

Use of a values inventory as a discussion aid about end-of-life care: A pilot randomized controlled trial

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(RECEIVED June 29, 2015; ACCEPTED July 18, 2015)

ABSTRACT

Objective: We examined the utility of a brief values inventory as a discussion aid to elicit patients' values and goals for end-of-life (EoL) care during audiotaped outpatient physician–patient encounters.

Method: Participants were seriously ill male outpatients ($n = 120$) at a large urban Veterans Affairs medical center. We conducted a pilot randomized controlled trial, randomizing 60 patients to either the intervention (with the values inventory) or usual care. We used descriptive statistics and qualitative methods to analyze the data. We coded any EoL discussions and recorded the length of such discussions.

Results: A total of 8 patients (13%) in the control group and 13 (23%) in the intervention group had EoL discussions with a physician ($p = 0.77$). All EoL discussions in the control group were initiated by the physician, compared with only five (38%) in the intervention group. Because most EoL discussions took place toward the end of the encounter, discussions were usually brief.

Significance of results: The outpatient setting has been promoted as a better place for discussing EoL care than a hospital during an acute hospitalization for a chronic serious illness. However, the low effectiveness of our intervention calls into question the feasibility of discussing EoL care during a single outpatient visit. Allowing extra time or an extra visit for EoL discussions might increase the efficacy of advance care planning.

KEYWORDS: Advance care planning, Terminal care, Randomized controlled trial, Veterans, Outpatients, Ambulatory care

INTRODUCTION

A meaningful and ongoing discussion about the end-of-life (EoL) values and care preferences of patients with advanced illness is a key element of advance care planning (ACP). ACP is a process employed to ensure that future medical care, particularly in the

event that patients are unable to make their own decisions, is based on explicit knowledge of the seriously ill patient's beliefs, values, and goals of care (Emanuel et al., 2000; Fried et al., 2009). Several studies have shown that ACP can lead to improved patient–provider communication and satisfaction with EoL care, and that engaging patients in EoL discussions increases the likelihood that future care is consistent with their care preferences (Newton et al., 2009; Chan & Pang, 2010; Detering et al., 2010; Carr, 2012). However, many patients and

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providers avoid EoL discussions (Curtis & Patrick, 1997; Cherlin et al., 2005; Fryer-Edwards et al., 2006; Back et al., 2007; Zhang et al., 2009; Huskamp et al., 2009) or postpone them until death is impending (Curtis et al., 2005; Selman et al., 2007; Glass & Nahapetyan, 2008; Yuen et al., 2011; Obler et al., 2012; Barakat et al., 2013). Studies have shown that fewer than 40% of patients with such serious illnesses as advanced cancer discuss EoL wishes with their physicians (Ruddick, 1999; The et al, 2000; Knauff et al., 2005). When EoL discussions do not take place, physicians are often unaware of their patients' EoL wishes and may use unwanted and futile therapies to prolong life (Harrington & Smith, 2008; Mack et al., 2010; Braun & McCullough, 2011).

Beginning a conversation about EoL care wishes may be difficult, and using a structured tool to elicit and document EoL values and preferences of seriously ill patients could be helpful. A growing body of evidence suggests that active participation of patients in decisions regarding their care leads to greater satisfaction with quality of care and a higher concordance between patients' care preferences and actual care received (Street & Voigt, 1997; Brown et al., 2012). Several randomized controlled trials on shared decision-making and treatment decisions have found that patient-targeted interventions such as question prompt sheets and decision aids can be effective in enhancing the decision-making process (McJannett et al., 2003; Clayton et al., 2007; Volandes et al., 2013; Walczak et al., 2013). However, relatively few studies have explicitly focused on interventions for the primary care setting (Tierney et al., 2001; Auer, 2008), and almost all have been focused on cancer patients. Thus, designing tools to engage patients with an advanced illness in care planning to facilitate effective communication between physicians and patients is certainly important. Previously, several investigators (Doukas & McCullough, 1991; Pearlman et al., 2005) have developed "value histories" to guide EoL decision making. However, few brief instruments exist that can be used to assess patients' values and to guide physicians in more ethical decision making for end-of-life care. The goal of our study was to examine the usefulness of a brief "values inventory" (VI) to elicit patient values and goals for EoL care and use it as a discussion aid during an outpatient physician–patient encounter to stimulate and facilitate EoL care discussions.

METHODS

Sample and Setting

After obtaining IRB approval from Baylor College of Medicine and the Veteran Affairs (VA) Research

and Development Committee at the Michael E. DeBakey VA Medical Center (study protocol number H-14348; clinical.trials.gov registration number NCT00122135), the investigators conducted this study at the latter site in Houston, Texas. Some 10 subspecialists (two each from cardiology, pulmonary/critical care, oncology, gastroenterology, and geriatrics) and 10 general internists were recruited. We recruited six patients from each physician panel ($n = 120$) with the respective physician's permission. Using a simple random number table, we randomized three of these patients to receive the VI and three to receive usual care. We oversampled for patients belonging to ethnic minorities to achieve a more diverse sample to represent the major ethnicities (African American, Hispanic, and White) served at the Houston Veterans Affairs Medical Center. After obtaining permission from the physicians, we screened their outpatient panels for seriously ill patients who were 55 years or older. Patients' physicians were not involved in the recruitment or consenting process other than allowing the research team access to screen their patients' electronic charts for eligibility. Potentially eligible patients received a postcard asking about participation in a study on decision making for ACP that included an opt-out phone number. If they did not opt out, trained research assistants called patients to explain the study and to obtain preliminary consent to participate. Screen-eligible patients were separated into three lists: patients likely to be white, African American, and Hispanic (per chart review); however, ethnicity was ultimately determined by self-identification. We aimed to achieve at least representative participation of all the major ethnic groups served at our VA center through purposive sampling and oversampling of minority patients.

We adopted inclusion criteria similar to those used in the SUPPORT study (Murphy et al., 1990) to recruit seriously ill patients with a 6- to 12-month life expectancy. Many patients would have been eligible for hospice care. We included patients with the following diagnoses: (1) congestive heart failure, with an ejection fraction less than 25% and at least one previous hospitalization for the condition; (2) chronic obstructive pulmonary disease/emphysema, who had required mechanical ventilation, with at least two past hospitalizations; (3) chronic liver disease with cirrhosis and ascites; (4) any metastatic solid tumor (e.g., colon carcinoma with liver metastases) and non-small-cell lung cancer, stage IIIb or IV; and (5) end-stage renal disease on hemodialysis.

Patients with dementia were excluded from participation because they would not be able to explain in sufficient detail the reasons for their healthcare decisions. We screened patients for dementia with the

Mini-Mental State Exam and excluded those with a score of 24 or less or a diagnosis of dementia listed in the patient's chart. The study site had no structured interventions or automatic reminders to clinicians in place at the time of our study.

Development of the Values Inventory (VI)

A values inventory (VI) is a tool used in self-assessment that allows patients to rate different values according to their relative importance. It gives the treating physician information about what is important to the patient and can thus be used as a discussion aid about ACP. Few brief instruments exist that can be employed to assess patients' values to guide clinical decision making. Doukas and McCullough (1991) developed a short values history geared specifically to EoL decision making. Pearlman and colleagues (2005) designed a similar but lengthier values history pertaining to EoL decision making integrated with more extensive information on EoL care. Two of the investigators (LM, UB) adapted the Doukas/McCullough and Pearlman values histories after reviewing both to develop a brief and culturally sensitive VI (see Appendix). We also combined empirical data from our ethnically diverse interviews (Braun et al., 2014) with the existing value histories. The ensuing product was tested with 10 patients (4 African Americans, 3 whites, and 3 Hispanics) and rewritten multiple times based on patient feedback. It was intentionally kept to just one page and at a 7th- to 8th-grade reading level.

Study Design

We followed the CONSORT guidelines for randomized controlled trials (Rennie, 2001). Patients were randomized into two arms: (1) the usual-care group (no intervention, 60 patients), and (2) the VI group (intervention group, 60 patients), who received and completed the discussion aid while waiting for their appointment. Patients in the intervention group were given explicit verbal instructions to use the VI as a starting point for future care planning with their physician during their visit. They also received explicit instructions to discuss the VI at the beginning of the visit. All patient-physician encounters were audiotaped with a small and unobtrusive boundary microphone. Study personnel placed the recording equipment and left the room. Physicians were not blinded to patients' assignments (because the patient was supposed to show them the VI and discuss it), but they did not know a priori if the patient had been assigned to the VI or usual-care group at the outset of the encounter. To avoid biasing physicians' behavior toward usual-care patients after interacting with

patients who were given the VI, we recorded all encounters of a participating physician with his usual-care patients first before taping the encounters with VI patients. After the encounters, the research team listened to the tapes. The tapes were then professionally transcribed and stored, according to Veterans Health Administration regulations. During transcription, all names mentioned were removed to maintain privacy.

Analysis

We used descriptive statistics and qualitative methods to analyze the data. A qualitative approach was best suited for our analysis because it allowed us to gain an in-depth understanding of how the values inventory was utilized during the patient-physician encounters. We conducted qualitative content analysis using a consensus-based coding approach to describe EoL discussions (Elo & Kyngas, 2008). All transcripts were carefully reviewed individually by all authors to identify and code text containing any EoL discussion. After identifying transcripts with any EoL discussion, we carefully coded the transcript line by line, marking any passages with EoL discussions. We coded transcripts as having an EoL discussion when a patient or a physician talked directly about any of the following: (1) patient wishes about EoL care, (2) clarification of EoL care preferences, (3) limited life expectancy or other prognostic information, (4) consideration of any future life-prolonging treatments, and (5) hospice care. We used an iterative process of rereading and recoding passages until a final consensus was reached. The investigators met regularly to discuss the codes and to reach consensus when there were disagreements. We documented the amount of time spent on EoL discussions (based on a word count) versus the amount of time spent on medication-related conversations (refills) and all other interactions, and thus calculated the length of the EoL discussion during the encounter. If the length of an EoL discussion (based on word count) was less than a quarter (<25%) of the total words in an encounter, it was coded as brief; if the EoL word count was 25–50% of the total discussion, it was coded as moderate; and if the EoL word count was >50% of the total discussion, it was coded as long. One goal of the VI was to empower patients to initiate an EoL discussion. We therefore also recorded information about the initiation of EoL discussions (initiated by the patient vs. by the physician) and the timing of such a discussion (at the beginning, in the middle, or toward the end of an encounter). We used ATLAS.ti 6.1 software (Scientific Software Development, Berlin, Germany) for data management.

RESULTS

See [Figure 1](#) for a flowchart of the study participants and their participation. Three patients from the intervention group declined to participate after initial consent (intervention group $n = 57$). Approximately 10% of patients listed as white, 50% as African American, and 80% as Hispanic who had been screened as study-eligible were randomly called and asked to participate. Participants in both groups did not have significant differences in demographic and clinical characteristics ([Table 1](#)). All participants were men. Most patients in both groups were white, followed by African Americans and Hispanics, consistent with the demographics at our VA Medical Center. More than two thirds of patients in both groups had either congestive heart failure or chronic obstructive pulmonary disease as their primary diagnosis.

A total of 8 patients (13%) in the control group and 13 patients (23%) in the intervention group had EoL discussions with their physician. The difference between the groups was not statistically significant ($p = 0.77$). Family members were present at almost half of the encounters (31/60 in the control group and 33/57 in the intervention group). However, the presence of a family member did not seem to have any systematic influence on the duration or quality of an encounter in either group.

Of the 13 patients in the intervention group who had an EoL discussion with their physician, none used the VI as instructed (i.e., at the beginning of the encounter). In a typical encounter, the physician started the conversation with a review of the health records and medication-refill status. End-of-life discussions occurred mostly at the end of a visit (see [Example 1](#)).

None of the EoL discussions in the control group were initiated by a patient ([Table 2](#)). While all patients in the control group relied on the providers to initiate discussion of EoL issues, 8 (62%) of the 13 discussions in the intervention group were initiated by the patient (see [Example 2](#)). However, after bringing up the VI, patients expected the physician to lead the discussion from there on. Thus, most patients did not discuss quality-of-life values in detail, as described in the values inventory.

Most encounters were focused on medication review, reconciliation, refills, and immediate clinical concerns. The average length of each visit was less than 20 minutes (range = 10–35 minutes). On average, at least 20% of the encounter time was spent on medication-related questions. The amount of time spent on EoL discussions in both groups was modest ([Table 2](#)). Most EoL discussions in both groups were brief and lasted for less than 25% of the encounter time. Patient-initiated EoL conversations happened at the end of visits, and in some cases the EoL discussion seemed introduced “out of the blue,” even when

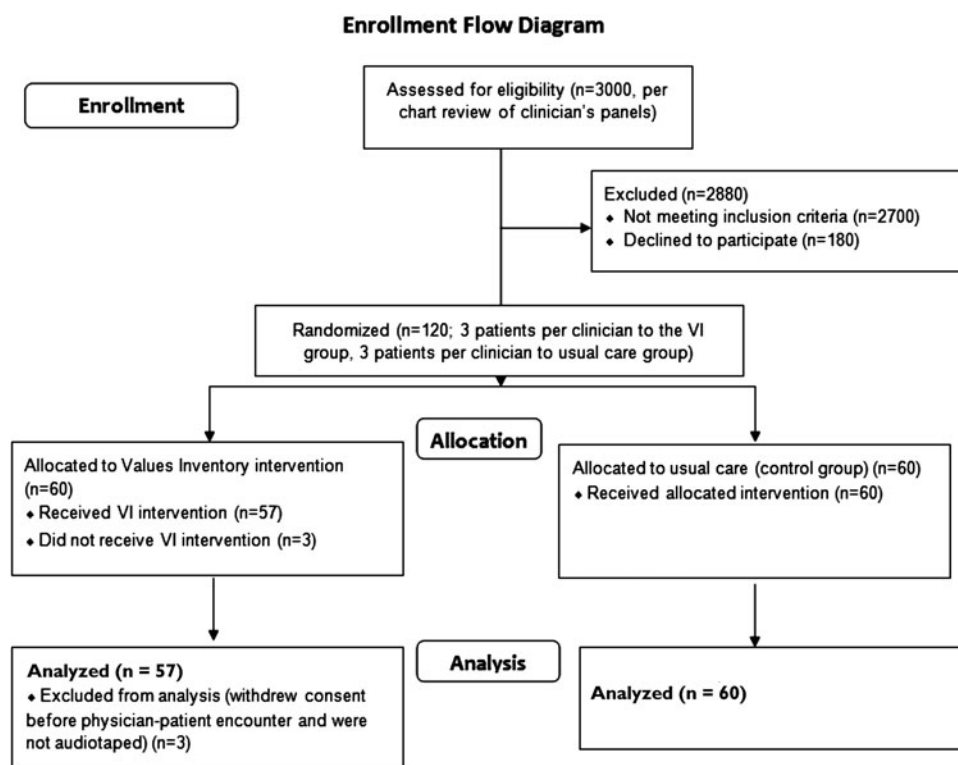


Fig. 1. Enrollment flow diagram.

Table 1. Participant characteristics

Characteristics	Control Group (<i>n</i> = 60)		Intervention Group (<i>n</i> = 57)†		<i>p</i>
	<i>n</i>	Range	<i>n</i>	Range	
Mean age	68.4	56–84	66.4	55–85	0.19
Race/ethnicity					0.46
Black	21	35	16	28	
Hispanic	14	23	13	23	
White	25	42	28	49	
Clinical characteristics: Diagnosis					0.39
CHF with EF < 25% *	25	42	28	49	
COPD with FEV1 < 35% [§]	19	32	14	25	
Cancer	7	12	7	12	
Renal failure	6	10	4	7	
Cirrhosis of the liver	3	5	4	7	

† **Note.** Three patients from the intervention group declined to participate in the study after recruitment, leading to only 57 who completed the study. All patients would have been hospice eligible

* CHF = congestive heart failure; EF = ejection fraction.

§ COPD = chronic obstructive pulmonary disease; FEV1 = forced expiratory volume in the first second.

it was physician-initiated and not prompted by use of a VI, with no “leading-up” conversation, and often they did not go into any depth (see [Example 3](#)).

Despite nonsignificant results in terms of number of EoL discussions, there were differences in that some conversations led to clarification of EoL treatment options. Some 9 of 13 EoL discussions in the intervention group as opposed to 3 of 8 in the control group led to clarification of treatment options, even though the discussions were not detailed and documentation of expressed EoL wishes might not have been systematic. In many cases, the physician also urged the patient to talk to a social worker to more formally document his preferences.

Table 2. Physician–patient EoL discussions

Characteristics of EoL Discussions	Control Group (<i>n</i> = 8)		Intervention Group (<i>n</i> = 13)	
	<i>n</i>	%	<i>n</i>	%
Initiated by physician	8	100	5	38
Length (word count)				
Brief	5	63	8	61
Moderate	2	25	4	31
Long	1	13	1	8
Clarified treatment options	3	38	9	69

Note. The 8 in the control group represented 13% (8/60) of all patients in the group, and the 13 in the intervention group represented 23% (13/57) of all patients in the group. Three patients in the intervention group declined to participate in the study after recruitment.

DISCUSSION

This was a pilot randomized controlled trial to test a brief values inventory as a discussion aid and conversation starter during an outpatient physician–patient encounter to facilitate EoL conversations. We found no significant difference in number of EoL discussions between groups. Despite the fact that the intervention group had completed the VI, less than a quarter of those patients used it as instructed to discuss with their physician, and none of them brought it up, as instructed, at the beginning of their visit. When patients had EoL discussions, the VI helped 9 of 13 patients to clarify their EoL treatment options versus only 3 of 8 patients in the control group. Although the VI helped some patients to initiate EoL conversations, it did not lead to an in-depth discussion about future care preferences.

There are several reasons why the patients in our study might not have used the VI. First, we found that a primary care visit may not have been the ideal place to discuss EoL issues. Although familiarity with the primary care setting and an established relationship with the primary care provider is expected to make EoL discussions easier (Smucker et al., 1993) and the primary care setting is the suggested “ideal” setting for discussing EoL care planning (Auer, 2008), the duration of office visits was short, and there were constant interruptions (pagers, phone calls, nurses interrupting visits by relaying messages). Physicians devoted most of their time to addressing immediate medical needs and did not appear to have enough time for a thoughtful discussion of EoL care. Second, discussing ACP might not have

Example 1. (Intervention Group): EoL Discussions Happened at the End of Visit

DR Any questions for me?
 PG Oh, other than these questions here.
 PT Possibly go over them or something?
 DR I think that this is for the research protocol?
 PG Yeah.
 PG2 She said to ask you questions.
 DR It's a good idea for a living will or an advance directive to be on file permanently.
 PT No, I think they, we did it one time.
 DR One time? Okay. I'm going to check with Social Work over here, and, if need be, they'll get in touch with you to do a permanent one.
 PG Yeah.

[INAUDIBLE] [TYPING/COMPUTER MOUSE]

[PAPERS RUSTLING]

PG And—
 PT Can I have the antibiotic prescription downstairs?
 DR Uh, for you to pick up? Yes.
 PG Yes.
 PG [INAUDIBLE] Okay.
 24 TG

Note. DR = physician, PG = family member, PT = patient.

been one of the patient's top priorities for their visit, as opposed to medication refills and discussion of symptoms. We do not believe that patients did not bring up the VI due to insufficient time to think about their goals and values—most had about an hour between filling out the VI and the encounter.

Despite receiving specific instructions to use the VI at the beginning of encounters, most patients waited until the very end of the visit to bring up the inventory, and some showed it to their physicians then. It is possible that most physicians were unprepared to carry out this difficult conversation at the conclusion of a visit and did not have enough time for an in-depth discussion about EoL care at that point. Thus, the discussions were brief and hurried, as physicians were pressed to move on to their next patient. Although this intervention was designed to empower patients to initiate an EoL discussion, most patients did not do so, and if they initiated a discussion at all, they accepted a very brief response if the clinician did not want to engage further. The hesitation of patients to initiate a

discussion about advance care planning is well documented. It is possible that most patients find it difficult to break the normative role expectations, with the physician leading the discussion about the patient's care. Although previous studies have found that such patient-targeted decision aids as instructional videos or question prompt lists (McJannett et al., 2003; Clayton et al., 2007; Volandes et al., 2013; Walczak et al., 2013) can facilitate EoL decisions, we found that an intervention targeted at patients alone was unsuccessful. A whole-systems approach directed at patients, physicians, and optimally even potential future surrogate decision makers might be more effective, but this was beyond the scope of our pilot study.

LIMITATIONS

Our study has several limitations. First, being conducted at a VA facility, the sample included only men and was done at a single site. The nature of this sample may limit generalizability to women,

Example 2. (Intervention Group): How the Values Inventory Was Used

- DR This is for you to fill out. Not with me.
- PG We already did.
- PT Well, she said we're supposed to go over them.
- PG2 She said to ask you questions.
- DR Oh, ask me the questions?
- PT Or either you ask us or something.
- PG It was—
- PG2 To go over the questions with them.
- PG So you have an idea what we did.
- DR Oh, that's right. I understand now. Okay.
- PG So if you need to add anything to his file, they would see it.
- DR Let me read through them. Do you have, uh, directives for, you know, advanced life support? Have you filled out that—?
- PT I don't want life support. It's going to get—
- DR You do not want—
- PT If it gets that far, she knows it.
- DR Uh-huh. And have you filled out before—
- PT I think I did.
- DR Okay. Have you worked—
- PG I think we have.
- DR Have you done that through Social Work over here?
- PT Yeah, I've—
- PG We haven't talked to social workers.
- DR They filled it out when you were an inpatient in the hospital.
- PG Right.
- PT Yeah, I believe it was.
- DR Well, usually, when you make statements like these, it's a good idea to have a, uh, living will or an advance directive to be on file permanently. When you're in the hospital as an inpatient, the ones that the residents get from you is only valid for that hospitalization, and when you get discharged that's obsolete.
- PT No, I think they, we did it one time.
- DR One time? Okay. I'm going to check with Social Work over here, and, if need be, they'll get in touch with you to do a permanent one.
- PG Yeah.
- DR Which will help her to perhaps, uh, quote your wishes in a written fashion, and, if need be, if in the future you decide to withdraw that or change your mind about what you would like to be done—
- PT Uh-huh.
- DR You can always do it.
- PG Well, we know what the will—
- PT No, I don't—
- PG If he's going to be a basket case for the rest of his life, you would want, you're the same way.
- DR That's what I would recommend you to do anyway, given the, uh, you know, circumstances with your heart and, uh, the severity of the pump function that you have.

Example 2. Continued

- PT Yeah.
- DR That's what I recommend to my heart failure patients. If it were to be determined to be futile, for people not to remain on life support, and, uh, if the physicians determine that the likelihood of recovery is low, in a meaningful way—
- PG Exactly.
- DR Then not to continue with futile—
- PT Right.
- DR Care.
- PT Right.
- DR And that would be my recommendation. If the physicians determine the advanced life support to be futile, the—
- PG Well, he doesn't want a transplant, either.
- DR No, right.
- 103 CS

Note. DR = physician, PG = family member, PT = patient.

Example 3. (Control Group): How an EoL Conversation Was Initiated by Physicians

- Dr: Okay, You are taking Dulcolax?
- PT: And a stool softener.
- Dr: Softener. And you are taking, uh, you are taking Colace. Okay, Okay, uh, and no chest pain, right?
- Dr: Okay, good. Something else we probably need to discuss. Have you ever discussed your end of life, uh, directives? What you want to have done in case your heart stops beating, or do you want to, uh, have them shock you and have CPR or put a tube down your throat if you stop breathing or—
- PT: Uh, do ever what's necessary, I suppose.
- Dr: Huh? Do what's, whatever is necessary?
- Pt: Yeah.
- Dr: Okay, Yeah, you want to be full code, then. Anything that they can do.
- Pt: Yeah
- 54 MS

Note. DR = physician, PG = family member, PT = patient.

those seeking medical treatment in other geographic regions, and those in other healthcare systems. However, we purposefully recruited a diverse group of patients in terms of ethnic composition, as well as type and severity of illness. By excluding patients who had completed advance directives from our sample, we attempted to include patients with limited ACP engagement. While it is possible that some patients

might have had prior information about ACP and were more familiar with the ACP process than others, we did not specifically capture this. Additionally, provider characteristics such as age, experience, training, and gender also have the potential to influence EoL discussions. Given our small sample size, we were unable to specifically analyze provider characteristics.

CONCLUSIONS

A brief values inventory with instructions to seriously ill patients to use it as a discussion aid about EoL care in a Veterans Administration outpatient clinic setting did not significantly increase physician–patient conversations about EoL care. Future interventions should focus on engaging both physicians and patients and might be more effective if time is dedicated during the encounter to EoL care planning. Additionally, an opportunity to engage the family members who might be present during a patient visit should be sought as well and might offer a chance to at least clarify a potential surrogate decision maker. Certainly, appropriate documentation of EoL values and wishes is critical in advance care planning.

ACKNOWLEDGMENTS

Thanks are extended to the patients and providers who took part in our study. This project was supported by the Department of Veterans Affairs, Veterans Health Administration, Health Services Research and Development Service, grant IIR –02-224 (Ursula Braun, Laurence McCullough). Dr. Braun was also supported by a Geriatric Academic Career Award (KO1HP20480) through the Health Resources and Services Administration. This research was also supported in part by resources at the VA Health Services Research and Development Center for Innovations in Quality, Effectiveness, and Safety (#CIN 13-413) at the Michael E. DeBakey VA Medical Center in Houston, Texas. Dr. Menon was supported by a Keck Center's Agency for Healthcare Research and Quality training fellowship in patient safety and quality. The views expressed in this article are those of the authors and do not necessarily represent the views of the Department of Veterans Affairs, the U.S. government, the Health Resources and Services Administration, or Baylor College of Medicine.

The preliminary results of our study were presented in part at the Annual Scientific Meeting of the Gerontological Society of America held in New Orleans, Louisiana, on November 19, 2012.

AUTHOR CONTRIBUTIONS

This project was conceptualized and led by Dr. Ursula Braun. Drs. Braun, McCullough, Beyth, and Ford contributed to the study concept and study design. All authors were involved in the data analysis. Manuscript preparation was done primarily by Drs. Menon and Braun, but all authors participated in preparing the final version of the manuscript.

COMPETING INTERESTS

Neither the principal investigator nor any coauthors have any conflicts of interest, including specific

financial interests and relationships and affiliations, relevant to the subject matter or materials discussed in this manuscript.

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APPENDIX

Values Section

Values are things that are important to us in our lives and our relationships with others—especially loved ones. Some values may be important in decisions about medical treatment and care when you are seriously ill. The purpose of this form is to help

you make sure that the people who decide your medical care (your family or friends) know what your values are, when you can no longer decide for yourself. We invite you to identify your most important values here.

A. Basic Life Values—Which of the following two statements is more important to you?

I want to live as long as possible, even if this means my quality of life is poor or may become worse.

I want to preserve as good a quality of life as possible, even if this means that I may die sooner.

B. Quality of Life Values—Many values help us define for ourselves what is important for our quality of life. Please review this list and feel free to either go

into more detail or add to it under item L. **For each row, check (✓) one answer indicating how important each value is to you.**

	Not Important	Somewhat Important	Very Important	Extremely Important
A. I want to remain able to think clearly.				
B. I want to avoid unneeded pain and suffering.				
C. I want to be treated with respect and dignity when I can no longer speak for myself.				
D. I do not want to be a financial burden on my family.				
E. I want to be able to make my own decisions about my medical care.				
F. I want to be with my loved ones before I die.				
G. I want to make decisions about my medical care with help from my family members or friends of my choice.				
H. I want to leave good memories of myself to my loved ones.				
I. I would like my religious or spiritual advisor (for example, a priest, pastor, rabbi, imam) to help me make decisions about my medical care.				
J. I want to be treated with respect for my religious beliefs and customs.				
K. I do not want to be a caregiving-burden on my family.				
L. Please add other values that are important to you or explain values above:				

C. Please circle the four most important values to you from section B (items A–L).