Using Video Images of Dementia in Advance Care Planning

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Background: Advance care planning is a process by which patients plan for future medical care under circumstances of impaired decision-making. Central to this process is the patient’s understanding and ability to imagine future health states.

Methods: A before and after oral survey was used to compare the effect of a video depiction with that of a verbal description of a patient with advanced dementia for individuals selecting level of medical care at 7 primary care clinics at 2 US medical centers. The study enrolled 120 adults, half of whom were nonwhite.

Results: A total of 120 subjects completed the interview. Before watching the video, 60 (50.0%) subjects preferred comfort care, 25 (20.8%) desired life-prolonging care, 22 (18.3%) chose limited care, and 13 (10.8%) were unsure of their preferences. Subject preferences changed significantly after the video: 107 (89.2%) of the subjects chose comfort care, none desired life-prolonging care, 10 (8.3%) chose limited care, and 3 (2.5%) were unsure of their preferences (P < .001). Unadjusted analysis revealed a statistically significant difference regarding preferences, based on race/ethnicity, before watching the video: 40% of African Americans and 43% of Latinos chose comfort care, compared with 58% of whites (P = .04). Differences were also noted for educational level (P = .03). After the video, differences in preferences based on race/ethnicity and educational level disappeared.

Conclusions: Watching the video significantly changed preferences for care, transcending apparent differences in preferences associated with race/ethnicity and educational level. This study suggests that using video in addition to improved verbal communication may lead to more informed advance care planning by enhancing the ability of patients to imagine a hypothetical health state.

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IN THE WAKE OF THE TERRI Schiavo case,¹ both physicians and the public have shown a heightened interest in advance care planning (ACP), a process by which patients plan for future medical care under circumstances of impaired decision making.² Advance care planning entails having a structured discussion regarding hypothetical health states and an exploration of the goals of care, followed by documenting the preferences of the patient in the medical record.³ These discussions often result in the completion of an advance directive, which may include a living will or the designation of a health care proxy.

Current approaches to ACP have unfortunately proven flawed.⁴⁻⁵ The problems plaguing advance directives are well documented, including lack of use and ineffectiveness when used.⁶⁻⁷ More damaging, however, are concerns raising doubts about the underlying premise of ACP, namely, that patients can realistically perceive hypothetical disease states that are often disturbing.⁸ Central to the process of ACP is the patient’s understanding of underlying health states and the ability to imagine future health states. Physicians verbally communicate information about future health states,⁹ and patients must be willing to imagine often difficult and uncomfortable hypothetical scenarios. There is growing recognition that what is needed is a new model of ACP that effectively elicits a patient’s goals of care in particular future health states.

Video is a powerful and underutilized medium that can assist physicians in discussions of future health states. The medium of video engages and allows patients to envision future health states in a manner not captured with verbal communication. We hypothesized that watching a video may enable patients to better vi-
ualize and imagine a future health state by concisely providing complex information vital for ACP.

Advanced dementia is an excellent model in which to test the hypothesis that visualizing a hypothetical health state affects medical decision making. Advanced dementia is an ultimately fatal, progressive, neurologic disease. Patients with advanced dementia are at high risk of developing multiple medical problems over the course of their illness, including aspiration pneumonia, pressure ulcers, and difficulty swallowing. By virtue of their cognitive impairment, patients will seldom be able to participate in decisions about their care at the time problems develop. Healthy patients or patients in the early stages of dementia can, however, influence the treatment they will receive through ACP. Such planning typically asks patients their goals of care and whether they would want specific interventions, such as cardiopulmonary resuscitation, intravenous antibiotics, or a feeding tube, if they had irreversible cognitive impairment and could not recognize family members.

We hypothesized that augmenting verbal descriptions with video images would alter patients’ preferences for care if they developed dementia. We conducted a before and after trial to examine whether a video as a decision aid would be redundant for such subjects. The disease is the optimal means of learning about the disease, the patient is hand-fed pureed food. The digital video was filmed without the use of prompts or stage directions to convey a candid realism. The narrative that accompanies the video was developed by a single physician (A.E.V.) between November 1, 2005, and February 28, 2006, in either Spanish or English. Approval for the project was granted by the institutional review boards of the affiliated hospitals.

**METHODS**

**SUBJECTS**

Patients older than 40 years scheduled to see a general internist at any of 7 study sites were eligible to participate. The study sites consisted of urban and suburban primary care clinics affiliated with 2 teaching hospitals in the greater Boston area. Two of the 7 sites served primarily African-American and Latino populations and were selected to provide an overrepresentation of African-American and Latino patients.

Subjects were excluded if they had had a close relationship with a person with advanced dementia, because they would likely have first-hand experience and knowledge of the disease. In our pilot work, subjects who had had a relationship with a person with advanced dementia had preferences for comfort care before and after watching the video. Because having first-hand experience with the disease is the optimal means of learning about the disease, the video as a decision aid would be redundant for such subjects.

Subjects were also excluded if, in the judgment of the physician interviewer, they lacked medical decision-making capacity at the time of the interview. All interviews were conducted by a single physician (A.E.V.) between November 1, 2005, and February 28, 2006, in either Spanish or English. 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 ACP and dementia literature and from consultations with experts in palliative care, geriatrics, and neurology.

After obtaining informed consent, the interviewer defined advanced dementia in simple language, highlighting functional impairments (Figure 1). He then outlined 3 levels of medical care and the goals associated with each level. The first level, life-prolonging care, aims to prolong life at any cost. It includes all potentially indicated medical care that is available in a modern-day hospital, including cardiopulmonary resuscitation and care in the intensive care unit. The second level, limited care, aims to maintain physical functioning. It includes treatments such as hospitalization, intravenous fluids, antibiotics, artificial hydration, and nutrition, but excludes attempted cardiopulmonary resuscitation and care in the intensive care unit. The third level, comfort care, aims to maximize comfort and to relieve pain. Only measures that comfort or relieve pain are performed. It includes oxygen and analgesics but excludes intravenous therapies and hospitalization unless necessary to provide comfort. All 3 levels of care were verbally described and visually outlined on a computer graphic that was shown to all subjects.

Subjects were asked their preferences in the event that they developed advanced dementia. Subjects not able to select a level of care were documented as “uncertain.” Next, the subjects viewed a 2-minute digital video of a patient with advanced dementia. Subjects were then asked the same question as before about their preferences for medical care. Perceived value of the video was also assessed by asking subjects whether they had a better understanding of the disease after viewing the video, whether they were comfortable watching the video, and whether they thought videos would be helpful for eliciting preferences for care in other diseases. These questions were scored on the following 3-point scale: very helpful, somewhat helpful, and not helpful. Answers to sociodemographic questions were self-reported by the subjects. The survey is available on request.

The 2-minute digital video depicts the salient features of advanced dementia based on the Functional Assessment Staging (FAST) in Alzheimer’s Disease criteria for advanced disease, including inability to communicate understandably with others, inability to ambulate without assistance, and inability to feed oneself. The video depicts a female patient with advanced dementia with her 2 daughters in a nursing home setting. The patient fails to respond to their attempts at conversation. The patient is then shown being pushed in a wheelchair. The patient is hand-fed pureed food. The digital video was filmed without the use of prompts or stage directions to convey a candid realism. The narrative that accompanies the video is identical to that previously used by the interviewer to define advanced dementia. The video was available in both English and Spanish. (The film clip is available online at: http://homepage.mac.com/avolandes/AlzheimersVideo/MovieTheater18.html.) The design, content, and structure of the video intervention were reviewed for accuracy by 3 geriatricians and 5 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. Consent was obtained from the patient’s family before filming her. The final version of the video was shown to study participants on a portable computer.

**Figure 1. Narrative describing advanced dementia.**

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(I am going to describe to you an illness called advanced dementia, like advanced Alzheimer 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 with advanced dementia are not able to move around or walk, get out of bed independently, eat by themselves, or communicate understandably with others. People with advanced dementia often have difficulty chewing or swallowing, and require assistance with feeding themselves. Advanced dementia is an incurable disease and most commonly occurs after many years of Alzheimer disease or as the result of strokes. People are not able to answer any questions or tell you about themselves.)
The primary outcome measure was change in the level of care selected. Secondary outcome measures included change in preferences stratified by socioeconomic factors (age, sex, race/ethnicity, educational level, marital status, religion, religious attendance, and health status) and participants’ perceived value of the video in terms of understanding, comfort, and the usefulness of video images generally for other diseases.

Changes in levels of care selected by subjects before and after watching the video were analyzed with the Bowker test for symmetry, a generalization of the McNemar test for situations involving more than a binary outcome. Confidence intervals (CIs) for proportions were calculated using a normal approximation for a binomial sampling distribution. Crude analysis for subject demographic characteristics were conducted with the Fisher exact test at baseline and after viewing the video. Unadjusted analyses were performed using contingency tables to study the relationship between subject demographic characteristics and their baseline preferences. The relationship between demographic characteristics and baseline preferences were compared using the chi-squared test or Fisher exact test when appropriate. All P values are 2-tailed. Statistical power calculations indicated that 30 subjects would be needed for each racial/ethnic group to detect a 0.20 increase in probability of change (from .05 to .25) in preferences after watching the video. The study was not powered for multivariate analysis. Data were analyzed using SAS software, version 9.1 (SAS Institute, Cary, NC).

SUBJECTS

A total of 197 eligible subjects were approached to participate in the study, of whom 148 (75.1%) agreed to be interviewed. Subjects who declined did not differ significantly from the recruited subjects in terms of age, gender, or race/ethnicity. The most common reason given for not participating was lack of time. Of the 148 subjects recruited for the study, 28 were disqualified because of a close relationship with a person with advanced dementia, resulting in a total of 120 study subjects.

The Table describes the characteristics of the survey sample. Of the 120 subjects, 69.2% were female and 52.5% had a high school education or less. African Americans and Latinos each constituted 25.0% of the study population by design. All of the interviews for Latinos were conducted in Spanish.

OUTCOMES

After hearing a brief verbal description of advanced dementia, 60 subjects (50.0%) preferred comfort care, 25 (20.8%) desired life-prolonging care, 22 (18.3%) chose limited care, and 13 (10.8%) were unsure of their preferences (Figure 2). The subjects’ preferences changed significantly after watching the video: 107 (89.2%) of the subjects chose comfort care, none desired life-prolonging care, 10 (8.3%) chose limited care, and 3 (2.5%) were unsure of their preferences (P < .001).

Of the 120 subjects, 56 (46.7%) subjects (95% CI, 0.38-0.56) changed their preferences or became uncertain of their preferences after viewing the video. None of the subjects who initially chose comfort care changed their mind.

Of the 60 subjects who did not initially choose comfort care, 56 subjects (93.3%) (95% CI, 0.84-0.98) altered their preferences from more aggressive levels of care or from being uncertain to desiring comfort care. No one opted for a more aggressive level of care.

All 25 subjects who chose life-prolonging care before watching the video changed their preferences or became uncertain after viewing the video. A majority, 18

Table. Characteristics of Study Sample*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD)</td>
<td>58 (12)</td>
</tr>
<tr>
<td>Women</td>
<td>83 (69.2)</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>60 (50.0)</td>
</tr>
<tr>
<td>African American</td>
<td>30 (25.0)</td>
</tr>
<tr>
<td>Latino</td>
<td>30 (25.0)</td>
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<tr>
<td>Educational level</td>
<td></td>
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<tr>
<td>Elementary school</td>
<td>19 (15.8)</td>
</tr>
<tr>
<td>High school</td>
<td>44 (36.7)</td>
</tr>
<tr>
<td>College</td>
<td>34 (28.3)</td>
</tr>
<tr>
<td>Postgraduate</td>
<td>23 (19.2)</td>
</tr>
<tr>
<td>Religion</td>
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<tr>
<td>Catholic</td>
<td>53 (44.2)</td>
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<tr>
<td>Protestant or other Christian</td>
<td>39 (32.5)</td>
</tr>
<tr>
<td>Jewish</td>
<td>19 (15.8)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (7.5)</td>
</tr>
<tr>
<td>Marital status</td>
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<tr>
<td>Married</td>
<td>69 (57.5)</td>
</tr>
<tr>
<td>Divorced</td>
<td>14 (11.7)</td>
</tr>
<tr>
<td>Widowed</td>
<td>13 (10.8)</td>
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<tr>
<td>Single</td>
<td>24 (20.0)</td>
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<tr>
<td>Religious attendance</td>
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<tr>
<td>Two times per month or more</td>
<td>62 (51.7)</td>
</tr>
<tr>
<td>One time per month or less</td>
<td>24 (20.0)</td>
</tr>
<tr>
<td>Never</td>
<td>34 (28.3)</td>
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<tr>
<td>Self-reported health status</td>
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<tr>
<td>Very healthy</td>
<td>58 (48.3)</td>
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<tr>
<td>Somewhat healthy</td>
<td>51 (42.5)</td>
</tr>
<tr>
<td>Not healthy</td>
<td>11 (9.2)</td>
</tr>
</tbody>
</table>

*Data are given as number (percentage) unless otherwise indicated.

Figure 2. Patient preferences for level of medical care before and after watching video. Data are given as number (percentage) of 120 subjects in each category. P < .001 for post-video overall results.
subjects (72.0%) (95% CI, 0.51-0.87), chose comfort care after viewing the video.

Among the 22 subjects who initially chose limited care, 18 subjects (81.8%) (95% CI, 0.60-0.95) changed their preferences or became uncertain after the video. The major- ity, 16 subjects (72.7%) (95% CI, 0.50-0.89), changed to comfort care. Two subjects (9.1%) (95% CI, 0.01-0.29) became uncertain. All of the 13 subjects who were unsure of their preferences before viewing the video changed their preference to comfort care after watching the video.

Unadjusted analysis revealed that, before watching the video, preferences varied according to race/ethnicity (P = .04), with 40.0% of African Americans and 43.3% of Latinos choosing comfort care, compared with 58.3% of whites (Figure 3). Preferences also varied by educational level (P = .03). Only 26.3% of the individuals with elementary education and 50.6% of high school and college graduates chose comfort care, whereas 65.2% of postgraduates chose comfort care.

Preferences were also significantly related to religious attendance (P = .03), with those who never attended religious services more likely to choose comfort care (64.7%) than those who attended once a month (39.1%) or more frequently (47.5%). Sex, age, religion, self-reported health, and marital status demonstrated no relationship to pre-video preferences.

After watching the video, all of the significant differences based on race/ethnicity, educational level, and religious attendance disappeared. The video did have a slightly greater effect on single individuals (95.7% chose comfort care) than on married (86.8%) and divorced or widowed (88.4%) subjects (P = .01).

The video was acceptable to the subjects: 93.3% said they were “very comfortable” or “somewhat comfortable,” 98.3% found the video “very helpful” or “some- what helpful,” and 98.3% thought that using videos for other diseases would be either “very helpful” or “some- what helpful.”

This study presents a novel approach to communicat- ing information vital to ACP for advanced dementia. The use of video was associated with a significant and dramatic change in subjects’ preferences for medical care in the event of advanced dementia. Subjects over- whelmingly felt comfortable viewing the video, welcomed the use of video in other medical situations, and indicated greater subjective understanding of dementia.

A key ingredient to informed ACP is the patient’s ability to accurately envision and understand a future health state such as dementia. This often requires imagining a health state that may be unimaginable for many patients. Viewing the video provided information not necessarily communicated through the verbal narrative.

After viewing the video, many subjects changed their preferences for medical care and indicated a greater sub- jective understanding of dementia after the video. The large number of subjects who chose comfort care before and after watching the video also had a greater under-
jects are subjectively better informed about the characteristics of dementia, there is little difference in medical care preferences between other races and whites.

Some have argued that there are values unique to other racial groups that explain their preferences for more aggressive care at the end of life. Our results argue against this claim. If preferences at the end of life were based on values unique to certain groups, then decisions based on those values should not change after viewing the video. Differences in preferences with regard to race/ethnicity, educational level, and religious attendance disappeared after watching the video. The relevant issue may not be diversity of values but diversity in learning, understanding, and communication. Video offers an additional modality by which to communicate health status accurately, objectively, and concisely.

Our study has several important limitations. Video clips can be manipulated to favor a particular perspective. To minimize the introduction of bias in the filming of the patient, the video was filmed and edited with close collaboration with expert geriatricians and neurologists. All filming and editing were done by the principal investigator (A.E.V.) in the cinema verité style of documentary film-making, which is a technique of filming that avoids the use of special effects or staging. Nonetheless, the use of video inherently involves aesthetic biases.

We also did not test the robustness of our findings using other video clips that varied the features of the patient, such as race/ethnicity, sex, and nursing home setting. In addition, our before and after study design did not isolate the effect of the video alone. We also did not study more detailed verbal descriptions of advanced dementia or the option to choose specific interventions. Instead, we attempted to recreate realistic discussions that occur clinically, focusing on brevity and the overall goals of care.

In addition, our sample was drawn from the metropolitan Boston area and included primarily middle-aged subjects. Attitudes toward the use of video and preferences for advanced dementia may differ by geographic location and age. Finally, our sample also did not include other large ethnic groups such as Asian-Americans.

Our use of video portrays the illness with a sense of verisimilitude that may be lacking in verbal descriptions. Previous uses of video have primarily focused on risks and benefits of procedures, and, to our knowledge, no previous study has investigated the use of video in ACP. Our use of video represents a different conceptual role for the medium. Furthermore, unlike previous efforts in ACP that have placed greater weight on the risks and burdens of possible medical interventions, our use of video redirects attention to the underlying health state, which is usually an unknown health state to patients. Video adds a textured portrait to be incorporated into the physician-patient discussion.

The next step in using videos for ACP is to investigate whether patients would be willing to document their preferences in the medical record or to complete an advance directive after viewing the video. Additional directions for this line of research would be to explore subject knowledge of dementia and decisional conflict before and after watching the video to more accurately measure the influence of the video. Furthermore, studying the stability of subject preferences longitudinally after watching the video would be of interest, especially because the subject matter and video may elicit an emotional response rather than reasoned judgment. Future studies might also include using the video in primary care settings with older subjects or subjects in the early stages of dementia who are randomized to an unexposed group without the video or to an exposed group with the video. Our present study and findings must be interpreted in the context of the study design, which was to examine the influence of a video in ACP.

Video offers an additional tool for physicians to use in their discussions of medical conditions and ACP. We suspect that numerous other diseases that are equally foreign to the illness experiences of patients, such as the persistent vegetative state and severe strokes, would also be more accurately conveyed to patients through a visual medium than solely by verbal descriptions. Many patients do not have any experience with these devastating diseases, and videos could better inform decision making for these hypothetical health states. Questions regarding the content of these videos, how they would be filmed, and who would approve them, must be carefully considered before expanding the use of video to other diseases. Close deliberations among caregivers of such patients, expert physicians, and film-makers is a first step toward answering these vital issues.

As patients seek ways to articulate and make known their preferences, it is the responsibility of the profession to help them make informed decisions. Using videos to ensure that patients accurately understand underlying health states is a promising step toward medicine’s commitment to respecting patient autonomy.

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Author Contributions: Dr Volandes had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: Volandes, Lehmann, and Gillick. Acquisition of data: Volandes. Analysis and interpretation of data: Volandes, Lehmann, Cook, Shaykevich, Abbo, and Gillick. Drafting of the manuscript: Volandes, Abbo, and Gillick. Critical revision of the manuscript for important intellectual content: Volandes, Lehmann, Cook, Shaykevich, Abbo, and Gillick. Statistical analysis: Volandes, Cook, and Shaykevich. Obtained funding: Volandes. Administrative, technical, and material support: Volandes, Lehmann, and Abbo. Study supervision: Volandes, Lehmann, and Gillick.

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REFERENCES

Errors in Figure. In the Original Investigation titled “Using Video Images of Dementia in Advance Care Planning” by Volandes et al, published in the April 23, 2007, issue of the Archives (2007; 167[8]:828-833), errors occurred in Figure 3 on page 831. In the pie charts printed in Figure 3, the portions of the post-video pie charts that were shaded to represent life-prolonging care should have been shaded to represent limited care. The corrected figure is reprinted here.

Figure 3. Patient preferences, based on race/ethnicity, for level of medical care, before (P=.04) and after (P=.16) watching video.