

Knowledge and attitudes toward end-of-life care in veterans with symptomatic metastatic cancer

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ABSTRACT

Objectives: The purposes of this study were to study symptomatic metastatic cancer patients' knowledge and attitudes toward end-of-life (EOL) care and to examine how patient-perceived health status affects attitudes toward EOL care and survival.

Methods: From 1999 to 2002, 254 symptomatic metastatic cancer patients at the VA New Jersey Health Care System completed the Vermont Voices on Care of the Dying Questionnaire. Survival status and location of death were obtained. Descriptive statistics and the chi square method were used to assess the differences between African Americans ($N = 109$) and Caucasians ($N = 135$), and between different patient-perceived health status groups. A log-rank test was performed to assess for differences in median survival length between different patient-perceived health-status groups.

Results: Veterans' responses to the Vermont questionnaire showed knowledge deficits regarding EOL care. There was wide variation in self-rankings of health status: 45.6% of patients rated their illness as serious and life threatening, 18.9% considered their health problem significant but not life threatening, 2.8% thought they were in good health, and one-third of patients were unsure about their health status. Most patients (86.2%) preferred physician frankness when communicating bad news and 61.8% preferred family involvement in EOL discussions. African American patients were less likely to have completed advance directives ($p < 0.0001$), to have knowledge about hospice programs ($p < 0.00001$), and to feel capable of assessing their health situation ($p = 0.04$). Patient-rated health status affected completion rates of advance directives and survival.

Significance of the research: These findings demonstrate knowledge deficits and racial differences in attitudes and values toward EOL care in veterans with cancer. The Vermont questionnaire enables patients to state their EOL preferences but may not be detailed enough for clinical applications. Patient-rated health status may be an important explanatory variable for EOL preferences and length of survival.

KEYWORDS: Knowledge, Attitudes and values about end of life care, Survival length, Health status, Racial disparity, Advanced veteran cancer patients

INTRODUCTION

High quality palliative care emphasizes honoring patient preferences and communication. Significant end of life (EOL) knowledge deficits have been documented in different patient population (Gamble et al., 1991; Uhlmann & Pearlman, 1991; Blackhall et al., 1995; Schonwetter et al., 1996; Hoffmann et al., 1997; Patrick et al., 1997; Fried et al., 1999; McKinley et al., 2000; Silveria et al., 2000; Wilson, 2000; Steinhauer et al., 2001; Schwartz et al., 2002; Vig et al., 2002), and the determinants of patient preferences are unknown (Hamel et al., 1999). Race has been correlated with levels of knowledge and preferences for life sustaining treatments (Emanuel, 1991; Blackhall et al., 1995; Hoffmann et al., 1997; Hornung et al., 1998; Hopp & Duffy, 2000; McKinley et al., 2000; Silveria et al., 2000; Waters, 2001). Caucasians usually had better understanding of EOL care options, less life-sustaining treatments, better communication with health professionals, and were more likely to complete living wills (Blackhall et al., 1995; Hoffmann et al., 1997; McKinley et al., 2000; Silveria et al., 2000). Another interesting explanatory factor may be patient perception of health status. In an interview study of hypothetical scenarios, patient perceptions of health status were important in their formulation of end-of-life preferences (Patrick et al., 1997).

Little is known about knowledge and attitudes toward EOL issues in veterans. It is important to study the palliative care needs of this population. Veterans account for a large percentage of deaths in the United States. The veteran population has a higher mortality rate (Fisher & Welch, 1995), reflects the lower 10% of the socioeconomic strata (Harris et al., 1989), and has poor health status scores compared with non-veteran populations (Kazis et al., 1998).

The Vermont Voices on Care of the Dying Questionnaire (Vermont Ethics Network, 1997) was developed to elicit knowledge and attitudes about EOL care from communities. We prospectively collected patient responses to the Vermont Voices on Care of the Dying Questionnaire to better characterize the preferences of veterans with metastatic cancer. The data was collected as part of demographic data in a cohort of symptomatic metastatic cancer patients who participated in the Unmet Needs Project (S.S. Hwang, V.T. Chang, Q. Zhang, Y. Alejandro, P. Osenenko, J. Cogswell, E. Morales, S. Srinivas, & B. Kasimis, submitted) at the VA New Jersey Health Care System (VANJHCS).

In this article, we present the results from the Vermont Voices on Care of the Dying Questionnaire with the following three main objectives: (1) to describe the knowledge and attitudes about

EOL care of veterans with symptomatic metastatic cancer, (2) to explore the relationship between race and EOL preferences, and (3) to explore the association between patient-perceived health status and survival.

METHODS

Patient Selection

The Section of Hematology/Oncology of the VANJHCS is the sole tertiary care provider in the state of New Jersey for veterans with cancer. From August 1999 to October 2002, a total of 296 symptomatic advanced cancer patients with distressing symptom(s), defined as presenting with at least "somewhat" distress for a minimum of one physical symptom or at least "occasional" frequency for a minimum of one psychological symptom measured by the Memorial Symptom Assessment Scale-Short Form (MSAS-SF; Chang et al., 2000), seen in the outpatient Hematology/Oncology clinic and the inpatient service, participated in the Unmet Needs Project and completed the Vermont Voices on Care of the Dying Questionnaire. Of the 296 patients, 42 patients were excluded from this analysis as 38 patients only had regional-advanced stage disease and four patients did not complete the Vermont Voices on Care of the Dying Questionnaire. The final data set contained 254 symptomatic metastatic cancer patients.

The protocol was approved by the Institutional Review Board and all patients signed informed consent. Outpatients completed the survey during their clinic visit and the inpatients completed the survey within two days of admission.

Instruments

The Vermont Voices on Care of the Dying Questionnaire was originally designed for and used in the Journey's End Project (Vermont Ethics Network, 1997) to assess the individual's knowledge of and attitude toward EOL issues through either community forums or personal interviews and to communicate these needs to health care providers. The questions cover the following areas: perception of health, awareness of hospice program, advance directives documentation, experience with dying, breaking bad news, communication, preference of location of death, and perception of pain and EOL care delivered by the current health care system. We chose this instrument as it was recommended by the Institute of Medicine (IOM; Field & Cassel, 1996) to assess the individual's knowledge and attitude about EOL care. The applicability of this

instrument in a sample of seriously ill patients has not been reported.

Statistical Analysis

Responses to the knowledge and values items about EOL care were tabulated. Based on the response to the question, "Which state applies best to your current health situation?" patients were grouped into the following four patient-perceived health groups: good health ($N = 7$, 2.8%), serious and life-threatening illness ($N = 116$, 45.6%), significant but not life-threatening health problems ($N = 48$, 18.9%), and don't know ($N = 83$, 32.7%).

The chi square test was used to assess for differences in response patterns for each knowledge and attitude item between inpatients and outpatients status, between three different age groups (<65 years vs. 66–75 years vs. >75 years), between four different health groups, and between different racial groups (African Americans vs. Caucasians). The survival status and location of death (home vs. hospital) as of December 30, 2002 for each subject was obtained and confirmed. The Log-rank test for equality of survivor functions was performed to assess for differences in median survival length between the four different health groups.

Statistical analyses were performed with the STATA program, v7.0. (StatCorp., 1997).

RESULTS

Patient Characteristics

The 254 patients were all men. The median age was 69 years (range 29–96). The four most common primary cancer sites were lung in 75 patients (29.5%), prostate in 65 patients (25.6%), colorectal in 19 patients (7.5%), and lymphoma in 18 patients (7.1%). There were 135 Caucasians (53.2%), 109 African Americans (42.9%), and other races in 10 patients (3.9%; Table 1).

Knowledge and Attitude toward EOL

The results regarding knowledge and attitudes toward EOL care are listed in Table 2. Most patients thought they had either a serious and life-threatening illness (45.6%) or had a significant but not life-threatening illness (18.9%); one-third of patients (32.7%) did not know how to answer this question. About 60% of patients knew little or nothing about hospice programs (61.1%) and did not have any terminal care documents (60.2%). The majority of patients had experienced the death of someone close to them (88.9%). One hundred eighty-two patients (71.7%) either had not re-

Table 1. Demographics

	Median (<i>N</i>)	Range (%)
Age	69 years	29–96 years
<50 years	13	5.1
51–65 years	80	31.5
66–75 years	89	35.0
>75 years	72	28.4%
Primary site of cancer		
Lung	75	29.5
Prostate	65	25.6
Colorectal	19	7.5
Lymphoma	18	7.1
Pancreatic	15	5.9
Head and neck	14	5.5
Multiple myeloma	9	3.5
Other	39	15.4
Inpatient status		
Inpatient	153	60.2
Outpatient	101	39.8
Races		
Caucasians	135	53.2
African Americans	109	42.9
Other races ^a	10	3.9
Relationship with main caregivers		
Spouse	108	42.5
No caregiver	80	31.5
Others	66	26.0

^aHispanic in 7, Asian in 3

ceived any care plans (58.3%) or did not know whether their physicians had offered them the care plans or not if they became critically ill (13.4%). Most patients (86.2%) preferred doctors to be quite frank in communicating bad news, and 7.9% of patients preferred doctors to discuss bad news with their family or close friends first. Nearly half of the patients (47.6%) thought everyone (patient, family members, and health care providers) should be involved in their EOL medical care decision making, and 34.3% of patients preferred to make the EOL medical care decision by themselves. If patients could choose the place of death, 43.3% preferred to die at home, 14.6% preferred to die in a hospital, and 42.1% did not have any preferences. More than half (56.7%) of patients thought that the current health care system is doing a good job of addressing the needs of patients with pain but only 28.0% of patients thought that the current health care system is doing a good job of taking care of dying persons.

There were no differences in patterns of responses to the items between three different age groups and by inpatient and outpatient status.

Table 2. Knowledge and Attitudes toward End-of-Life Care

Items	N	%
1. Which state applies best to your current health situation?		
I am in good health	7	2.8
I have a serious illness which may end my life soon	116	45.6
I have a significant health problem, but not life threatening	48	18.9
I don't know how to answer it	83	32.7
2. Do you know what a "HOSPICE" program is?		
Yes, I have had personal experience with hospice	25	9.8
Yes, I have a general idea about what a hospice is	74	29.1
I know little or nothing about hospice	155	61.1
3. About Advance Directives		
I have either terminal care document or power of attorney for health care	101	39.8
I don't have either	153	60.2
4. Have you been involved in the dying of someone close to you?		
Yes, within the past 2 years	74	29.1
Yes, more than 2 years	152	59.8
Never	28	11.1
5. Has your doctor ever offered to plan with you for the care you might want if you became critically ill?		
No	148	58.3
Yes	55	21.6
I don't know	34	13.4
I don't want the plan now	17	6.7
6. When people are seriously ill, some want doctors to be frank about the bad news, others prefer that the doctors keep the bad news to themselves or just tell the family. How about you? Do you want doctors in your care to:		
Be quite frank	219	86.2
Keep the bad news to themselves	2	0.8
Talk first with my family or close friends	20	7.9
Ambivalent	3	1.2
No preference	10	3.9
7. Do you think decisions about medical care at end of life should be made?		
Best left to doctor	10	3.9
Patients should have final say	87	34.3
Doctor should consult family	36	14.2
Everybody involved	121	47.6
8. If you could die at a place of your own choosing would it be?		
In a hospital	37	14.6
At home	110	43.3
Not sure	107	42.1
9. Do you think the current health care system is doing a good job of taking care of patients with pain?		
No	21	8.3
Yes	144	56.7
Unsure	89	35.0
10. Do you think the current health care system is doing a good job of taking care of dying persons?		
No	13	5.1
Yes	71	28.0
Unsure	170	66.9

Comparison of Knowledge and Attitudes toward EOL and Location of Death between Racial Groups

In comparison with Caucasians, African American patients had significantly higher responses in the following items: uncertainty about their current

health situation (40.3% vs. 23.7%), lack of knowledge about hospice programs (77.1% vs. 46.7%), absence of terminal care documents (72.5% vs. 49.7%), desire for bad news to be discussed with their family or friends first (13.8% vs. 3.7%), and uncertainty about the preferred location of death (57.8% vs. 31.9%). In contrast, Caucasian patients

had higher responses in the following areas: knowledge of the severity of illness (53.3% vs. 38.5%), desire for frankness when breaking bad news (90.4% vs. 79.8%), preference to die at home (51.1% vs. 32.1%), and belief that the current health care system is not doing a good job in addressing the needs of patients with pain (12.6% vs. 3.7%) or in taking care of dying persons (8.9% vs. 0.9%; Table 3).

Patient-Perceived Health Status and Knowledge and Attitudes toward EOL Care

There were significant differences in the following items between patients in the four different self-perceived health groups (good health vs. serious and life-threatening illness vs. significant but not life-threatening health problems vs. don't know) by chi square analysis: awareness of hospice program ($p = 0.02$), knowledge of care plans if illness becomes critical ($p = 0.02$), preference in the location of death ($p = 0.02$), and perception of health care system in taking care of pain ($p = 0.05$; see Table 4). The results remained the same after removing the good-health group.

Survival Outcomes

As of December 30, 2002, 190 patients (74.8%) had died (102 Caucasians and 88 African Americans) with median survival of 5.7 months (25–75% range: 1.7–16.1 months). The location of death included VANJHCS ($N = 95$, 48.7%), other hospitals and long term care facilities ($N = 30$, 15.4%), and home ($N = 70$, 35.9%). A significantly higher proportion of African American patients died in the hospital compared to Caucasians (78.4% vs. 52.9%; $\chi^2 = 13.4$, $p < 0.0001$).

There were no differences in median survival length between different racial groups and different age groups. Patients who perceived themselves as having a serious and life-threatening illness had the shortest median survival of 4.3 months (25–75% range: 1.5–12.5 months), followed by the don't know group (median 5.6 months, 25–75% range: 1.5–14.0 months), the good-health group (median 8.3 months, 25–75% range: 3.8–10.2 months), and the significant but not life-threatening health problems group (median 9.4 months, 25–75% range: 4.0–21.1 months; $\chi^2 = 5.3$, $p = 0.15$).

If we compared only the survival length between the serious and life-threatening illness and the significant but not life-threatening problems groups, then there was a significant difference between these two groups ($\chi^2 = 4.7$, $p = 0.03$). The Kaplan-

Meier survival curve for these two groups is illustrated in Figure 1.

DISCUSSION

In this study, we have reported responses of veterans with metastatic cancer to the Vermont Voices on Care of the Dying Questionnaire to better understand patient preferences for EOL care. Our findings confirm previous reports that patients have significant knowledge deficits with regards of EOL care (Hoffmann et al., 1997; McKinley et al., 2000; Silveria et al., 2000). Sixty percent of patients in our study reported either no knowledge about hospice programs or no advance directives ready at time of interview, and one-third of our patients were unsure about their own health status. Even though we make efforts to educate our patients at each step of the disease, a lack of knowledge of EOL care and the severity of their disease is still evident. There are a number of possible explanations. Some of the patients were newly referred patients. Some patients may have thought "health situation" was for the doctor to decide, or the question itself difficult to understand. Some patients may have been uncertain about their health because they had cancer or because they used denial as a coping mechanism. Age and inpatient status did not account for the lack of knowledge. The reasons for this knowledge deficit need to be further studied.

The results from our study are similar to a survey of 70 veteran outpatients from a general medical clinic who were interviewed regarding living wills. Forty-three percent of patients had never heard of living wills. Those who had heard of a living will and intended to complete one were more likely to be Caucasian and express poorer self-perceived health status (Sugarman et al., 1992).

The VA prioritizes care to veterans with service-connected disabilities and those with low income (Skydell, 1998). It has been suggested that the VA can serve as a medical safety net provider and mitigate racial disparities in access to outpatient care for minority veterans (Washington et al., 2002). Our study confirms findings in other populations that there are significant disparities between African American and Caucasian veterans in advanced care planning, EOL decision making, and location of death (McKinley et al., 2000; Silveria et al., 2000). Previous experiences with being denied medical care, distrust of the medical system (Elazer et al., 1995; Hallenbeck et al., 1996), a fear of being treated differently and receiving less care if they had a living will (Carlais et al., 1993), and religious values and cultural beliefs (Garrett et al., 1993) have all been suggested to explain low rates of

Table 3. Knowledge and Attitudes toward End-of-Life Care: Comparison between Caucasians and African Americans

	African Americans N = 109		Caucasians N = 135		χ^2	P value
	N	%	N	%		
1. Which state applies best to your current health situation?					8.23	0.04
I am in good health	3	2.8	4	3.0		
I have a serious illness which may end my life soon	42	38.5	72	53.3		
I have a significant health problem, but not life threatening	20	18.4	27	20.0		
I don't know how to answer it	44	40.3	32	23.7		
2. Do you know what a "HOSPICE" program is?					23.3	<0.0001
Yes, I have had personal experience with hospice & I have a general idea about what a hospice is	25	22.9	72	53.3		
I know little or nothing about hospice	84	77.1	63	46.7		
3. About Advance Directives					13.1	<0.0001
I have either terminal care document or power of attorney for health care	30	27.5	68	50.3		
I don't have either	79	72.5	67	49.7		
4. Involved in the dying of someone close to you?					0.06	0.8
Yes, within the past 2 years & Yes, more than 2 years	98	88.9	120	89.9		
No	11	11.1	15	10.1		
5. Has your doctor ever offered to plan with you for the care you might want if you became critically ill?					3.1	0.4
No	58	53.2	83	61.5		
Yes	24	22.0	30	22.5		
I don't know	27	24.8	22	16.0		
6. When people are seriously ill, some want doctors to be frank about the bad news, others prefer that the doctors keep the bad news to themselves or just tell the family. How about you? Do you want doctors in your care to:					10.9	0.03
Be quite frank	87	79.8	122	90.4		
Keep the bad news to themselves	2	1.8	0	0.0		
Talk first with my family or close friends	15	13.8	5	3.7		
Ambivalent	1	0.9	2	1.5		
No preference	4	3.7	6	4.4		
7. Do you think decisions about medical care at end of life should be made?					2.4	0.5
Best left to doctor	3	2.7	6	4.4		
Patients should have final say	35	32.1	51	37.8		
Doctor should consult family	13	12.0	19	14.1		
Everybody involved	58	53.2	59	43.7		
8. If you could die at a place of your own choosing would it be?					17.0	0.001
In a hospital	11	10.1	23	17.0		
At home	35	32.1	69	51.1		
Not sure	63	57.8	43	31.9		
9. Do you think the current health care system is doing a good job of taking care of patients with pain?					6.2	0.04
No	4	3.7	17	12.6		
Yes	63	57.8	73	54.1		
Unsure	42	38.5	45	33.3		
10. Do you think the current health care system is doing a good job of taking care of dying person?					7.6	0.02
No	1	0.9	12	8.9		
Yes	32	29.4	35	25.9		
Unsure	76	69.7	88	65.2		

Table 4. Comparison of Knowledge and Attitudes between Different Patient-Perceived Health Groups

	Good health (N = 7)		Serious and life threatening illness (N = 116)		Significant health problems, not life threatening (N = 48)		I don't know (N = 83)		χ^2	P
	N	%	N	%	N	%	N	%		
1. Do you know what a "HOSPICE" program is?										
Yes, I have had personal experience with hospice & I have a general idea about what a hospice is	2	28.6	57	49.1	17	35.4	23	27.7	10.0	0.02
I know little or nothing about hospice	5	71.4	59	50.9	31	64.6	60	72.3		
2. About Advance Directives										
I have either terminal care document or power of attorney for health care	2	28.6	56	48.3	11	22.9	32	38.5	9.6	0.02
I don't have either	5	71.4	60	51.7	37	77.1	51	61.5		
3. Involved in the dying of someone close to you										
Yes, within the past 2 years & Yes, more than 2 years	4	57.1	108	93.1	41	85.4	73	87.9	9.95	0.02
No	3	42.9	8	6.9	7	14.6	10	12.1		
4. Has your doctor ever offered to plan with you for the care you might want if you became critically ill?										
Yes	2	28.6	27	23.3	11	22.9	15	18.1	11.3	0.08
No	5	71.4	73	63.0	28	58.3	42	50.6		
Don't want any plan	0	0.0	16	13.7	9	18.8	26	31.3		
5. If you could die at a place of your own choosing would it be?										
At home	5	71.4	50	43.1	27	56.3	28	33.7		
In the hospital	0	0.0	23	19.8	5	10.4	9	10.8	14.8	0.02
Not sure	2	28.6	43	37.1	16	33.3	46	45.5		
6. Do you think the current health care system is doing a good job of taking care of patients with pain?										
Yes	6	85.7	58	50.0	33	68.8	47	56.6	12.0	0.05
No	0	0.0	13	11.2	5	10.4	3	3.6		
Unsure	1	14.3	45	38.8	10	20.8	33	39.8		

advance care planning among African Americans. Hopp and Duffy (2000) interviewed 540 proxy respondents and concluded that race was a significant predictor of advance care planning and treatment decisions. McKinley et al. (2000) studied the differences in EOL decision making between black and white ambulatory cancer patients in North Carolina and found that black patients wanted more life-sustaining treatments and were less likely to complete a living will. In contrast, Blackhall et al. (1995) interviewed senior citizens from Los Angeles and found that African Americans and Caucasians had similar preferences for receiving information on diagnosis and prognosis and for who should make decisions.

Further studies to identify the factors associated with racial disparities in EOL care decision making

and how they may affect delivery of palliative care at VA settings are needed.

The importance of communication as a component of quality palliative care has been demonstrated in surveys of patients and providers (Curtis et al., 2001). Discomfort discussing death and dying (Curtis & Patrick, 1997) and physician's reluctance to discuss death with patients have been suggested as the most significant EOL communication barriers (Morrison et al., 1994; Pfeifer et al., 1994). We found that 90% of our patients wanted physicians to be frank when delivering bad news and more than 60% of patients would like to involve their family members in EOL care decision making. How to design and deliver effective EOL care educational programs and how to assess the EOL care communication and educational out-

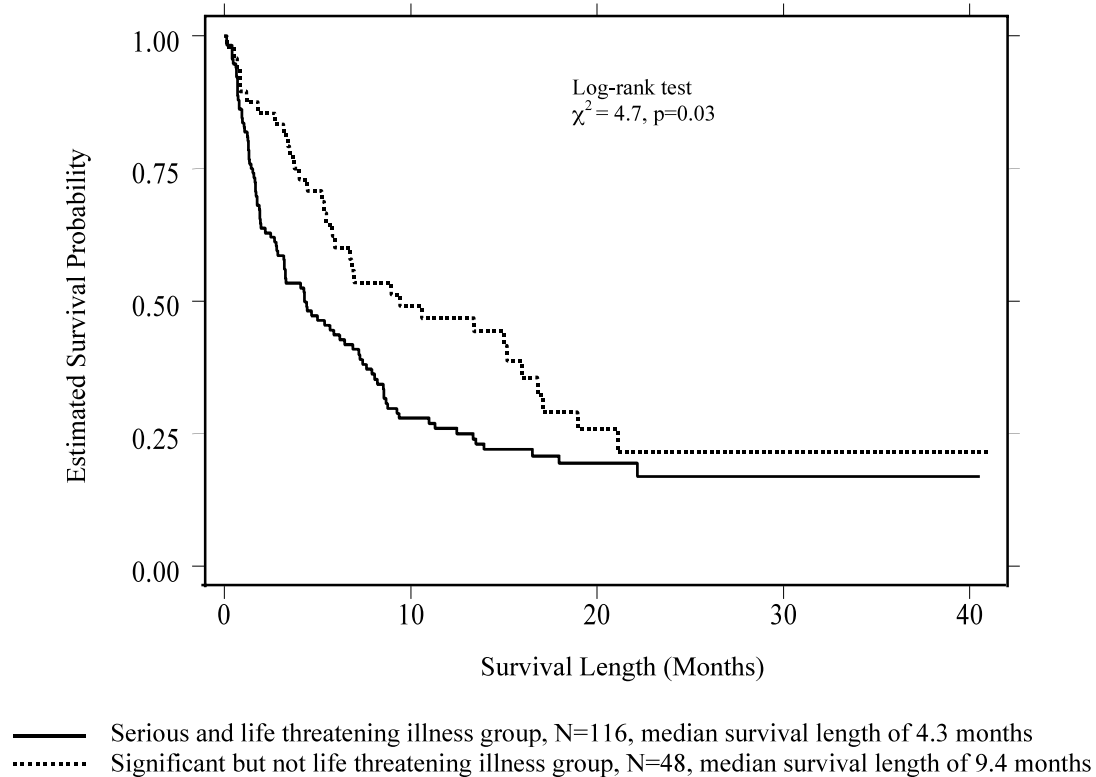


Fig. 1. Kaplan-Meier survival estimates, by patient-perceived health groups.

comes remains challenging and deserves further study.

This study provides information on the association between patient-perceived health status and knowledge and attitudes toward EOL care and survival. This data has not been reported before in veteran patients with cancer. We found that patients who perceived themselves as having a serious and life-threatening illness had significantly higher rates in completion of advance directives and increased awareness of hospice programs. These findings extend the conclusions by Patrick et al. (1997), who showed that hypothetical changes in health status can be associated with changes in EOL care preferences. We also found that patients who perceived themselves as having serious and life-threatening illness had the shortest median survival. Perceptions of health have been linked to survival in studies of elderly patients (Kaplan et al., 1988; Leung et al., 1997) and in patients with diabetes (Dasbach et al., 1994). In a survey study of 2657 medical inpatients at nine VA medical centers, poor self-rated health at baseline and at the time closest to death were predictors of mortality (Lavretsky et al., 2002). These studies suggest that patient self-rated health predicted survival independently. Our results support the potential

clinical usefulness of patient-rated health assessments as a way of understanding patient preferences and discussing treatment goals (Shadbolt et al., 2002).

To the best of our knowledge, this is the first time that the Vermont questionnaire has been used in seriously ill patients. This study provides a better understanding of the strengths and limitations of the Vermont Questionnaire. The “Vermont Voices on Care of the Dying Questionnaire” allows patients to express their preferences, but in retrospect, we feel that while this instrument may be useful in community forums, the items do not reflect specific aspects of knowledge and attitudes of patients with metastatic cancer in the hospital setting. Several potentially important clinical issues such as treatment burden, detailed discussion of EOL care options, perception of death, and preferences for life-sustaining treatments are not included in the Vermont questionnaire. Some of these issues are addressed in recently developed instruments such as the “Needs at the End-of-Life Screening Tool” (Emanuel et al., 2001) and the “Quality of Dying and Death Questionnaire” (Patrick et al., 2001; Curtis et al., 2002). Second, as there were no female patients, further studies should be done in different populations. Third, several potentially im-

portant factors such as education level, oncologic treatment information, and comorbidity were not available for analysis. Further studies, including both genders in community settings with more socioeconomic and demographic variables, and newly validated multidimensional instruments can effectively address these limitations.

In conclusion, the results demonstrate knowledge deficits and racial differences related to EOL care in veteran cancer patients. The Vermont questionnaire may not be detailed enough for the seriously ill patients and for clinical applications. Patient-rated health status may be an important explanatory variable for EOL preferences and length of survival.

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