

## Health Literacy not Race Predicts End-of-Life Care Preferences

ANGELO E. VOLANDES, M.D.,<sup>1</sup> MICHAEL PAASCHE-ORLOW, M.D., M.A., M.P.H.,<sup>2</sup>  
MURIEL R. GILLICK, M.D.,<sup>3</sup> E.F. COOK, Sc.D.,<sup>4</sup> SHIMON SHAYKEVICH, M.Sc.,<sup>4</sup>  
ELMER D. ABBO, M.D., J.D.,<sup>5</sup> and LISA LEHMANN, M.D., Ph.D.<sup>6</sup>

### ABSTRACT

**Background:** Several studies have reported that African Americans are more likely than whites to prefer aggressive treatments at the end of life.

**Objective:** Since the medical information presented to subjects is frequently complex, we hypothesized that apparent differences in end-of-life preferences and decision making may be due to disparities in health literacy. A video of a patient with advanced dementia may overcome communication barriers associated with low health literacy.

**Design:** Before and after oral survey.

**Participants:** Subjects presenting to their primary care doctors.

**Methods:** Subjects were asked their preferences for end-of-life care after they heard a verbal description of advanced dementia. Subjects then viewed a 2-minute video of a patient with advanced dementia and were asked again about their preferences. For the analysis, preferences were dichotomized into comfort care and aggressive care. Health literacy was measured using the Rapid Estimate of Adult Literacy in Medicine (REALM) and subjects were divided into three literacy categories: low (0–45, sixth grade and below), marginal (46–60, seventh to eighth grade) and adequate (61–66, ninth grade and above). Unadjusted and adjusted logistic regression models were fit using stepwise algorithms to examine factors related to initial preferences before the video.

**Results:** A total of 80 African Americans and 64 whites completed the interview. In unadjusted analyses, African Americans were more likely than whites to have preferences for aggressive care after the verbal description, odds ratio (OR) 4.8 (95% confidence interval [CI] 2.1–10.9). Subjects with low or marginal health literacy were also more likely than subjects with adequate health literacy to have preferences for aggressive care after the verbal description, OR 17.3 (95% CI 6.0–49.9) and OR 11.3 (95% CI 4.2–30.8) respectively. In adjusted analyses, health literacy (low health literacy: OR 7.1, 95% CI 2.1–24.2; marginal health literacy OR 5.1, 95% CI 1.6–16.3) but not race (OR 1.1, 95% CI 0.3–3.2) was an independent predictor of preferences after the verbal description. After watching a video of advanced dementia, there were no significant differences in the distribution of preferences by race or health literacy.

**Conclusions:** Health literacy and not race was an independent predictor of end-of-life preferences after hearing a verbal description of advanced dementia. In addition, after viewing a video of a pa-

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<sup>1</sup>General Medicine Unit, Massachusetts General Hospital, Boston, Massachusetts.

<sup>2</sup>Department of Medicine, Boston Medical Center, Boston, Massachusetts.

<sup>3</sup>Harvard Medical School, Boston, Massachusetts.

<sup>4</sup>Brigham and Women's Hospital, Boston, Massachusetts.

<sup>5</sup>Section of General Internal Medicine, Department of Medicine, University of Chicago, Chicago, Illinois.

<sup>6</sup>Boston, Massachusetts.

**tient with advanced dementia there were no longer any differences in the distribution of preferences according to race and health literacy. These findings suggest that clinical practice and research relating to end-of-life preferences may need to focus on a patient education model incorporating the use of decision aids such as video to ensure informed decision-making.**

## INTRODUCTION

SEVERAL STUDIES have reported that African Americans are more likely than whites to prefer more aggressive treatments at the end of life.<sup>1-9</sup> Speculation about this finding has focused on African Americans' unique cultural and spiritual belief systems,<sup>1,4-7,9</sup> and their lack of trust in the health care system perhaps due to historical experiences such as Tuskegee, in which African American men were deprived of treatment for syphilis as an experiment.<sup>1-4</sup> Although low health literacy is a prevalent barrier to accurate communication and could confound the relationship between race and informed decision-making, no prior studies on end-of-life decision-making have explored the confounding effects of health literacy.

More than 90 million adults in the United States have insufficient literacy skills to be independent health care users,<sup>10</sup> and low health literacy is associated with race, age, education, and having chronic illness.<sup>11</sup> Distinguishing the effect of health literacy from race is important in this context.<sup>12</sup> Ethnicity and culture are factors that may shape preferences and should be respected. By contrast, low health literacy is an obstacle to communicating information for informed decision-making that we should strive to surmount so that we can accurately elicit and respect individual values.

There are multiple communication techniques that could be used to overcome barriers posed by health literacy. Visual images have been shown to improve communication of information with patients.<sup>13-17</sup> Prior interventions to improve decision-making have included print, audio, video, and Web-based pictorial materials,<sup>15,18-25</sup> with mixed results.<sup>26</sup> The medium of video allows patients to envision health states in a manner not easily captured with verbal communication and can both engage people and efficiently communicate information about the experience of illness.<sup>27</sup>

We hypothesized that after hearing a verbal description of advanced dementia, subjects' preferences for care at the end of life for themselves would be independently predicted by health literacy and not race. Additionally, we hypothesized that a video of a patient with advanced dementia would overcome communication barriers associated with low health literacy.

## METHODS

### *Participants*

Patients over the age of 40 scheduled to see a general internist at six study sites were eligible to participate. The age of 40 was chosen since most adults after that age have usually been involved with end-of-life decision making for a loved one. Patients were given a flyer outlining the study at the time of their clinic visit. The study sites consisted of urban and suburban primary care clinics affiliated with two teaching hospitals in the greater Boston area. Subjects were excluded if they had previously had a close relationship with a person with advanced dementia, since they will likely have had first-hand experience and knowledge of the disease. Previous work suggested that subjects who had a close relationship strongly favored comfort care and that a video did not better inform preferences.<sup>27</sup> Subjects were also excluded if, in the judgment of the physician interviewer, they lacked medical decision-making capacity at the time of the interview, or if they did not speak English, the language of our validated tools. Only subjects who self-reported their race as African American or white were included in the analysis since this study attempted to compare the preferences of African Americans and whites. All interviews were conducted by two white, male physicians between December 1, 2005 and January 31, 2007. Approval for the project was granted by the Institutional Review Boards of the affiliated hospitals.

### *Design*

A structured questionnaire was developed for this study. Survey questions were generated from a review of the medical ethics literature, and consultations with medical ethics, palliative care, geriatric, and neurology experts. Early versions of the survey were tested with subjects recruited from primary care clinics.

After obtaining verbal informed consent, interviewers defined advanced dementia in simple language, highlighting functional impairments based on the Functional Assessment Staging (FAST)<sup>28</sup> criteria including inability to communicate understandably with others, inability to ambulate without assistance,

and inability to feed oneself<sup>27</sup> (See Appendix A for verbal description). We then outlined three levels of medical treatments and the goals associated with each level. The first level, life-prolonging care, aims to prolong life at any cost. It includes all medically indicated treatments. The second level, limited care, aims to maintain physical functioning. It includes treatments such as hospitalization, intravenous fluids, antibiotics, and artificial nutrition and hydration, but excludes attempted cardiopulmonary resuscitation and treatments in the intensive care unit. The third level, comfort care, aims to maximize comfort and to relieve pain. It includes oxygen and analgesics but excludes intravenous therapies and hospitalization unless necessary to provide comfort. Subjects were asked which level they preferred in the event they developed advanced dementia. Subjects not able to select a level of treatments were documented as “don’t know.”

Each subject next viewed a 2-minute video of a white patient with advanced dementia. The video depicts the salient features of advanced dementia. The narrative that accompanies the video is identical to the verbal description used to assess subjects’ initial preferences. The design, content, and structure of the video intervention were reviewed for accuracy by three geriatricians and five neurologists, all of whom specialize in the care of patients with dementia. The video was also designed with the close collaboration of caregivers of patients with advanced dementia.<sup>27</sup> The video was available only in English. (The film clip is available online at [advancecareplanningvideos.com](http://advancecareplanningvideos.com).)

The subject was then asked exactly the same questions as previously regarding preferences for level of medical care. Answers to sociodemographic questions (age, race, gender, etc.) were self-reported by the subjects. Health literacy was measured at the end of the interview using the validated Rapid Estimate of Adult Literacy in Medicine tool (REALM).<sup>29</sup> The survey is available upon request.

### *Statistical analysis*

The main outcome measure was preferences for care after hearing a verbal description of advanced dementia. We dichotomized preferences into two groups: comfort care and aggressive care (life-prolonging care, limited care, and do not know). As others have done, we included subjects preferring “do not know” in the aggressive care group since in clinical practice the default for such patients is life-prolonging treatments.<sup>27,30</sup>

Our measure for health literacy was the 66-word REALM.<sup>29</sup> This is a 2- to 3-minute English test of

medically relevant vocabulary. The REALM is a valid test of word pronunciation and has been shown to correlate well with tests that evaluate a range of literacy skills.<sup>31</sup> As others have done, we defined three categories for literacy: low literacy (REALM score of 0–45, sixth grade and below); marginal literacy (REALM score of 45–60, seventh to eighth grade); and adequate literacy (REALM score of 61–66, ninth grade and above).<sup>11,32</sup> Fisher’s exact test was used to compare the proportion of subjects who chose comfort care across levels of health literacy.

Univariate analyses for subject characteristics (health literacy, age, gender, education, marital status, religion, religious attendance, and health status) with race and preferences for care were conducted utilizing the Fisher’s exact test. Unadjusted odds ratios (ORs) were calculated using contingency tables to compare subject demographic characteristics to their preferences.

Multivariate logistic regression analyses were used to identify factors independently associated with preferences. Stepwise algorithms were used to assess the independent role of each variable. Factors significant at  $p < 0.10$  were retained. Factors thus selected were simultaneously entered into the logistic regression model. Another backward stepwise algorithm, using  $p < 0.05$ , was used to determine the final model.

The distribution of levels of care after the verbal description compared to the distribution of preferences after the video were analyzed utilizing the McNemar’s test of correlated proportions. All  $p$  values are two-tailed. Data were analyzed using SAS software, version 9.1 (SAS Institute, Cary, NC).

## RESULTS

### *Study participants*

A total of 214 subjects were approached to participate in the study, of whom 173 (81%) agreed to be interviewed. The most common reason given for not participating was lack of time. Of the 173 subjects recruited for the study, 23 were disqualified due to a prior history of a close relationship with a person with advanced dementia. Four subjects were excluded due to being Asian American (1), Native American (1), or Latino (2); 2 subjects were excluded from the analysis due to refusal to participate in the health literacy assessment. The resulting dataset included 144 subjects.

Table 1 describes the characteristics of the survey sample. Of the 144 subjects, 64 (44%) were

TABLE 1. CHARACTERISTICS OF STUDY SAMPLE

Characteristics	Total	African Americans	Whites	p value
Number of subjects, no. (%)	144	80 (56)	64 (44)	
Age, mean (SD)	57 (11)	56 (11)	58 (12)	0.3
Women, no. (%)	92 (64)	55 (69)	37 (58)	0.22
Health literacy, no. (%)				<0.0001
Low	27 (19)	23 (29)	4 (6)	
Marginal	30 (21)	26 (33)	4 (6)	
Adequate	87 (60)	31 (39)	56 (88)	
Education, no. (%)				<0.0001
High school or less	80 (56)	65 (81)	15 (23)	
College or beyond	64 (44)	15 (19)	49 (77)	
Marital status, no. (%)				0.001
Married	77 (53)	33 (42)	44 (69)	
Nonmarried	67 (47)	47 (59)	20 (31)	
Religion, no. (%)				<0.0001
Christian	116 (81)	74 (93)	42 (66)	
Non-Christian	28 (19)	6 (8)	22 (34)	
Religious attendance, no. (%)				0.0001
Two times per month or more	61 (42)	43 (54)	18 (28)	
One time per month or less	23 (16)	16 (20)	7 (11)	
Never	60 (41)	21 (26)	39 (61)	
Self-reported health status, no. (%)				0.0002
Very healthy	77 (53)	31 (39)	46 (72)	
Somewhat healthy	61 (42)	44 (55)	17 (27)	
Not healthy	6 (4)	5 (6)	1 (2)	

SD, standard deviation.

whites and 80 (56%) were African Americans. African Americans had significantly lower health literacy, lower education, more religious attendance, and poorer health.

### Outcomes

After hearing a verbal description of advanced dementia, treatment preference was associated with race, health literacy, education, and health status (Table 2).

### Preferences after verbal description by race

Of the 64 whites, 55 (86%) preferred comfort care and 9 (14%) preferred aggressive care (Fig. 1). Of the 80 African Americans, 45 (56%) preferred comfort care and 35 (44%) preferred aggressive care (Fig. 1). Few whites or African Americans indicated “do not know” as their preferences after the verbal description, 2 (3%) and 5 (6%) subjects, respectively.

Unadjusted analysis revealed that compared to whites, African Americans were more likely to have preferences for aggressive care after the verbal description, OR 4.8 (95% CI 2.1–10.9; Table 2). In the multiple logistic regression stepwise model, the effect of race was no longer significant, OR 1.1 (95% CI 0.3–3.2; Table 3).

### Preferences after verbal description by health literacy

Preferences after the verbal description were also strongly associated with health literacy (Fig. 1). Of the 27 subjects with low health literacy, 18 (67%) preferred aggressive care. Of the 30 subjects with marginal health literacy, 17 (57%) chose aggressive care. Of the 87 subjects with adequate health literacy, only 9 (10%) selected aggressive care. There was an increasing preference for comfort care after the verbal description with increasing health literacy that was highly statistically significant ( $p < 0.0001$ ).

Unadjusted analyses revealed that subjects with low health literacy were more likely to have preferences for aggressive care after the verbal description when compared to those subjects with adequate health literacy, OR 17.3 (95% CI 6.0–49.9), as did those with marginal health literacy, OR 11.3 (95% CI 4.2–30.8; Table 2). In the multiple logistic stepwise model, health literacy remained a significant and independent predictor of preferences for care (low literacy OR 7.1, 95% CI 2.1–24.2; marginal literacy 5.1, 95% CI 1.6–16.3; Table 3).

Of all the other characteristics (age, education, gender, marital status, religion, religious attendance, and health status), only education remained in the model

TABLE 2. UNADJUSTED ODDS RATIOS OF INITIAL PREFERENCES FOR AGGRESSIVE CARE AFTER VERBAL DESCRIPTION

Characteristic	Initial preferences for aggressive care <sup>a</sup> after verbal description	
	Unadjusted OR	95% CI
Race		
African American	4.8	2.1–10.9
White	1.0	
Health literacy		
Low	17.3	6.0–49.9
Marginal	11.3	4.2–30.8
Adequate	1.0	
Education		
High school or less	15.0	5.0–45.2
College or beyond	1.0	
Gender		
Male	1.0	0.5–2.1
Female	1.0	
Marital status		
Nonmarried	1.8	0.9–3.7
Married	1.0	
Religion		
Non-Christian	1.8	0.7–4.8
Christian	1.0	
Religious attendance		
≤1 month	1.3	0.5–3.8
≥2 month	1.7	0.8–3.7
Never	1.0	
Health status		
Not healthy	1.6	0.3–9.7
Somewhat healthy	2.1	1.0–4.4
Very healthy	1.0	

<sup>a</sup>Aggressive care includes those subjects who chose one of the following: life-prolonging care, limited care, or don't know. OR, odds ratio; CI, confidence interval.

after the stepwise approach (Table 3). Education was also associated with preferences after the verbal description. Subjects with a high school education or less were more likely to have preferences for aggressive care when compared to those with a college or higher education, OR 15.0 (95% CI 5.0–45.2; Table 2). In adjusted analysis controlling for race and health literacy, education was still a significant and independent predictor of preferences after the verbal description, OR 4.5 (95% CI 1.1–18.6; Table 3).

#### *Change in initial preferences after the video*

The distribution of subjects' preferences after viewing the video changed significantly compared to the distribution of preferences after hearing the verbal description ( $p < 0.0001$ ). The vast majority of subjects across both races and all health literacy groups chose comfort care after viewing the video (Fig. 2). After the

video, no whites and 10 (13%) African Americans preferred aggressive care (Fig. 2). After the video, 3 (11%) subjects with low health literacy and 3 (10%) subjects with marginal health literacy preferred aggressive care. Of the subjects with adequate health literacy, 4 (3%) preferred aggressive care after the video.

## DISCUSSION

Previous studies have suggested that African Americans are more likely than whites to prefer aggressive care at the end of life. This finding was observed in the current study as well; however, adjusted analyses reveal that health literacy mediates the relationship between race and end-of-life preferences for African Americans. The influence of health literacy on end-of-life decision-making reflected a dose-response effect with increasing health literacy leading toward comfort care. This suggests that race should not be the primary focus of research and patient care regarding end-of-life preferences. Rather, health literacy and a heightened commitment to patient education and communication should be the top priority. The importance of patient education and communication is corroborated by the finding in our study that a video intervention designed to compensate for low health literacy skills had a large impact on patient preferences. Indeed, after viewing the video there were no significant differences in end-of-life preferences by race or health literacy status. Carefully crafted video decision aids designed to overcome barriers posed by health literacy may improve decision-making at the end of life for patients with low health literacy. Furthermore, racial disparities in features of clinical medicine that may be heavily dependent on health literacy, such as we found to be the case in this study, can be influenced by interventions like video that target deficits in health literacy. Video offers a unique and widely accessible means of communication that engages patients in a way not achieved with words.

None of the studies previously cited regarding African American preferences at the end of life studied health literacy,<sup>1–9</sup> and few asked about education.<sup>2,3,6</sup> Education is closely related to health literacy, but the two variables clearly represent different constructs. Education level represents how far a person progressed in formal education, not how much literacy skill he/she acquired. Various forces such as social promotion can lead to significant variance between education level and observed literacy. In this country, the average adult English reading level is between eighth and ninth grade,<sup>33</sup> and, the quality of educa-

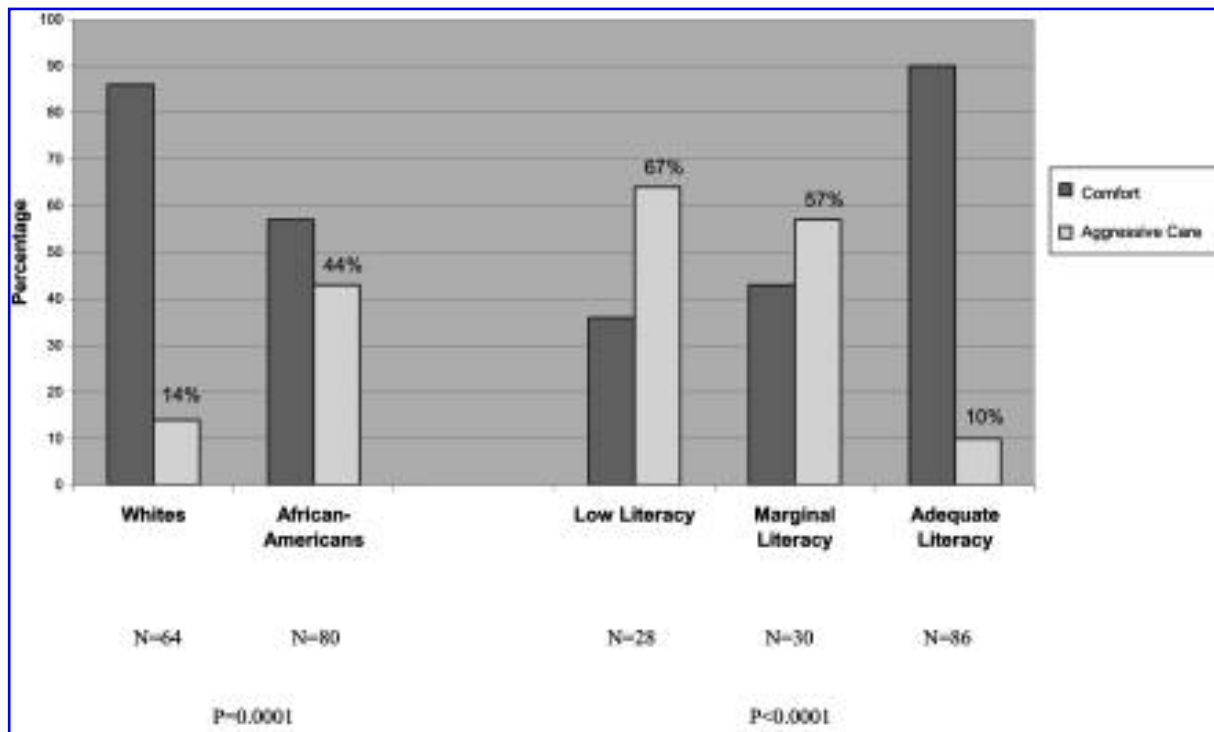


FIG. 1. Preferences after verbal description by race and health literacy. The Fisher’s exact test was used to compare each variable (race, literacy) with the proportion of subjects who chose comfort care.

tional outcomes varies significantly.<sup>34</sup> Our results show that both education and health literacy were independently associated with end-of-life care preferences. We posit that health literacy will be more closely related to communication barriers than educa-

tion because health literacy is a direct measure of a patient’s current skills. Future studies exploring in detail the increasingly recognized roles of health literacy and education at the end of life are important.<sup>35–36</sup>

Our study has several important limitations. First, the distribution of low or marginal health literacy between African Americans and whites was not parallel. There were only 8 whites with low or marginal health literacy. Future research on the relationship between race, health literacy, and end-of-life preferences could benefit from a more balanced or simply larger analytic sample. This would permit exploration of additional potential confounders, such as socioeconomic status. In addition, our sample was drawn from the metro Boston area. These findings should be evaluated in a nationally representative sample that includes other large minority groups such as Latinos and Asian Americans.

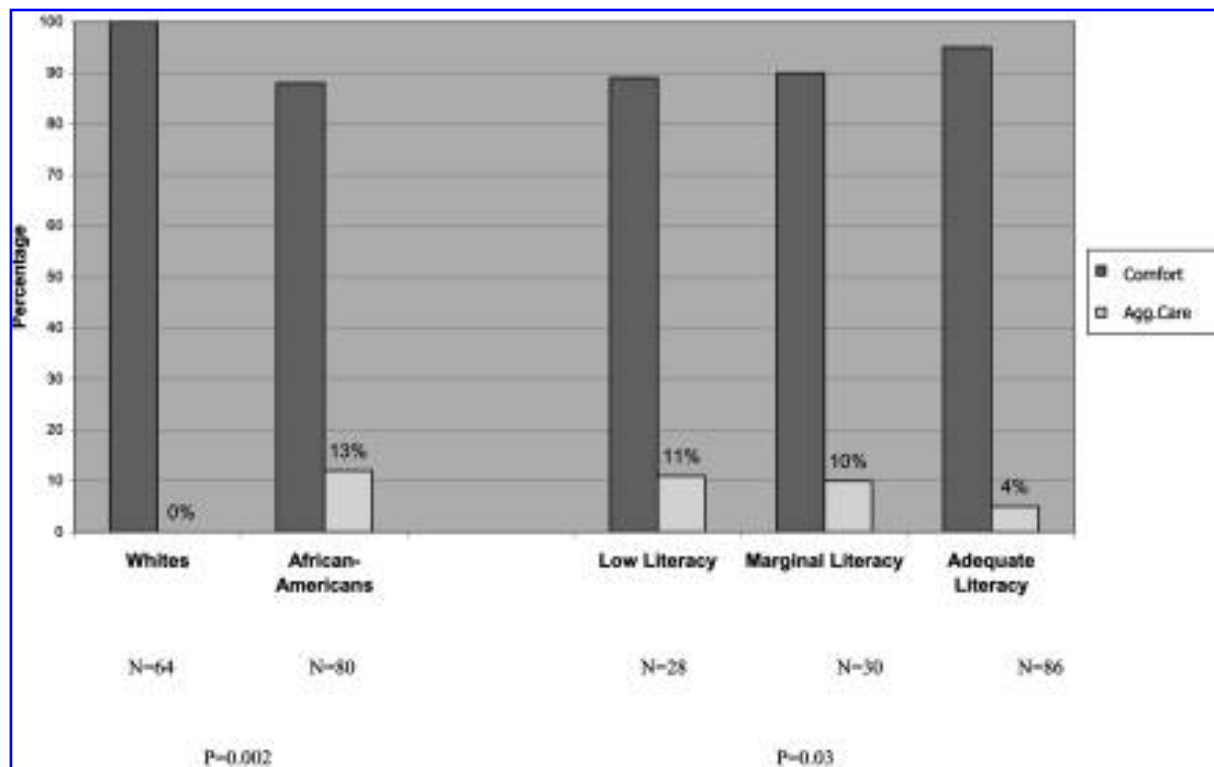
We used a before and after study design in which individual subjects heard the description of dementia twice, verbally and then with the video. Subjects with limited health literacy may simply have benefited from the repetition of information. Future studies isolating the effect of the video would be helpful. Additionally, preferences for level of care at the end of life may change over the course of time. Our study looked at the preferences of subjects at a particular point in time.

TABLE 3. ADJUSTED ODDS RATIOS FOR INITIAL PREFERENCES FOR AGGRESSIVE CARE AFTER VERBAL DESCRIPTION

Characteristic <sup>a</sup>	Initial preferences for aggressive care after verbal description	
	Unadjusted OR	95% CI
Race		
African American	1.1	0.3–3.2
White	1.0	
Health literacy		
Low	7.1	2.1–24.2
Marginal	5.1	1.6–16.3
Adequate	1.0	
Education		
≤High school	4.5	1.1–18.6
≥College	1.0	

<sup>a</sup>Other characteristics (age, gender, religion, religious attendance and health status) were excluded from the stepwise model as they were not related to the outcome at a  $p < 0.10$ .

OR, odds ratio; CI, confidence interval.



**FIG. 2.** Preferences after video by race and health literacy. The Fisher's exact test was used to compare each variable (race, literacy) with the proportion of subjects who chose comfort care.

Future work looking at the stability of preferences over time would be helpful, especially in the context of completing advance directives or more formalized advance care planning that incorporates the video.

Video is a powerful medium that can be manipulated to sway patient perspectives. We studied the use of a single video clip that was designed to portray advanced dementia in order to overcome barriers posed by health literacy. Future studies exploring the designing and filming of videos to overcome literacy barriers would be useful. It would also be interesting to explore the preferences of subjects using other video clips that varied the features of the patient, such as race and gender. It is important to note that special care needs to be taken to develop patient education materials and decision-aids that empower—not manipulate—patients. Our study asked questions about preferences if patients would be in a state of advanced dementia, a common end-of-life scenario. Preferences for end-of-life care in other disease states may be different. Other studies using disease states such as a persistent vegetative state, severe stroke, end-stage chronic obstructive pulmonary disease (COPD) and severe congestive heart failure (CHF) may be fruitful.

Discussions regarding treatments at the end of life will increasingly involve a more diverse pool of patients, and consideration of each patient's culture is important. Yet our data show that accepting a patient's preferences based on a verbal conversation about a future disease state may not reflect a patient's fully informed preferences for end-of-life treatments: the diversity of preferences that have often been attributed to racial and cultural differences are a result of differences in health literacy, not race. Video in addition to improved verbal communication may be one means to overcome barriers posed by health literacy. Prematurely accepting aggressive preferences for end-of-life treatments may inadvertently condemn patients to an unwanted and misunderstood course of medical treatments at the end of life.

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Address reprint requests to:  
 Angelo E. Volandes, M.D.  
 General Medicine Unit  
 Massachusetts General Hospital  
 50 Staniford Street, 9th Floor  
 Boston, MA 02114

*E-mail:* avolandes@partners.org

#### APPENDIX A. NARRATIVE DESCRIBING ADVANCED DEMENTIA

“I am going to describe to you an illness called advanced dementia, like advanced Alzheimer’s dementia, that you may or may not be familiar with. Advanced dementia is an incurable disease of the brain in which one is not able to communicate with others. People in advanced dementia are not able to move around or walk, get out of bed independently, eat by oneself, or communicate understandably with others. People with advanced dementia often have difficulty chewing or swallowing, and require assistance with feeding oneself. Advanced dementia is an incurable disease and most commonly occurs after many years of Alzheimer’s disease or as the result of strokes. People are not able to answer any questions or tell you about themselves.”

#### Narrative Describing the Goals of Care

“I am going to ask you a question about your preferences for medical care if you had a disease called

advanced dementia. I will ask you what you prefer. You have three choices for medical care if you had this condition. I will first review these three choices with you. The three choices for medical care that I want you to think about for advanced dementia are life-prolonging care, limited care, and comfort care.

#### *Life-prolonging care*

The goal of this category of care is to prolong life. There are no limits to care. This choice includes everything a modern hospital has to offer to maintain your life. Such procedures include: cardiopulmonary resuscitation or CPR in which a doctor pushes on your chest when the heart stops and will often use electricity to shock the heart. Being placed on a breathing machine, also known as life support, in which a tube is placed down your throat into the lungs. And other medical procedures performed in the intensive care unit or ICU. The goal is to prolong life.

#### *Limited care*

The goal of this category is to maintain physical and mental functions. Care will depend on your physical and mental functioning. Such care includes intravenous (IV) therapies like antibiotics, feeding tubes and hospitalization. But does not include CPR and ICU care. The goal is to maintain physical and mental functioning.

#### *Comfort care*

The goal of this category is to maximize comfort. Only measures that comfort or relieve pain are performed. The aim is to relieve pain and to be kept as pain-free as possible. Comfort care does not include CPR respirators, ICU care, and generally would not include IV therapy, feeding tubes, or hospitalization. The goal is maximizing comfort and relieving pain.