Preparing for the End of Life: Preferences of Patients, Families, Physicians, and Other Care Providers

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Abstract

To examine patients', families', and health care providers' preferences regarding preparation for the end of life, attributes of preparation were generated in qualitative focus group discussions and subsequently tested for generalizability in a quantitative national survey. Respondents from all groups showed consensus on the importance of naming someone to make decisions, knowing what to expect about one's physical condition, having financial affairs in order, having treatment preferences in writing, and knowing that one's physician is comfortable talking about death and dying. Patients were more likely than physicians to want to plan funerals and know the timing of death and less likely than all other groups to want to discuss personal fears. Participants in care of dying patients agree overwhelmingly with the importance of preparation. However, significant barriers to preparation impede it from being a common part of clinical encounters. Further research and training are needed to ensure that the desire for greater preparation is translated into improved action toward preparation in medical practice. J Pain Symptom Manage 2001;22:727–737 *© U.S. Cancer Pain Relief Committee, 2001.*

Key Words

Palliative care, physician-patient relationship, quality of life

Introduction

"It's not that I'm afraid to die. I just don't want to be there when it happens." (Allen Stewart Konigsberg, 1935, *Without Feathers*, "Death (A Play)," 1976).[1] Woody Allen's quip captures our popular culture's ideal of denying

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our own death. Such an image fits well with a medical culture that has often defined death not as a natural part of life but rather as the negative outcome in the fight against disease. To discuss death, we fear, is to remove hope.[2,3]

However, avoidance has consequences for patients, families, and physicians alike. A recent study of prognostication in pediatric cancer patients showed considerable delay between parental and physician recognition that the child was beyond cure.[4] Delay was associated with protracted curative and often invasive therapies. Alternatively, earlier recognition was linked to greater emphasis on lessening suffering, a value critical to both parents and providers. Too frequently in medicine, a crisis arrives in the absence of forethought. As a result, patients' wishes may not be known, family members are confused about choices, and health care providers may find themselves engaged in interventions perceived as futile.[5]

Frustration with these scenarios has propelled the ascendance of the hospice movement and other public and medical community efforts to improve end-of-life care. It suggests our society's growing dissatisfaction with a culture of denial. Though we often speak of desiring a quick or sudden death, most of us know this is unlikely, and therefore, want the opportunity to prepare for the end of our lives. However, our vocabulary to speak about preparation is limited in breadth, lacking the perspectives of the range of participants in care of the dying. What do patients consider important in the process of preparing for the end of their lives and how do their perspectives differ from the values of family members or health care providers?

One study of advance directive discussions among patients with HIV has begun to develop our understanding of what patients consider essential elements in their preparation for the end of life.[6] Facing death, a sense of control, and strengthening relationships were three components found in the discussions of these patients and provide an initial step in defining a language and conceptual model of preparation.

The purpose of this study is to expand the taxonomy of preparation using the results of both qualitative and quantitative data. These mixed modalities allow both richness of description and breadth of generalizability on important considerations at the end of life. We examine variability in definitions of preparation and the subsequent conflicts inherent in those definitions. We also present related attributes of life completion. We then consider the role that family members and providers play in contributing to the preparation process for patients, as well as the personal preparation they find helpful in the care of dying patients.

Methods

This study uses two data sources. First, we conducted focus group discussions and in-depth interviews to elicit, qualitatively, attributes of a good death. Subsequently, we distributed a national survey to quantitatively affirm or reject those themes. Detailed descriptions of the methods can be found elsewhere.[5,7]

Qualitative Data Design

Subjects. Over a 4-month period, we convened 12 focus groups, each of which had an average of 6 participants. A full spectrum of persons involved with end-of-life care—physicians, nurses, social workers, chaplains, hospice volunteers, patients, and recently bereaved family members—were included.

Data Collection. We asked focus group participants to discuss their experience with the deaths of family members, friends, or patients and to reflect upon what made those deaths good or bad. When necessary, we asked probing questions to clarify a comment or obtain more detail. After repeatedly analyzing focus groups transcripts, we conducted in-depth interviews with two members from each group. No new themes emerged through these interviews, thereby confirming exhaustiveness.[8] The interviewees were presented with our analyses and were asked to evaluate our interpretations. Trustworthiness was noted when participants responded affirmatively to researchers' interpretations.[8]

Analysis. Focus groups and interviews were audiotaped and transcribed. We used the grounded theory method of "constant comparisons" and its related open and axial coding techniques.[8,9] After identifying more than 70 attributes, we collapsed the full list into 6 broad domains. Although the themes are presented as conceptually distinct, attributes overlapped between domains. The illustrative quotes have been edited for ease of reading. We did not make any substantive changes but deleted repeated words and corrected grammatical inconsistencies that are common in spoken language.

Quantitative Data Design

This second phase of the study was a cross-sectional stratified random national survey of 1) physicians, 2) non-physician health care providers (nurses, social workers, chaplains, and hospice volunteers), 3) seriously ill patients, and 4) recently bereaved family members.

Subjects. Each group (physicians, non-physician providers, patients, and families) included 500 potential participants. Health care providers were selected at random from samples of membership lists of national professional associations. Physician and non-physician health care provider sample composition, sometimes weighted toward a particular sex, reflected the demographic profile of each association's national membership. Each group contained adequate representation to permit statistical analyses of the effects of sex. Patients were randomly selected from the National VA Patient Treatment File database for a variety of advanced chronic illnesses (lung, colon, gastric, esophageal, pancreatic, head and neck, and lymphatic cancer; end stage renal disease; advanced COPD; or CHF). All patients had been hospitalized within the year prior to the study. Family members were selected at random from national samples of recently bereaved relatives of VA patients who died between six months to one year earlier.[10–13] Patient and family samples reflected the ethnic and socioeconomic composition of VA patients. However, we over-sampled female patients (20%).

Design. We mailed 500 surveys to each of the four groups. Our choice of sample size was guided by a priori power calculations to provide adequate power to detect differences between groups.

Measurements. The full survey asked respondents to rate the importance of 44 attributes of experience at the end of life (see http://hsrd.durham.med.va.gov/PMEPC/htm). This study presents the results of those attributes associated with preparation and life completion. Participants rated the importance of each item on a 5-point scale: "strongly disagree," "disagree," "neither agree nor disagree," "agree," and "strongly agree."

Analysis. For descriptive parsimony (see Table 5), we collapsed the five response categories into three: "agree," "neither agree nor disagree" and "disagree." We used chi-square and, when appropriate, Fisher's exact tests of independence to compare responses between groups.

To identify independent correlates of two questions, we conducted exploratory analyses of factors associated with item endorsement category. We used stepwise logistic regression to model the likelihood of responding 'disagree' or 'neither agree nor disagree' versus 'agree' for a given statement (e.g., did physicians have greater odds than patients of not agreeing with a desire to know the timing of death?). Initial logistic regression models included an entrance criterion of $P < 0.15$ and removal criterion of $P < 0.20$. Results of the stepwise procedure were examined to select a final model for each question. Final model selection employed a stricter selection criterion of $P < 0.05$. Each question was initially tested on the full sample using the same set of covariates (Table 2); we present odds ratios and confidence limits only for significant covariates. Because income and education were co-linear with role, full sample SES effects could not be evaluated; the effects of income and education on patient and family responses were tested in separate analyses. Exploratory analyses revealed no differences in patients' responses by diagnosis; therefore, it was excluded from the multivariate models. In analyses not shown, we also modeled items as a three-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, SAS Institute, Cary, NC). The institutional review boards of the Veterans Affairs Medical Center and Duke University Medical Center approved both studies.

Results

Focus group participants ranged in age from 26 to 77 years (mean age 47 years) (Table 1).

Sixty-four percent were women, 70% were white, and 28% were African American. Most of the sample was Protestant (61%), 18% was Roman Catholic, and 8% identified themselves as Jewish. Six themes emerged: pain and symptom management, clear decision-making, preparation for death, completion, contributing to others, and affirmation of the whole person. As mentioned, we present data related to preparation and completion.

Of the 2000 mailed surveys, 1885 potential subjects were reachable (i.e., had not moved or died). We received 361 of 486 responses from physicians (74%), 429 of 490 non-physicians providers (88%), 340 of 444 of patients (77%) and 332 of 465 bereaved family members (71%). (Total $n = 1462$). Respondents had an average age of 57; 51% were male, 81% were Caucasian (Table 2). Non-respondents did not differ from respondents with regard to sex, ethnicity, diagnosis, or geographic location.[7] In the next section, we present results of the national survey showing the affirmation or rejection of attributes of preparation and completion. We then offer qualitative illustrations of those themes.

Components of Preparation

Ten survey items were related to issues of preparation (Table 3) Patients, family members, and health care providers overwhelmingly agreed with the general importance of being prepared for the end of life and knowing that one's family is prepared. Respondents from all groups also showed consensus on the importance of five other components of preparation: naming someone to make decisions, knowing what to expect about one's physical condition, having financial affairs in order, having treatment preferences in writing, and knowing that one's physician is comfortable talking about death and dying.

Table 1

Focus Group Participant Characteristics ($n = 75$)

Age range	26–77
Mean age	46.8
Sex	
Male	36%
Female	64%
Ethnicity	
African American	28%
Asian American	3%
White	70%
Religious affiliation	
Protestant	61%
Roman Catholic	18%
Jewish	8%
Other	3%
No affiliation	11%
Recruitment source	
VA Medical Center	57%
University Medical Center	24%
Community hospice	19%

Some categories do not sum to 100%, due to rounding.

Patients, family members, and non-physician health care providers were significantly more likely ($P < 0.0001$) than physicians to agree with the importance of having funeral arrangements planned. Survey respondents expressed broad variation regarding the importance of knowing the timing of death (39% of patients agreed) and controlling the time and place of death (40% of patients agreed).

All focus group discussions, (physicians, non-physician providers, patients, and families) mentioned the importance of preparation. Their comments, that follow, provide a richer illustration of the survey results and offer some clinically relevant insights.

”If one has time to prepare for death then they have more control over whether their own death is good or bad,” was a common sentiment expressed in focus group discussions. The motivation for much of patients' desire for preparation was to remove burden from loved ones. One man with AIDS told us that planning the details of his funeral, cremation, and service, “eases my mind.” Or as one social worker explained,

> I've already made a will because I'm a single parent and I didn't want my children to have to go through making decisions that would be difficult, so to take the burden off them.

Making treatment preferences known was also perceived as a way of removing burden. Family members expressed relief in knowing they were following the wishes of their loved one. The process allowed one chaplain later to describe his mother's death as a good death.

> My sister and I had an opportunity to sit down with my parents and talk about their advance directives, talk about their funeral arrangements, and spend the whole afternoon thinking about death and what would happen in this situation and that situation.

Table 2
Demographics of Survey Respondents

Variable	Total	Patient	MD	HCP	Family
Sex (%)					
Male	51	78.2	81.7	27.3	21.3
Female	49	21.8	18.3	72.7	78.7
Mean age (yrs.)	57	68	52	51	62
Ethnicity (%)					
African American	7.4	15.6	1.4	3.3	11.3
Asian American	3.6	2.5	10.3	0.5	1.3
Caucasian/White	81.6	69	80.4	94.8	77.8
Latino	2.2	2.8	2.8	0.7	2.8
Native American	3.4	8.6	0.3	0	6.3
Other	1.9	1.5	4.7	0.7	0.6
Education (%)					
Less than high school	15.8	30.4	–	0	22
High school/GED	29.3	44.2	–	3.5	48.3
Associate of Arts Degree	7.4	10.1	–	3.7	9.6
Bachelors Degree	8.2	5.8	–	8.7	9.9
Graduate/Professional	39.3	9.5	100	84.1	10.2
Income (%)					
$0–9,999	26.3	29.7	*	*	22.7
$10,000–$19,999	32.8	40.9	*	*	24.1
$20,000–$34,999	10.4	19.8	*	*	19.9
$35,000–$49,999	10.4	6.6	*	*	14.3
more than $50,000	10.7	3	*	*	18.9
Religion (%)					
Protestant	54.7	60.3	33.9	62.4	61.9
Roman Catholic	22.7	24.8	24.3	18.9	23.8
Jewish	6.5	1.5	18.1	5	0.6
Muslim	0.6	0	2.5	0	0
Other	5.3	3.6	9	3.5	5.1
No religion	10.2	9.7	12.1	10.2	8.6
Living arrangement (%)					
Spouse	34	40.6	33.2	41.3	18.9
Parent	1.9	2.8	0.9	1.8	2.3
Child	36.7	20.8	55	43.1	35.4
Alone	24.5	35.8	10.9	30.6	43.4
Marital status (%)					
Married	62.7	47.9	86.6	75.1	34.9
Widowed	17	17.6	2.8	3.3	50
Divorced/Separated	12.9	27.9	3.1	10.8	11.1
Never Married	7.5	6.7	7.5	10.8	4
Importance of faith (%)					
Very important	66.2	61.3	47.5	81.1	72.3
Somewhat important	27.4	32	39.9	15.8	23.4
Not at all important	6.6	6.7	12.6	3.1	4.4
Attend religious service (%)					
More than once a week	10.7	8.4	4	16.1	13.1
Every week	26.5	16.2	22.7	38.1	25.9
2 or 3 times a month	11.2	8.4	12.5	12.5	10.9
Once a month	12.2	15	18.1	7.1	9.3
Once or twice a year	23	28.7	25.2	17.7	21.4
Never	16.4	23.4	17	8.5	19.2
General health (%)					
Excellent	27.3	0.6	54.7	38.4	9.3
Very good	26.9	4.9	28.8	44.1	24.5
Good	21.2	20.7	14.5	14.4	37.9
Fair	16.1	41.7	1.4	2.8	23.6
Poor	8.6	32	0.6	0.2	4.7
Overall mood (%)					
Not at all depressed	57.3	32.1	75.1	73	42.8
Slightly depressed	29.8	40.1	21.5	24.2	35.3
Moderatley depressed	8.6	16.5	3.4	1.9	15
Quite depressed	3.2	8	0	0.5	5.3
Extremely depressed	1.1	3.4	0	0	1.6
With someone in last hour (%)					
Yes	83.3	60.1	97.2	94.4	77.3
No	16.7	39.9	2.8	5.6	22.7

*Health care providers were not asked to report their income.
MD = doctor; HCP = health care provider.

Table 3
Preparation Attributes

Attribute	Patient (%)	Family (%)	MD (%)	HCP (%)
Name someone to make decisions	98	98	98	99
Know what to expect about one's physical condition	96	93	88	94
Have financial affairs in order	94	94	91	90
Know that one's doctor is comfortable talking about death and dying	86	85	93	97
Feel family is prepared for one's death	85	88	83	90
Feel prepared to die	84	81	79	87
Have funeral arrangements planned	82		58	
Treatment preferences in writing	81	85	73	90
Control the time and place of one's death	40	38	36	44
Know the timing of one's death	39	49	26	35

MD = doctor; HCP = health care provider.

Unfortunately, we heard many alternative stories that left patients suffering, families confused, and physicians engaged in treatment perceived as futile, as in the case of a woman with advanced breast cancer and brain metastases who arrived in the emergency room.

> There was a full code in progress. I walked in the room and could see this person had no hair and one breast was missing. And I said, "Wait a minute, why are we flogging this person?" They said, the husband wasn't ready for her to go. And, I think he needed to see what "do everything you can" meant. Unfortunately, the patient is the one that suffers.—**Nurse**

In response, we repeatedly heard comments about the importance of both the patient and family knowing what to expect about the course of illness. One nurse suggested this begin

> . . . by educating people about death. In particular some of the chronic pulmonary disease patients that are so fearful of being short of breath—with their wives, family members and caregiver—educate them, talk with them about it.

Another nurse proposed that end-of-life preparation was, "something that we need to incorporate into our living, learning about how to die successfully."

Family members spoke with gratitude about hospice volunteers who educated them about their husband or wife's physical decline, from changes in eating to sleeping to breathing.

> Whatever you ask, they tell you, whether you want to hear it or not, that's good. I asked, "Why is his urine brown?' She told me, "His kidneys are shutting down." After, my husband would ask what we were talking about and I would tell him. He may not have wanted to hear it, but we'd talk about it.

One woman told us about her stepchildren who would say, "Daddy is starving to death." She had never experienced a death before and because hospice prepared her, she was able to tell the family, "No, he's not. His body's shutting down and we have to realize that."

However, while most spoke about the importance of preparation, we also heard stories about the difficulty of beginning the conversation.

> We don't often times, when we know that their prognosis is not particularly good, start the preparation early on.—**Nurse**

Caring for dying patients evokes feelings of one's own mortality, "a universal struggle with the finitude we human beings have," as one chaplain noted. The degree to which one has reconciled those emotions effects one's ability to attend to the fears of another.

> When it comes to death, you carry all your own baggage with you. You may think you're meeting the patient where they're at, but you're also meeting the patient where you're at. It's hard to navigate your own stuff while trying to help someone else.—**Social worker**

In response, many of the non-physician health care providers spoke at length about the importance of developing a personal philosophy of caring for dying patients. That philosophy often included a willingness to address the complexity of caring for patients with serious chronic illness.

> I want to do everything I can to encourage living long and healthy, trying to not have an

> air of pessimism, give optimism. But, I also want to be real with them. These issues are important.

Many suggested that facings one's own fears of helplessness in the face of death and learning to balance the need for hope and preparation are central to much of the conflict in end-of-life care. **—Social worker**

Components of Completion

Participants reported that if one had adequate time to prepare for the end of life, they may engage in a process of achieving a sense of completion or closure (Table 4). The results of the national survey show strong consensus about several specific items relating to the theme of completion. All groups agreed with the value of saying goodbye to important people, sharing time with close friends, resolving unfinished business, and remembering personal accomplishments.

Patients were significantly more likely than physicians to say this time included coming to peace with God and praying ($P < .0001$). Health care providers, including physicians, were significantly more likely than patients to agree with the importance of talking about the meaning of death and discussing personal fears about dying (Table 5).

Most focus group participants spoke extensively about the importance of resolving and expressing feelings about the meaning of life and death, and frequently about their understanding of their relationship with their God.

> When terminally ill patients discuss death and dying, religion and spirituality issues almost always come up. Patients do a lot of reflecting on their lives. A lot of times they want to share what their experience has been on earth or with God. Sometimes you see fear of the unknown. Comfort in discussing it depends on how strong their faith or what their relationship is with their supreme being. **—Social worker**

Many non-physician providers, when reflecting on deaths they have attended, spoke with regret about not being more proactive in facilitating discussion of fears that, as a result, left patients and families unresolved at the time of death. One nurse related a widespread sentiment when discussing the death of her brother.

> I never really felt like they communicated those last wishes or thoughts. As a result, I think he died pretty much alone. To go through that experience again, I would definitely have a lot more input.

Multivariate Analyses

Four items related to preparation and completion showed a broad range of importance ratings, and therefore demand further analyses to test possible sources of variation. Results of two items, controlling time and place of death and talking about the meaning of death have been summarized elsewhere.[7] We, therefore, focus on multivariate analyses of preference for knowing the timing of death and discussing personal fears.

Knowing the Timing of Death. A desire to know the timing of death was related to participant's role (e.g., physician vs. patient). Physicians were significantly less likely (odds ration [OR] 0.54; confidence interval [CI] 0.38–0.77) than patients to agree with the importance of knowledge of the timing of one's death. Family members were significantly more likely to agree (OR 1.49; CI 1.1–2.1). Non-physician health

Table 4
Completion Attributes

Attribute	Patient (%)	Family (%)	MD (%)	HCP (%)
Say good-bye to important people	90	92	95	99
Be at peace with God	89		65	
Resolve unfinished business with family or friends	86	85	87	97
Share time with close friends	85	91	91	96
Pray	85		55	
Remember personal accomplishments	74	80	78	91
Discuss personal fears about dying	61	80	88	94
Have a chance to talk about meaning of death	58	72	66	86

MD = doctor; HCP = health care provider.

Table 5
End-of-life Considerations with Broad Respondent Variation

	Patient (%)			Family (%)			MD (%)			HCP (%)		
Attribute	Agree	Neither	Disagree	Agree	Neither	Disagree	Agree	Neither	Disagree	Agree	Neither	Disagree
Discuss personal fears	61	28	11	80	16	4	88	11	1	94	5	1
Have a chance to talk about the meaning of death	58	33	9	72	26	3	66	29	5	86	12	1
Control the time and place of one's death	40	35	24	38	40	22	36	39	25	44	30	25
Know the timing of one's death	39	39	22	49	35	16	26	46	29	35	47	18

MD = doctor; HCP = health care provider.

care providers were less likely to rate preference for knowing timing of death, but not significantly so. In separate analyses for patients and families, neither income nor education level were significantly associated with preference for knowing the timing of death; those who never married were significantly less likely (OR 0.32; CI 0.15–0.65) to agree. Preference appeared not to be associated with sex, ethnicity, religious affiliation, or religiosity.

Discussing Personal Fears about Dying. Preference for discussing personal fears was significantly associated with role, sex, and religiosity. Unexpectedly, physicians (OR 5.56; CI 3.57–8.33), nonphysician providers (OR 6.67; CI 4.0–11.1), and family members (OR 1.92; CI 1.20–3.03) were all more likely to agree with the importance of discussing fears than were patients. As expected, women were more likely (OR 1.72; CI 1.15–2.56) to show preference for discussing personal fears. Those for whom faith or spirituality was somewhat (OR 0.55; CI 0.38–0.78) or not at all important (OR 0.48; CI 0.26–0.89) were less likely than those for whom faith was important to want to discuss personal fears. Preference for discussing fears was not associated with income, education, ethnicity, or religious affiliation.

Discussion

Despite our popular cultural notions of death denial, both focus group and national survey data show an overwhelming preference for an opportunity to prepare for the end of life. All role groups agreed naming someone to make decisions and having those decisions in writing are two key components of that preparation. Respondents also showed consensus on the desire to know what to expect about their physical condition. Most affirmed the importance of knowing that one's family was prepared for their death which often included having finances in order, and for patients, having funeral arrangements planned.

We also heard that when patients have adequate warning, they are given an opportunity to resolve unfinished business, remember personal accomplishments, and say goodbye to important people, a process sometimes referenced as "integrated dying."[14,15] Interestingly, while physicians agreed with the importance of these individual items, they were significantly less likely than patients to note the importance of feeling life was complete. Physicians' focus group discussions about completion and life review were more limited in length and frequency than all other groups.[5]

Knowing the Timing of Death

A desire to know the timing of death has implications for the importance of prognostication in clinical practice. To what extent do patients and their families desire preparation in the form of predictions of the timing of the very end of life, and how do those preferences compare with the desires and practices of physicians? Patients and families in this sample were significantly more likely than physicians to consider such knowledge important. Despite controlling for sex, ethnicity, religiosity, and presence at another's death, role was the predominant characteristic driving variation in this attribute.

In previous studies, researchers have shown the complexity of attitudes regarding prognostication; 60.4% of physicians reported such discussions were stressful and 56.8% reported inadequate training in prognosis.[16] Furthermore, physician respondents in that survey showed considerable variation in definitions of terminal illness ranging from less than 4 weeks to more than 36 weeks to live. Preparation for the end of life in the form of predictions of timing may, therefore, be limited by discomfort, skill deficits, and ambiguity in knowledge of appropriate definitions of the "end of life."

Discussing Personal Fears

As expected, women and those with higher levels of religiosity were more likely to express a preference for discussing personal fears at the end of life. However, patients were the least likely of any role group to want to discuss their fears. This finding is similar to previous analyses showing patients also were less likely to want to talk about the meaning of death.[7]

Yet patients clearly value many dimensions of overall preparation as well as attention to life completion and spirituality. There are several possible explanations for this contradiction. The findings may suggest that patients desire a meaningful death without fear, but may have less of a need to process verbally those emotions. Health care providers may work to be sensitive to the extent to which patients process such issues internally versus through an interactive process of reflection. Response to this question also may be influenced by the veteran status and cohort of the sample. Older male veterans may be more likely to portray stoicism in the face of fear. Finally, and perhaps most importantly, it also simply may be that discussing personal fears is the hardest part of preparation. Tasks of having finances in order or planning a funeral may occur at any point in serious illness or even in the absence of illness. However, feeling personal fears suggests that death is more imminent and evokes some of the fundamental questions of being human. It causes patients to explore sometimes painful emotions and often opens a door to the unknown: what has my life meant and what is next? It challenges hope and many believe that hope cures. Some evidence suggests that patients in "denial" live longer and we are afraid to diminish quantity of life.[17–19] Patients, families, and physicians each may be afraid to begin that exploration; they also may desire to protect others from feeling pain.

Family members showed the strongest preference for discussing personal fears, and these data remind us of the centrality of families in the unit of care. Families have the dual task of attending to the patient's need for preparation and attending to their own preparation for the patient's death and their own future. For example, learning what to expect about physical decline permits families to make appropriate choices about participation in home care or planning timing of when relatives may travel for final goodbyes.[5] Because many in our culture are removed from care of the dying, clinical benchmarks signaling impending death to physicians may not be obvious to family members. Furthermore, previous research has shown significant association between caregivers being informed and overall satisfaction with practitioners.[20] Some evidence also suggests that longer participation in palliative care decreases anxiety among family members prior to bereavement.[21]

The most interesting interpretation of these data may not be what they confirm about the importance of preparation, but the contradiction they expose. Although most respondents advocated the value of preparation, previous studies show actual discussions about preparing for end of life are less frequent.[22,23] The data in this survey prohibit a test of causality, but prior research offers some possible explanations. First, it may expose disparities in skill training. Physicians are only recently beginning to receive training in communication at the end of life. Rather than experiencing frustration with "nothing left to offer" dying patients, appropriate palliative medicine training may equip physicians to propose an array of non-curative therapies.

Second, discussions to prepare for death and dying may evoke discomfort due to a sense of failure or removal of hope. One study showed 75.1% of physicians surveyed found it helpful to "shade prognosis to the positive," or, when patients are optimistic, reinforce their perceptions (63.5%). Physicians (43.7%) also said they waited to be asked by patients before offering a prediction.[16] Two recent studies note that a sense of hopelessness was associated with a greater desire for physician-assisted suicide and hastened death.[24,25] Removal of hope is clearly at the heart of many physicians' fears. Could their prognosis become a self-fulfilling prophecy?[26] Physicians know how to treat depression, but there is no pill for hopelessness. With patients avoiding emotions and protecting others from pain and physicians resisting fears of hopelessness, each party is waiting for the other to begin the conversation.[27] However, given the disparity in medical knowledge and fiduciary nature of the physician–patient relationship, it is the physician's responsibility to begin conversations of preparation.[28]

In addition to acquiring specific communication training, physicians may be reminded that many allied health professionals are available to facilitate discussions of preparation. In previous focus groups and interviews, most social workers, nurses, and chaplains engaged in extensive discussions about the multiple dimensions of preparation. In a recent study of pediatric oncology patients and their families, the presence of a psychologist or social worker increased the likelihood of prognostic discussions and preparation for death via cessation of curative therapies.[4]

Non-physician health care providers also articulated their personal preparation for dealing with dying patients that involved exploration of their own issues of mortality.[5] Physicians' own emotions play a large role in their comfort discussing these issues with patients. Therefore, they need greater exposure to personal awareness and self reflection in training.[29]

Limitations

This study has several limitations. Patients and family members were recruited, for the survey, from VA Medical Centers, and therefore generalizations to other groups should be made cautiously. However, participants' preferences reflected deaths in a variety of settings including hospitals, hospice, and home. Patients and families participating in the study represented broad age, educational, and socioeconomic ranges. Many also received care in the private sector, and their opinions reflect experiences in multiple settings. The majority of patients were men; the survey sample included 20% women patients to permit sufficient statistical power to detect sex differences. Also, patients were predominantly African American and Caucasian. Finally, patients were recruited based on illness from chronic disease rather than accident or trauma.

Prior to the 20th century in Western culture, sudden death, without preparation, was considered a tragedy.[30] In the last fifty years, the denial of death may have reached its cultural apex. Though not always certain of how to proceed, the data from this study reveal broad consensus from all participants regarding a desire for preparation for the end of life and may signal a realignment in the way Americans view death and want to shape the end of their lives. The sheer number of baby boomers caring for dying parents and moving through their own dying, in the next 50 years, will force a certain degree of collective attention to end-of-life issues. These data confirm that end-of-life preparation will include understanding physical changes and anticipating the concomitant psychosocial and spiritual changes that occur as death approaches. Further research and training are needed to ensure that the desire for greater preparation is translated into improved action toward preparation in medical practice.

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