known in advance directives. *Ann Long Term Care* 2005;13(5):14.
- Stelter KL, Elliott BA, Bruno CA. Living will completion in older adults. *Arch Intern Med* 1992;152:954–959.
- Hussain MJ, Jeune J, Louis B et al. Factors influencing older adults to complete advance directives. *Palliat Supportive Care* 2010;8:267–275.
- Parker RM, Baker DW, Williams MV et al. The Test of Functional Health Literacy in Adults (TOFHLA): A new instrument for measuring patients' literacy skills. *J Gen Intern Med* 1995;10:537–542.
- McNutt LA, Wu C, Xue X et al. Estimating the relative risk in cohort studies and clinical trials of common outcomes. *Am J Epidemiol* 2003;157:940–943.
- Zou G. A modified Poisson regression approach to prospective studies with binary data. *Am J Epidemiol* 2004;159:702–706.
- Zhang J, Yu KF. What's the relative risk? A method of correcting the odds ratio in cohort studies of common outcomes. *JAMA* 1998;280:1690–1691.
- Rubin SM, Strull WM, Fialkow MF et al. Increasing the completion of the durable power of attorney for health care. *JAMA* 1994;271:209–212.
- Crawley LV, Payne R, Bolden J et al. Palliative and end-of-life care in the African American community. *JAMA* 2000;284:2518–2521.
- Johnson KS, Elbert-Avila KI, Tulsy JA. The influence of spiritual beliefs and practices on the treatment preferences of African Americans: A review of the literature. *J Am Geriatr Soc* 2005;53:711–719.
- Tierney WM, Dexter PR, Gramelspacher GP et al. The effect of discussions about advance directives on patients' satisfaction with primary care. *J Gen Intern Med* 2001;16:32–40.
- Volandes AE, Barry MJ, Chang Y et al. Improving decision making at the end of life with video images. *Med Decis Making* 2010;30:29–34.
- Volandes AE, Paasche-Orlow MK, Barry MJ et al. Video decision support tool for advance care planning in dementia: Randomised controlled trial. *BMJ* 2009;338:b2159–b2167.
- Volandes AE, Paasche-Orlow M, Gillick MR et al. Health literacy not race predicts end-of-life care preferences. *J Palliat Med* 2008;11:754–762.
- Mueller LA, Reid KI, Mueller PS. Readability of state-sponsored advance directive forms in the United States: A cross sectional study. *BMC Med Ethics* 2010;11:6–12.
- Weiss BD, Coyne C, Michielutte R et al. Communicating with patients who have limited literacy skills: Report of the National Working Group on Literacy and Health. *J Fam Pract* 1998;46:168–176.
- Sudore RL, Landefeld CS, Barnes DE et al. An advance directive redesigned to meet the literacy level of most adults: A randomized trial. *Patient Educ Couns* 2007;69:165–195.
- Mack JW, Paulk ME, Viswanath K et al. Racial disparities in the outcomes of communication on medical care received near death. *Arch Intern Med* 2010;170:1533–1540.
- Halpern NA, Pastores SM, Chou JF et al. Advance directives in an oncologic intensive care unit: A contemporary analysis of their frequency, type, and impact. *J Palliat Med* 2011;14:483–489.
- Bullock K. Promoting advance directives among African Americans: A faith-based model. *J Palliat Med* 2006;9:183–195.
- Smith AK, Davis RB, Krakauer EL. Differences in the quality of the patient-physician relationship among terminally ill African-American and White patients: Impact on advance care planning and treatment preferences. *J Gen Intern Med* 2007;22:1579–1582.
- Smith AK, McCarthy EP, Paulk E et al. Racial and ethnic differences in advance care planning among patients with cancer: Impact of terminal illness acknowledgment, religiousness, and treatment preferences. *J Clin Oncol* 2008;26:4131–4137.
- Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist* 2005;45:634–641.