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Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers

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DYING PATIENTS CONFRONT complex and unique challenges that threaten their physical, emotional, and spiritual integrity. The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT) documented that many patients die prolonged and painful deaths, receiving unwanted, expensive, and invasive care.¹ Patients' emotional suffering at the end of life can be profound, yet physicians are too frequently ill equipped to address this suffering.^{2,3} In response, medical societies, health care organizations, and the public have identified improved end-of-life care as a high national priority. The American Medical Association and the Institute of Medicine have outlined goals for improved care of the dying, and The Robert Wood Johnson Foundation has devoted millions of dollars to public education on this issue through the Last Acts initiative.⁴⁻⁶

These efforts depend, in part, on certain presumptions regarding how dying patients and their families define quality at the end of life. During the latter part of the 20th century, advances in biomedical technology propelled us to see a "good" death as one involving

Context A clear understanding of what patients, families, and health care practitioners view as important at the end of life is integral to the success of improving care of dying patients. Empirical evidence defining such factors, however, is lacking.

Objective To determine the factors considered important at the end of life by patients, their families, physicians, and other care providers.

Design and Setting Cross-sectional, stratified random national survey conducted in March-August 1999.

Participants Seriously ill patients (n = 340), recently bereaved family (n = 332), physicians (n = 361), and other care providers (nurses, social workers, chaplains, and hospice volunteers; n = 429).

Main Outcome Measures Importance of 44 attributes of quality at the end of life (5-point scale) and rankings of 9 major attributes, compared in the 4 groups.

Results Twenty-six items consistently were rated as being important (>70% responding that item is important) across all 4 groups, including pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a "whole person." Eight items received strong importance ratings from patients but less from physicians ($P < .001$), including being mentally aware, having funeral arrangements planned, not being a burden, helping others, and coming to peace with God. Ten items had broad variation within as well as among the 4 groups, including decisions about life-sustaining treatments, dying at home, and talking about the meaning of death. Participants ranked freedom from pain most important and dying at home least important among 9 major attributes.

Conclusions Although pain and symptom management, communication with one's physician, preparation for death, and the opportunity to achieve a sense of completion are important to most, other factors important to quality at the end of life differ by role and by individual. Efforts to evaluate and improve patients' and families' experiences at the end of life must account for diverse perceptions of quality.

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the fight against disease. Partly in response to this view, the modern hospice movement emerged, redefining a good death as one that included acceptance and closure, most often at home. Unfortunately, empirical support for a notion of a good death that might best structure end-of-life care is lacking, as is a comprehensive understanding about how the definition of a good death might vary across relevant constituencies.

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Empirical evidence defining a good death would assist efforts to improve end-of-life care by documenting the breadth of preferences of dying patients and their families. Such data would provide clinicians with information to help guide patients through this challenging and uncertain time. Therefore, we investigated what patients, family members, physicians, and others consider to be important attributes at the end of life.

METHODS

This study was a cross-sectional, stratified random national survey of seriously ill patients, recently bereaved family members, physicians, and other care providers (nurses, social workers, chaplains, and hospice volunteers).

Subjects

Patients were randomly selected from the national Veterans Affairs (VA) Patient Treatment File database using *International Classification of Diseases, Ninth Revision* diagnostic codes for a variety of advanced chronic illnesses (lung, colon, gastric, esophageal, pancreatic, head and neck, and lymphatic cancer; end-stage renal disease; advanced chronic obstructive pulmonary disease; and congestive heart failure). All patients had been hospitalized for these diagnoses within the prior year. Family members were randomly selected from national samples of relatives of VA patients who had died 6 months to 1 year earlier. We chose this period so that family members would be past the immediate stages of grief, yet the death would not be so distant that the risk of retrospective bias would be introduced.⁷⁻¹⁰ Patient and family samples reflected the racial/ethnic and socioeconomic composition of VA patients. However, we oversampled female patients (20%).

Individuals involved in end-of-life care were randomly selected from membership lists of national professional associations (American College of Physicians–American Society of Internal Medicine, American Nurses Association, National Association of Social

Workers, Association of Professional Chaplains, and National Hospice Volunteers). The sample composition reflects the demographic profile of each association's membership.

We mailed surveys to 500 subjects from each of the 4 groups (total potential n=2000). Sample size was calculated to provide adequate power to detect differences among groups. We used several well-established techniques to maximize response rates and data quality.^{11,12} Participants who did not respond to the initial survey within 5 weeks received a second survey that included return postage. In the first wave only, we provided a nominal financial incentive. Survey completion time was less than 15 minutes. The institutional review boards of the Durham VA and Duke University Medical Centers, Durham, NC, approved the study.

Measurements

The survey asked respondents to rate the importance of 44 attributes of experience at the end of life (survey available at <http://hsrd.durham.med.va.gov/pmepc/Program.html>). Survey items were generated on the basis of 12 previously conducted focus groups and in-depth interviews with patients, family members, physicians, and other care providers in which participants were asked to define attributes of a good death.¹³ Participants rated the importance of each item on a 5-point scale: strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree. Respondents also were presented with the 9 items most frequently identified in the focus groups and asked to rank-order them from 1 (most important) to 9 (least important). The rank sum for each respondent for the 9 items was constrained to be 45; tied ranks were permitted.

Analysis

We examined the distribution of responses for all 44 items, including frequency, mean, median, and range. For descriptive parsimony, we collapsed the 5 response categories into 3: agree, disagree, and neither agree nor disagree.

Based on natural breaks in the distribution of the data, items for which more than 70% of respondents in all 4 groups chose "agree" or "strongly agree" were identified as having substantial agreement. We used χ^2 and, when appropriate, Fisher exact tests of independence to compare responses among groups. We also assessed mean rank score for the 9 ranked items and conducted Friedman tests to examine whether rankings within groups were different than would be expected by chance alone. Wilcoxon tests were used to examine the significance of specific response differences among groups.

To identify independent correlates of 4 selected attributes with the most varied ratings of importance, we conducted multivariate exploratory analyses of factors associated with item response. We used logistic regression to model the likelihood of responding "disagree" or "neither agree nor disagree" vs "agree" for a given item. We used a stepwise procedure to identify covariates strongly associated with response. Our final models also included variables in which we had a substantive interest, regardless of their precise significance level. Each question was initially evaluated in the pooled sample using the same set of covariates. We present odds ratios (ORs) and 95% confidence intervals (CIs) only for significant covariates. Because income and education were strongly associated with role, socioeconomic status effects on the full sample could not be evaluated; hence, the effects of income and education on patient and bereaved family member responses were tested in separate analyses. Exploratory analyses revealed no differences in patients' responses by diagnosis; therefore, it was excluded from the multivariate models. Because only female patients were oversampled, we present results of unweighted analyses. In analyses not shown, we also modeled items as a 3-category response variable, using multinomial logistic regression. Because the results were nearly identical, we report the less cumbersome binary models. Statistical analyses were conducted using

SAS Version 8.0 software (SAS Institute Inc, Cary, NC).

RESULTS

Of the 2000 mailed surveys, 1885 potential subjects could be reached (ie, had not moved or died). We received responses from 340 (77%) of 444 patients, 332 (71%) of 465 bereaved family members, 361 (74%) of 486 physicians, and 429 (88%) of 490 other care providers (120 chaplains [96%], 105 hospice volunteers [84%], 107 social workers [86%], and 97 nurses [78%]), for a total of 1462 participants. The average age of respondents was 57 years; 51% were men and 82% were white (TABLE 1). Nonrespondents did not differ from respondents with regard to sex, race/ethnicity, diagnosis, or geographic location.

Ratings of Attribute Importance

Based on responses to the survey, we classified the 44 attributes into 3 categories: (1) items with strong agreement regarding importance among the entire sample (>70% of every group agreed that the attribute is important); (2) items with strong agreement regarding importance (>70%) among patients but less agreement among physicians; and (3) items with broad response variation among the entire sample (ie, large percentages of respondents agreeing, disagreeing, and neither agreeing nor disagreeing that the item is important).

Attributes Rated As Important Among All Participants. Twenty-six survey items displayed strong agreement in all 4 groups (TABLE 2). Of the 26 items, 5 were associated with symptoms or personal care: freedom from pain, freedom from anxiety, freedom from shortness of breath, being kept clean, and having physical touch. Four items related to preparation for the end of life: having financial affairs in order, feeling prepared to die, believing that one's family is prepared for one's death, and knowing what to expect about one's physical condition. Three items related to achieving a sense of completion about one's life: saying good-bye to important people, re-

Table 1. Demographics of Survey Participants*

Characteristics	Patients (n = 340)	Bereaved Family Members (n = 332)	Physicians (n = 361)	Other Care Providers (n = 429)	Overall (n = 1462)
Sex, male	78.2	21.3	81.7	27.3	51
Age, mean, y	68	62	52	51	57
Race/ethnicity					
African American	15.6	11.3	1.4	3.3	7.4
Asian American	2.5	1.3	10.3	0.5	3.6
White	69	77.8	80.4	94.8	81.6
Latino	2.8	2.8	2.8	0.7	2.2
Native American	8.6	6.3	0.3	0	3.4
Other	1.5	0.6	4.7	0.7	1.9
Education					
Less than high school	30.4	22	NA	0	15.8
High school	44.2	48.3	NA	3.5	29.3
Associate of arts degree	10.1	9.6	NA	3.7	7.4
Bachelor's degree	5.8	9.9	NA	8.7	8.2
Graduate degree	9.5	10.2	100	84.1	39.3
Annual income, \$					
0-9999	29.7	22.7	26.3
10 000-19 999	40.9	24.1	32.8
20 000-34 999	19.8	19.9	10.4
35 000-49 999	6.6	14.3	10.4
≥50 000	3	18.9	10.7
Religion					
Protestant	60.3	61.9	33.9	62.4	54.7
Roman Catholic	24.8	23.8	24.3	18.9	22.7
Jewish	1.5	0.6	18.1	5	6.5
Muslim	0	0	2.5	0	0.6
Other	3.6	5.1	9	3.5	5.3
No religion	9.7	8.6	12.1	10.2	10.2
Living arrangement					
With spouse	40.6	18.9	33.2	41.3	34
With parent	2.8	2.3	0.9	1.8	1.9
With child	20.8	35.4	55	43.1	36.7
Alone	35.8	43.4	10.9	30.6	24.5
Marital status					
Married	47.9	34.9	86.6	75.1	62.7
Widowed	17.6	50	2.8	3.3	17
Divorced/separated	27.9	11.1	3.1	10.8	12.9
Never married	6.7	4	7.5	10.8	7.5
Importance of faith					
Very important	61.3	72.3	47.5	81.1	66.2
Somewhat important	32	23.4	39.9	15.8	27.4
Not at all important	6.7	4.4	12.6	3.1	6.6
Attend religious service					
More than once a week	8.4	13.1	4	16.1	10.7
Every week	16.2	25.9	22.7	38.1	26.5
2-3 times a month	8.4	10.9	12.5	12.5	11.2
Once a month	15	9.3	18.1	7.1	12.2
Once or twice a year	28.7	21.4	25.2	17.7	23
Never	23.4	19.2	17	8.5	16.4
General health					
Excellent	0.6	9.3	54.7	38.4	27.3
Very good	4.9	24.5	28.8	44.1	26.9
Good	20.7	37.9	14.5	14.4	21.2
Fair	41.7	23.6	1.4	2.8	16.1
Poor	32	4.7	0.6	0.2	8.6

Table 1. Demographics of Survey Participants* (cont)

Characteristics	Patients (n = 340)	Bereaved Family Members (n = 332)	Physicians (n = 361)	Other Care Providers (n = 429)	Overall (n = 1462)
Overall mood					
Not at all depressed	32.1	42.8	75.1	73	57.3
Slightly depressed	40.1	35.3	21.5	24.2	29.8
Moderately depressed	16.5	15	3.4	1.9	8.6
Quite depressed	8	5.3	0	0.5	3.2
Extremely depressed	3.4	1.6	0	0	1.1
Been with someone in their last hour of life	60.1	77.3	97.2	94.4	83.3

*All data except age are reported as percentages. NA indicates not applicable; ellipses, physicians and other care providers were not asked to report their income.

Table 2. Attributes Rated as Important by More Than 70% of All Participants

Attributes	Participants Who Agreed That Attribute Is Very Important at End of Life, %			
	Patients (n = 340)	Bereaved Family Members (n = 332)	Physicians (n = 361)	Other Care Providers (n = 429)
Be kept clean	99	99	99	99
Name a decision maker	98	98	98	99
Have a nurse with whom one feels comfortable	97	98	91	98
Know what to expect about one's physical condition	96	93	88	94
Have someone who will listen	95	98	99	99
Maintain one's dignity	95	98	99	99
Trust one's physician	94	97	99	97
Have financial affairs in order	94	94	91	90
Be free of pain	93	95	99	97
Maintain sense of humor	93	87	79	85
Say goodbye to important people	90	92	95	99
Be free of shortness of breath	90	87	93	87
Be free of anxiety	90	91	90	90
Have physician with whom one can discuss fears	90	91	94	93
Have physician who knows one as a whole person	88	92	92	95
Resolve unfinished business with family or friends	86	85	87	97
Have physical touch	86	94	90	97
Know that one's physician is comfortable talking about death and dying	86	85	93	97
Share time with close friends	85	91	91	96
Believe family is prepared for one's death	85	88	83	90
Feel prepared to die	84	81	79	87
Presence of family	81	95	95	96
Treatment preferences in writing	81	85	73	90
Not die alone	75	93	84	88
Remember personal accomplishments	74	80	78	91
Receive care from personal physician	73	77	82	82

menting personal accomplishments, and resolving unfinished business. Two items involved decisions about treatment preferences: having treat-

ment preferences in writing and naming someone to make decisions in the event that one cannot. Seven items were associated with what focus group par-

ticipants in a prior study¹³ called "being treated as a whole person": maintaining one's dignity, maintaining a sense of humor, having a physician who knows one as a whole person, presence of close friends, not dying alone, and having someone who will listen. Finally, 5 items were linked to patients' relationships with health care professionals: receiving care from one's personal physician, trusting one's physician, having a nurse with whom one feels comfortable, knowing that one's physician is comfortable talking about death and dying, and having a physician with whom one can discuss personal fears.

Attributes Important Among Patients. The second category included 8 items that were consistently rated as important among patients (>70%) but were significantly less important to physicians ($P<.001$) (TABLE 3). These included being mentally aware, having funeral arrangements planned, feeling that one's life was complete, not being a burden to family or society, being able to help others, coming to peace with God, and praying. These differences persisted after conducting multivariate analyses controlling for sex, race/ethnicity, socioeconomic status, household composition, religion, and religiosity (data available on request).

Attributes With Broad Response Variation Among All Participants. A final category comprised 10 items with a broad distribution of responses among the 4 groups. These items included attributes relating to treatment preferences, preparation, and completion or spirituality (TABLE 4). For example, the groups showed wide response variation regarding the importance of knowing the timing of death. A slight majority of the sample agreed with the importance of meeting with a clergy member, having a chance to talk about the meaning of death, and discussing spiritual beliefs with one's physician. However, a sizable percentage of each group disagreed or neither agreed nor disagreed about the importance of these items (Table 4). Compared with patients, bereaved family members more frequently agreed with and physicians

less frequently agreed with the importance of meeting with clergy.

Multivariate Analyses

Multivariate models were created controlling for role, sex, race/ethnicity, income, education, religion, religiosity, being present during the last hour of someone's life, household composition, self-reported health status, and, for patients, diagnosis. Only ORs that were significant are presented herein.

Use of All Available Treatments. Physicians (OR, 0.1; 95% CI, 0.1-0.2) and other care providers (OR, 0.08; 95% CI, 0.04-0.14) were significantly less likely than patients to agree with the im-

portance of using all available treatments no matter what the chance of recovery, whereas bereaved family members were equally likely to agree (OR, 0.8; 95% CI, 0.6-3.3). African American (OR, 3.3; 95% CI, 2.0-4.0) and other nonwhite ethnic groups (OR, 2.5; 95% CI, 1.4-3.3) were significantly more likely than white participants to agree with the importance of using all available treatments. Persons who had not been present during the last hour of another person's life were also more likely to agree (OR, 1.7; 95% CI, 1.0-2.5). Sex, religion, and the other variables were not associated with the response to this question. Among patients and bereaved family members, respondents with more education (bachelor's degree, OR, 0.5; 95% CI, 0.3-0.8; graduate/professional degree, OR, 0.4; 95% CI, 0.2-0.9 vs no college) and higher annual income (\$20 000–\$40 000, OR, 1.0; 95% CI, 0.6-1.7; ≥\$50 000, OR, 0.3; 95% CI, 0.2-0.8 vs <\$20 000) were significantly less likely to agree with the importance of use of all available treatments.

Controlling Time and Place of Death. Religiosity was the only covariate significantly associated with preference for controlling the time and place of death. Participants who considered faith or spirituality not at all important were significantly more likely (OR, 1.7; 95% CI, 1.1-2.0) than were those who

considered it very important to agree with the importance of such control.

Dying at Home. Other care providers (OR, 1.7; 95% CI, 1.1-2.0) were significantly more likely to agree with the importance of dying at home compared with patients. Physicians (OR, 1.4; 95% CI, 1.0-2.0) and bereaved family members (OR, 0.8; 95% CI, 0.6-1.3) were not significantly different from patients. Roman Catholic (OR, 1.4; 95% CI, 1.0-2.0) and "other" respondents were significantly less likely than Protestants (the reference point) or Jews (OR, 0.8; 95% CI, 0.5-1.3) to disagree. Separate logistic analyses showed no significant covariates among patients and families.

Talking About the Meaning of Death. Physicians (OR, 2.0; 95% CI, 1.3-2.5), other care providers (OR, 1.7; 95% CI, 1.1-2.0), and bereaved family members (OR, 1.7; 95% CI, 1.1-2.7) were significantly more likely than patients to agree that talking about the meaning of death is important. Those for whom faith or spirituality was not at all (OR, 0.3; 95% CI, 0.2-0.5) or somewhat (OR, 0.4; 95% CI, 0.3-0.6) important were significantly less likely than those for whom spirituality was very important to agree that this attribute was important. Among patients and family members, women were significantly more likely to agree with talking about the meaning of death (OR, 2.0; 95% CI, 1.3-2.5).

Table 3. Attributes Rated as Important by More Than 70% of Patients But Not Physicians*

Attributes	Participants Who Agreed That Attribute Is Very Important at End of Life, %	
	Patients	Physicians
Be mentally aware	92	65
Be at peace with God	89	65
Not be a burden to family	89	58
Be able to help others	88	44
Pray	85	55
Have funeral arrangements planned	82	58
Not be a burden to society	81	44
Feel one's life is complete	80	68

*P<.001 for all comparisons.

Table 4. Attributes With Broad Variation Among Participants Regarding Importance at End of Life

Attributes	Patients, %			Bereaved Family Members, %			Physicians, %			Other Care Providers, %		
	Agree	Disagree	Neither	Agree	Disagree	Neither	Agree	Disagree	Neither	Agree	Disagree	Neither
Use all available treatments no matter what the chance of recovery	48	31	22	38	44	18	7	81	12	5	83	12
Not be connected to machines	64	16	20	63	17	20	50	9	41	61	10	30
Know the timing of one's death	39	22	39	49	16	35	26	29	46	35	18	47
Control the time and place of one's death	40	24	35	38	22	40	36	25	39	44	25	30
Discuss personal fears	61	11	28	80	4	16	88	1	11	94	1	5
Die at home	35	12	53	30	16	54	44	5	51	46	2	52
Be with one's pets	37	18	45	47	10	44	42	8	50	73	2	24
Meet with a clergy member	69	7	24	83	1	17	60	4	36	70	1	30
Have a chance to talk about the meaning of death	58	9	33	72	3	26	66	5	29	86	1	12
Discuss spiritual beliefs with one's physician	50	13	37	54	7	39	49	10	41	51	7	42

Ranking Attributes

We measured the mean rank scores for the 9 preselected attributes, with 1 being most important and 9 being least important (TABLE 5). Friedman tests were significant ($P < .001$), suggesting that the rankings by each group were different than would be expected by chance alone. Freedom from pain was ranked as most important (ie, received the lowest mean score) by patients (3.07), bereaved family members (2.99), physicians (2.36), and other care providers (2.83). Coming to peace with God and presence of family were ranked second or third in importance in all groups. For patients and families, the difference between the ranking of freedom from pain and being at peace with God was trivial (0.09 and 0.12 difference, respectively), suggesting that these items are nearly identical in importance for both groups. Physicians' mean score difference between the items was 2.46; other care providers had a difference of 0.88 in mean score ($P < .001$). Of note, dying at home received the least important relative ranking by all groups except other care providers, who ranked it second to last.

COMMENT

Our results reveal areas of strong agreement and variation among end-of-life care participants' definitions of what constitutes a good death. More than half of the survey items showed consensus among all 4 groups. For example, in concert with previous findings in the palliative care literature, survey participants overwhelmingly endorsed pain and symptom management.¹⁴⁻¹⁶ Regardless of role, respondents also converged on the importance of preparation for the end of life. These findings echo the results of a recent study that showed that many patients wish to plan ahead for their own deaths and support the importance of prognostication in clinical practice.¹⁷⁻²⁰ Additionally, respondents expressed a strong preference for having an opportunity to gain a sense of completion in their lives. Life review, saying good-bye, and

Table 5. Mean Rank Scores of 9 Preselected Attributes*

Attributes	Patients	Bereaved Family Members	Physicians	Other Care Providers
Freedom from pain	3.07 (1)	2.99 (1)	2.36 (1)	2.83 (1)
At peace with God	3.16 (2)	3.11 (2)	4.82 (3)	3.71 (3)
Presence of family	3.93 (3)	3.30 (3)	3.06 (2)	2.90 (2)
Mentally aware	4.58 (4)	5.41 (5)	6.12 (7)	5.91 (7)
Treatment choices followed	5.51 (5)	5.27 (4)	5.15 (5)	5.14 (5)
Finances in order	5.60 (6)	6.12 (7)	6.35 (8)	7.41 (9)
Feel life was meaningful	5.88 (7)	5.63 (6)	5.02 (4)	4.58 (4)
Resolve conflicts	6.23 (8)	6.33 (8)	5.31 (6)	5.38 (6)
Die at home	7.03 (9)	6.89 (9)	6.78 (9)	7.14 (8)

*Attributes are listed in the mean rank order based on patient response. Numbers in parentheses are mean rank order, with lowest rank score (1) indicating most important attribute and highest rank score (9) indicating least important. Friedman tests were significant at $P < .001$, suggesting that rankings by each group were different than would be expected by chance alone.

resolving unfinished business provide both patients and their families with an opportunity for human development at the end of life.²¹ Finally, all groups advocated strong relationships between patients and health care professionals that emphasized more than just the patient's disease.

Results of this study also highlight one of the challenges of comprehensive end-of-life care: attending to aspects of care that are not intuitively important to clinicians but are critical to patients and their families. For example, in contrast with physicians, patients strongly endorsed the importance of being mentally aware. When forced to choose between attributes (Table 5), patients ranked pain control higher than mental awareness; however, the mean rank difference was only 1.51. In contrast, the average difference between the same items among physicians was 3.76, suggesting physicians may be more willing than patients to sacrifice lucidity for analgesia. Similarly, other care providers generally emphasize what patients need to receive, but our results indicate that being able to help others is central to patients' conceptions of quality at the end of life.¹³ Finally, patients highly valued attention to spirituality; in particular, the importance of coming to peace with God and praying. Rank-ordered responses showed that coming to peace with God and pain control were nearly identical in importance for patients and bereaved family members.

Perhaps the most interesting findings of our study are items for which there was broad response variation within and across all groups. They serve as a reminder that there is no one definition of a good death; quality end-of-life care is a dynamic process that is negotiated and renegotiated among patients, families, and health care professionals, a process moderated by individual values, knowledge, and preferences for care. We choose to illustrate this point with discussion of 4 critical issues raised in the survey.

Consistent with previous research,^{22,23} African Americans had higher odds than white participants of wanting all available treatments, which may reflect a preference for life-sustaining treatment or distrust of the predominantly white medical culture.²² The disagreement by physicians and other care providers with use of all available treatments may reflect greater familiarity with life-sustaining treatments. In one study, patients were less likely to want cardiopulmonary resuscitation after receiving additional information about the procedure.²⁴ In addition, despite many patients valuing use of all treatments, most disagreed with the importance of being connected to machines. In contrast, physicians equate these interventions and disagreed with both.

Respondents displayed broad variation in their desire to control time and place of death. Those with less religiosity were most likely to want control.

Given the strong public support for the hospice movement and its emphasis on home care, we expected to find overwhelming preference for dying at home.²⁵ However, fewer than half of all participants in our sample agreed that this was an important attribute in quality of dying. Moreover, dying at home was consistently ranked least in importance among 9 selected attributes. Religion and role were associated with a preference for dying at home. Recently, Fried et al demonstrated a similar preference among older adults.²⁶ The notion of dying at home may be romantic among health care professionals who want to provide a good death. However, as symptoms accelerate in the last 24 to 48 hours, some patients and families may feel overwhelmed by concerns about symptom control or a dead body in the home and, therefore, prefer a skilled care environment.²⁶ Therefore, although for many patients an appropriate goal is to allow them to die at home, this should not be assumed.

While we anticipated that religiosity and female sex would be associated with a desire to talk about the meaning of death, we did not expect that physicians, other care providers, and bereaved family members would be more likely to agree with its importance than were patients. Similarly, patients as a group were least likely to rate discussing personal fears as important. All groups lacked consensus in assigning importance to meeting with clergy and discussing spiritual beliefs with one's physician. Spirituality, however, was clearly important to patients, as illustrated by their strong consensus surrounding the need for coming to peace with God and praying. These findings suggest that for some patients, issues of faith that are resolved with oneself are more important than social or interpersonal expressions of spirituality.²⁷

This study has several limitations. Patients and family members were recruited from VA medical centers; therefore, generalizations to other groups should be made cautiously. However, participants' preferences reflected death in a variety of settings, and patients and

families participating in the study represented broad age, educational, and socioeconomic ranges. The individuals comprising other care providers are a diverse group and are not necessarily expected to form a cohesive whole. However, given their role in end-of-life care, it is important to determine their viewpoints, although future studies should evaluate differences within these groups.

CONCLUSIONS

The results of this survey suggest that for patients and families, physical care is expectedly crucial, but is only one component of total care. Whereas physicians tend to focus on physical aspects, patients and families tend to view the end of life with broader psychosocial and spiritual meaning, shaped by a lifetime of experiences. While physicians' biomedical focus is a natural outgrowth of medical care that emphasizes the physical self, physicians should recognize patients' other needs and facilitate means for them to be addressed. Physicians also should recognize that there is no one definition of a good death. Quality care at the end of life is highly individual and should be achieved through a process of shared decision making and clear communication that acknowledges the values and preferences of patients and their families.

Patients, families, and care providers each play a critical role in shaping the experience at the end of life. As our cultural lexicon of death and dying expands, further research is needed to define both the common ground and areas for negotiation as participants gather to construct quality at the end of life. A challenge to medicine is to design flexible care systems that permit a variety of expressions of a good death.

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REFERENCES

1. SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA*. 1995;274:1591-1598.
2. Wanzer S, Federman D, Adelstein S, et al. The physician's responsibility toward hopelessly ill patients: a second look. *N Engl J Med*. 1989;320:844-849.
3. Garvin J, Chapman C. Clinical management of dying patients. *West J Med*. 1995;163:268-277.
4. Council on Scientific Affairs, American Medical Association. Good care of the dying patient. *JAMA*. 1996;275:474-478.
5. Field M, Cassel C. *Approaching Death*. Washington, DC: Institute of Medicine; 1997.
6. Gibson R. The Robert Wood Johnson grantmaking strategies to improve care at the end of life. *J Palliat Med*. 1998;1:415-417.
7. Addington-Hall J, MacDonald LD, Anderson HR, Freeling P. Dying from cancer: the views of bereaved family and friends about experiences of terminally ill patients. *Palliat Med*. 1991;5:207-214.
8. Seale C. Communication and awareness about death. *Soc Sci Med*. 1991;32:943-952.
9. Seale C, Addington-Hall J. Dying at the best time. *Soc Sci Med*. 1995;40:589-595.
10. Schmidt T, Harrahill R. Family response to out-of-hospital death. *Acad Emerg Med*. 1995;2:513-518.
11. Hendrick C, Borden R, Geisen M, Murray J, Seyfried B. Effectiveness of integration tactics in a cover letter on mail questionnaire response. *Psychon Sci*. 1972;26:349-351.
12. Childers T, Ferrell O. Response rates and perceived questionnaire length in mail surveys. *J Market Res*. 1979;16:429-431.
13. Steinhilber K, Clipp E, McNeilly M, Christakis N, McIntyre L, Tulskey J. In search of a good death: observations of patients, families, and health care providers. *Ann Intern Med*. 2000;132:825-832.
14. Singer P, Martin D, Merrijoy K. Quality end-of-life care. *JAMA*. 1999;281:163-168.
15. Solomon M. The enormity of the task: the SUPPORT study and changing practice. *Hastings Cent Rep*. 1995;25:S28-S32.
16. Hanson L, Danis M, Garrett J. What is wrong with end-of-life care? opinions of bereaved family members. *J Am Geriatr Soc*. 1997;45:1339-1344.
17. Emanuel E, Emanuel L. The promise of a good death. *Lancet*. 1998;251:21-29.
18. Martin DK, Theil EC, Singer PA. A new model of advance care planning. *Arch Intern Med*. 1999;159:86-92.
19. Christakis N. *Death Foretold: Prophecy and Prognosis in Medical Care*. Chicago, Ill: University of Chicago Press; 2000.
20. Christakis N, Iwashyna T. Attitude of self-reported practice regarding prognostication in a national sample of internists. *Arch Intern Med*. 1998;158:2389-2395.
21. Erikson E. *The Life Cycle Completed: A Review*. New York, NY: WW Norton Co Inc; 1982.
22. Tulskey J, Cassileth B, Bennett C. The effect of ethnicity on ICU use and DNR orders in hospitalized AIDS patients. *J Clin Ethics*. 1997;126:381-388.
23. Garrett J, Harris R, Norburn J, Patrick D, Danis M. Life-sustaining treatments during terminal illness: who wants what? *J Gen Intern Med*. 1993;8:361-368.
24. O'Brien L, Grisso J, Maislin G, et al. Nursing home residents' preferences for life-sustaining treatments. *JAMA*. 1995;274:1775-1779.
25. National Hospice Organization. *New Findings Address Escalating End-of-Life Debate*. Arlington, Va: National Hospice Organization; 1996.
26. Fried T, van Doorn C, O'Leary J, Tinetti M, Drickamer M. Older persons' preference for site of terminal care. *Ann Intern Med*. 1999;131:109-112.
27. King D. Beliefs and attitudes of hospital inpatients about faith healing and prayer. *J Fam Pract*. 1994;39:349-352.