

Quality End-of-Life Care Patients' Perspectives

Peter A. Singer, MD, MPH, FRCPC

Douglas K. Martin, PhD

Merrijoy Kelner, PhD

BECAUSE EVERYONE DIES, END-OF-life care is among the most prevalent issues in health care. Both health care professionals and patients see room for improvement.¹ Encouragingly, major initiatives, such as the American Medical Association's Education for Physicians on End-of-Life Care project, Open Society Institute's Project on Death in America, and Robert Wood Johnson Foundation's Last Rites Campaign, are under way to improve the quality of end-of-life care.

A necessary scientific step to focus these efforts is the development of a taxonomy or conceptual framework for quality end-of-life care.² However, what end-of-life care means and how to measure it is still a matter of debate and ongoing research. Three expert groups have recently published frameworks for quality end-of-life care (TABLE 1).³⁻⁵ These taxonomies derive from the medical expert perspective rather than the perspective of patients and families.⁶ We are unaware of any descriptions of quality end-of-life care from the patient perspective, from which quality end-of-life care is arguably most appropriately viewed. This is the perspective that clinicians and health care organizations will need to understand to improve the quality of care they deliver to dying patients. Therefore, the purpose of this study was to identify and describe elements of quality end-of-life care as identified by those most affected: patients.

METHODS

Design

This study used a qualitative research method called *content analysis*, in which

Context Quality end-of-life care is increasingly recognized as an ethical obligation of health care providers, both clinicians and organizations. However, this concept has not been examined from the perspective of patients.

Objective To identify and describe elements of quality end-of-life care from the patient's perspective.

Design Qualitative study using in-depth, open-ended, face-to-face interviews and content analysis.

Setting Toronto, Ontario.

Participants A total of 126 participants from 3 patient groups: dialysis patients (n = 48), people with human immunodeficiency virus infection (n = 40), and residents of a long-term care facility (n = 38).

Outcome Measures Participants' views on end-of-life issues.

Results Participants identified 5 domains of quality end-of-life care: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones.

Conclusion These domains, which characterize patients' perspectives on end-of-life care, can serve as focal points for improving the quality of end-of-life care.

JAMA. 1999;281:163-168

www.jama.com

“standardized measurements are applied to metrically defined units [of text] and these are used to characterize and compare documents.”⁷

Participants

We analyzed data from interviews with patients who participated in 3 recent studies.⁸⁻¹⁰ Participants from the 3 studies were dialysis patients, persons infected with the human immunodeficiency virus (HIV), and residents of a long-term care facility. In this study, we examined all participant interviews from the dialysis (n = 48) and long-term care (n = 38) studies, and a random selection of 40 participant interviews (from a total of 140 participants) from the HIV study.

Dialysis patients were a sample of individuals receiving hemodialysis at all 6 units serving adults in metropolitan Toronto, Ontario. They were originally enrolled in a study examining the accept-

ability of generic vs dialysis-specific advance directive (AD) forms¹¹ and interviewed 6 months later.⁸ Participants were excluded if they were younger than 18 years, were unable to understand written English, were incapable of completing an AD form, would experience undue emotional distress from completing an AD form, had received dialysis for less than 3 months, or refused to participate in the research. Of 532 patients receiving hemodialysis, 310 were excluded, 81 refused, 43 withdrew, 7 died, 43 were not approached, and 48 completed the study.

Author Affiliations: Toronto Hospital and the Department of Medicine (Dr Singer), Joint Centre for Bioethics (Drs Singer and Martin), and the Institute of Human Development, Life Course, and Aging (Dr Kelner), University of Toronto, Toronto, Ontario.

Corresponding Author and Reprints: Peter A. Singer, MD, MPH, FRCPC, University of Toronto Joint Centre for Bioethics, 88 College St, Toronto, Ontario, Canada M5G 1L4 (e-mail: peter.singer@utoronto.ca).

Participants with HIV were a sample of persons who responded to the study advertisements or posters distributed by the AIDS Committee of Toronto and placed in the waiting rooms of the Toronto Hospital Immunodeficiency Clinic. They were originally enrolled in a previous study that examined the preference for either an HIV-specific or generic AD form¹² and interviewed 6 months later.⁹ Participants were excluded if they were younger than 16 years, were not fluent in English, could not read, were incapable of completing an AD form (as measured by a Standardized Mini-Mental State Examination test score <23), would experience undue emotional distress from completing an AD form, resided outside metropolitan Toronto, or refused to participate in the research. Of 587 possible participants, 200 were not approached for the study, 85 were excluded, 52 refused, 93 withdrew, 17 died, and 140 were interviewed (of whom 40 were randomly selected for this analysis).

Long-term care residents were a sample of persons from a 398-bed hospital in Toronto that provides both rehabilitative and long-term care for adults who are chronically ill and disabled by neurological problems, respiratory conditions, amputations, and age-related disorders.¹⁰ The purpose of the original study was to examine residents' views about control at the end of life. Three criteria were estab-

lished for selecting participants: patients had to be 65 years or older, capable of understanding and answering questions in English, and healthy enough, both physically and mentally, to take part in a short interview. Nurse managers recruited participants in each unit of the hospital in which appropriate patients could be identified. No patients refused. The 38 participants represent the total population of eligible patients during the data collection period.

Data Collection

Data were gathered by in-depth, open-ended, face-to-face interviews. The interviewer asked open-ended questions, followed up participants' responses, pursued themes as they arose, and sought clarification or elaboration as required. In the dialysis and HIV studies, the interviews were audiotaped and transcribed; in the long-term care study, the interviewer wrote down the participants' comments. Opportunities were consistently made available for participants to express unsolicited opinions and recount their clinical experiences and life histories. As the interviews proceeded and ideas were suggested by patients' reflections and clarifications, new questions were added and others were refined. The interview guide was modified to follow up issues emerging from the data as the interviews and analysis progressed.

The initial interview guide for dialysis patients covered 3 themes: (1) had the

participant completed an AD form? (2) if not, why not? and (3) if so, what was the process and was it acceptable?

In the HIV study, participants were asked about their reasons for engaging in advance care planning (ACP), the process and content of their ACP discussions, their perspective on the importance of ACP, and their evaluation of the ACP process.

Long-term care residents were asked the following questions about patient control at the end of life: (1) had they previously thought about it? (2) what were their general views on control over decision making at the end of life? (3) what would be their personal preference "when the time comes"? (4) did they see any potential obstacles to having their wishes honored? and (5) what were their personal views about withdrawal or termination of treatment, as well as euthanasia and physician-assisted suicide?

Data Analysis

The data were read and participants' views regarding quality end-of-life care were identified. These units of text were underlined and descriptive notes were written in the margins of the transcripts, a process referred to as *coding*. Coded units were then labeled as specific end-of-life care issues. Many issues were not mutually exclusive, but issues that were conceptually different were given different descriptive labels. Labeled issues were then compared within and between interviews. Similar issues were grouped together under 1 overarching domain label and the data were recoded by domain. The prevalence of each domain was recorded and descriptive statements about each were developed using the patients' words. Quotes that were selected for presentation in the article were good illustrations of the domain and provide data from the various patient populations. This process was conducted by 1 analyst (D.K.M.), who frequently consulted with a second analyst (P.A.S.) regarding excerpts of the primary transcript data and the clustering of the data into domains.

Several steps were taken to verify the results, a concept in qualitative research analogous to reliability and va-

Table 1. Domains of Quality End-of-Life Care

<i>Journal of the American Geriatrics Society Statement</i> ³	<i>Institute of Medicine Committee</i> ⁴	<i>Emanuel and Emanuel</i> ^{5*}	<i>Patient Perspectives</i> [†]
<ul style="list-style-type: none"> Physical and emotional symptoms Support of function and autonomy Advance care planning Aggressive care near death Patient and family satisfaction Global quality of life Family burden Survival time Provider continuity and skill Bereavement 	<ul style="list-style-type: none"> Overall quality of life Physical well-being and functioning Psychosocial well-being and functioning Spiritual well-being Patient perception of care Family well-being and perceptions 	<ul style="list-style-type: none"> Physical symptoms Psychological and cognitive symptoms Social relationships and support Economic demands and caregiving needs Hopes and expectations Spiritual and existential beliefs 	<ul style="list-style-type: none"> Receiving adequate pain and symptom management Avoiding inappropriate prolongation of dying Achieving a sense of control Relieving burden Strengthening relationships

*Modifiable dimensions of patient's experience" from Emanuel and Emanuel.⁵
 †Patient perspectives are from the current study.

lidity in quantitative research.^{13,14} These included (1) use of 3 separate data sets to verify the conceptual domains, (2) general familiarity with the data sets by investigators (P.A.S. and M.K.) other than the primary analyst, (3) systematic checking of the developing conceptual domains against supporting quotations by a second analyst (P.A.S.), (4) review of the manuscript by an independent scholar studying quality end-of-life care (James Tulsky, MD), and (5) explicit comparison of our taxonomy with 3 other taxonomies derived from a different methodological perspective.³⁻⁵

Sample Size

Sample size was not formally calculated. Instead, participants were enrolled until no new concepts arose during analysis of the successive interviews, a concept called *saturation* by qualitative researchers.

Research Ethics

All 3 studies were approved by the University of Toronto Committee on Research With Human Subjects, and written informed consent was obtained from all subjects.

RESULTS

Demographic characteristics of the 126 patients from the 3 data sets are shown in TABLE 2. As shown in TABLE 3, the analysis identified 5 domains of quality end-of-life care: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening of relationships with loved ones. The next most prevalent theme was mentioned by less than 5% of participants. We present a description of these domains with verbatim quotes from participants.

Receiving Adequate Pain and Symptom Management

Pain was a concern for many respondents. A few participants mentioned other symptoms such as vomiting, breathlessness, and diarrhea.

I've been adamant that I wanted treatment in sort of end stage to be minimal—pain reduc-

tion, but not life sustaining. I don't—if anyone could say they did—like being in pain and I don't find the idea of being incontinent or bowel-dysfunctional, not to mention mentally incompetent, remotely interesting.

I wouldn't want a lot of pain; it's one of the worst ways to go.

If I'm in pain, severe pain, and the doctors can do nothing, the pain persists and there's nothing to take the pain away, I don't think it's fair to let me suffer like that, or anybody. We don't let the animals suffer; why should we?

Avoiding Inappropriate Prolongation of Dying

Participants were afraid of “lingering” and “being kept alive” after they no longer could enjoy their lives. Quality-of-life concerns seemed to fuel this fear; many

were terrified of becoming a “vegetable” or living in a coma. These participants adamantly denounced “being kept alive by a machine.” They wanted to be “allowed to die naturally” or “in peace.”

I didn't want to be kept alive artificially forever just to die later on and suffer, you know, without need for an extra year. Let me go anyway. Get it done with the first time.

I wouldn't want life supports if I'm going to die anyway. There's no dignity in it. It's just a guinea pig thing.

I've always told my mother . . . if it ever comes down to being put on a life-support system, I wouldn't go for it unless there's a chance that I would come around and be normal again. But if there is a chance of me being put on a life-support system and becoming a vegetable, I said forget it.

Table 2. Participant Characteristics

Characteristics	Participants		
	Dialysis (n = 48)	HIV* (n = 40)	Long-term Care (n = 38)
Sex, No.			
Male	30	35	13
Female	18	5	25
Race/ethnicity, No.			
White	30	37	35
African American	8	0	0
Hispanic	2	1	0
Asian	3	0	0
Other	5	2	3
Education, No.			
No high school	2	0	6
Some high school	4	3	12
High school graduate	13	3	9
Some college	7	17	3
College graduate	22	17	8
Age, mean (range), y	48.3 (20-80)	39.6 (25-54)	76.3 (65-≥85)†

*HIV indicates human immunodeficiency virus.

†In long-term care study, data were gathered by strata. Therefore, mean age was derived using an estimated and weighted calculation.

Table 3. Domains of End-of-Life Care From Patients' Perspectives*

	Participants			
	Dialysis (n = 48)	HIV/AIDS (n = 40)	Long-term Care (n = 38)	Total (N = 126)
Receiving adequate pain and symptom management	3 (6.2)	10 (25.0)	15 (39.5)	28 (22.2)
Avoiding inappropriate prolongation of dying	23 (47.9)	29 (72.5)	25 (65.8)	77 (61.1)
Achieving a sense of control	9 (18.8)	21 (52.5)	18 (47.4)	48 (38.1)
Relieving burden	14 (29.2)	21 (52.5)	13 (34.2)	48 (38.1)
Strengthening relationships with loved ones	16 (33.3)	21 (52.5)	12 (31.6)	49 (38.9)

*Data are number (percentage). HIV indicates human immunodeficiency virus; AIDS, acquired immunodeficiency syndrome.

Achieving a Sense of Control

Participants were adamant that they wanted to retain control of their end-of-life care decisions while they were capable of doing so, and that they wanted the proxy of their choice to retain control if they became incapable.

I have very definite ideas of what I would want done and what I wouldn't want done, especially after watching various friends go through their deaths.

I want control, but it shouldn't be disruptive. It can be productive if it's thoughtful and if others are consulted.

That's my life. Nobody has any right to tell me that. I can't let a stranger talk me out of anything. That's what I want. They don't know how I live. It's very, very important to me now that I can make choices for myself.

Relieving Burden

The participants were greatly concerned about the burden that their dying would impose on loved ones. They identified 3 specific burdens: provision of physical care, witnessing their death, and substitute decision making for life-sustaining treatment.

I don't want them making the decisions for me without knowing how I would decide the same thing. It just makes life easier for everybody. They don't have to say, 'Well, what would he do in this situation?' if it's already written down. I know if I was incapacitated, it would be a stressful time for the people I've chosen as my proxy. It would be tough in some situations to make those decisions. So by doing it in advance I save them the bother. . . . I chose not to designate my parents as proxies. I felt that would probably be a little bit hard on them. I mean, I'm sure they'd be willing to do so, but I think from the standpoint of just saving their feelings as much as possible, I'd rather not have them make those decisions, if the time came that it was necessary.

I'd want to die here, not at home. I wouldn't want to put that burden on my family.

I hope to stop myself from becoming a burden to them [children]. Looking after somebody either takes a lot of money, in which case you may get somebody to baby-sit for you, or you have to do it yourself, and I do not wish my children to be in the position of having to do that. Therefore, I would rather die faster than later.

Strengthening Relationships With Loved Ones

A majority of participants felt that considerations with respect to loved ones

were integral to their dying experience. For the dying experience to be meaningful, participants desired the full involvement of loved ones in communication about their dying. At times, this meant overcoming resistance, their own and others', to engage with uncomfortable subject matter. But even so, participants felt that the need for communication with loved ones was of overwhelming importance. When this intimacy was achieved, participants found their relationships strengthened.

I've never told anyone in my family that I was HIV-positive. And so, in order to complete my living will, I had to tell him [brother] I was HIV-positive, which was really quite a challenge for me. And I did tell him, and everything has just worked out fine. He's a hundred percent supportive and it couldn't be better. Our relationship is even closer now; we were close before—we've always been a close family. But now we're really close.

It was one of the decisions we discussed and she [wife] says when I am in this situation she is capable to make decisions for me. She didn't want to leave it to me because I cannot make decisions when I, you know. It was nice because she was showing me this kind of love and this kind of sympathy; when I am in that situation, she will be able to continue assisting me. So I was very happy about that, really. She always tells me she is going to be there for me when I cannot make a decision.

It helped me get closer to my family, to get an idea how they feel about me. There were so many times I wanted to get their opinion on certain things, and when I discussed that with them they showed me that they are going to be there for me every time.

COMMENT

From these patients' perspectives, quality end-of-life care includes 5 domains: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden on loved ones, and strengthening relationships with loved ones.

Comparison With Expert Models

Table 1 compares the patients' perspectives on quality end-of-life care with 3 models derived from an expert perspective. The similarities among the models support the validity of the con-

ceptual domains with respect to all the models.

There are also important differences between patient- and expert-derived models. First, compared with taxonomies from an expert perspective, the patient-derived description of quality end-of-life care is simpler and more straightforward. For instance, it has the fewest domains of the 4 models. Second, the patient-derived taxonomy is more specific. For example, rather than using general labels such as "psychological," the patient perspective speaks of "achieving a sense of control"; rather than "social," it speaks of "relieving burden" and "strengthening relationships." Third, the patient-derived taxonomy is less bound by established concepts for which measurement scales are available (such as quality of life). This raises the question of whether the measurable has been driving out the important in the development of expert-derived taxonomies of quality end-of-life care. Fourth, the patient-derived model omits general and possibly vague concepts such as "global quality of life," "overall quality of life," and "patient perception of care." Fifth, the patient-derived taxonomy is more homogeneously focused on outcomes rather than processes of care (such as ACP or "provider continuity and skill") or periods of care (such as "bereavement"). Finally, the description is derived from the perspective of patients, giving it inherent authenticity. The patient's (and family's) concerns rightfully belong in the center of our focus because they are at the center of the dying experience. The following comments explore the individual domains from the patient's perspective with reference to existing knowledge.

Receiving Adequate Pain and Symptom Management

Although the issue of treating pain and other symptoms has been championed by the palliative care movement, it is still a problem for many dying patients. For instance, Lynn et al¹⁵ found that 4 in 10 dying patients had severe pain most of the time. Greater attention to the attitudes and skills of health care workers with respect to pain and symptom control may be warranted. Clearer guide-

lines separating appropriate pain control from euthanasia may also help alleviate clinicians' fears with respect to pain management.

Avoiding Inappropriate Prolongation of Dying

Ahronheim et al¹⁶ found that 47% of incurably ill patients with advanced dementia and metastatic cancer received nonpalliative treatments. Solomon et al¹⁷ found that 78% of health care professionals surveyed reported that they sometimes felt the treatments they offered patients were overly burdensome. Hanson et al¹⁸ found that a frequent recommendation of bereaved family members was to improve end-of-life care, emphasizing better communication. Based on their own observations and data from Tulskey et al,¹⁹ which highlighted inadequacies in end-of-life communication, Hanson et al speculated that "discussions that focus on specific treatment decisions may not satisfy the real needs of dying patients and their families."¹⁸ This is also the sense that one gets when reading the data from our study. The current approach of asking for consent to specific treatments may not meet the needs of dying patients and their families. Dying patients sometimes overestimate their survival probabilities, and these estimates may influence their treatment choices.²⁰ Specific treatment discussions may not adequately support the patient's hope and discourage false hope. Indeed, emphasizing consent for specific procedures may often be a way to avoid confronting the larger issue of death and discussing the patient's dying. Physicians may use informed consent discussions as a proxy for the more important communications about values and dying. Although such consent is legally required and, therefore, necessary, it is not sufficient. The primary focus of discussions about the use of life-sustaining treatment should be on the realistic and achievable goals of care.^{21,22}

Achieving a Sense of Control

When participants said they wanted to achieve a sense of control, they seemed to have in mind a psychosocial out-

come rather than a precise specification of what treatments would be received. Although the SUPPORT study²³ showed that incorporating patients' wishes into care may not affect the rate of use of life-sustaining treatments, this may not be the outcome patients have in mind, based on our data. Patients want a voice in their end-of-life care rather than specific control over each life-sustaining treatment decision. This finding further supports the notion discussed herein that our current approach to end-of-life communication, which focuses on the use of individual treatments, may be too specific to address patients' psychosocial needs in the face of death.

Relieving Burden and Strengthening Relationships With Loved Ones

Participants emphasized their desire to relieve burdens and strengthen relationships with their loved ones. These psychosocial outcomes were achieved through involving loved ones in decisions about end-of-life treatments. When dying patients had discussions with their loved ones, they seemed to feel less isolated in the face of death. The discussions also relieved their loved ones of the burden of having to make treatment decisions alone. These social and family considerations are not well captured in the current approach to end-of-life decision making in bioethics, which focuses on the patient's rights individually and not in his or her social and family context. Traditional approaches to bioethics may underestimate the importance of social and family ties.²⁴⁻²⁷ As noted by Byock,²⁸ dying offers important opportunities for growth, intimacy, reconciliation, and closure in relationships. Although most commentators focus on end-of-life communication between physicians and patients,^{29,30} these results suggest that communication between dying people and their loved ones is crucial.

Implications for Research and Practice

This taxonomy has implications for research and practice. Researchers are be-

ginning to improve end-of-life care in "breakthrough" collaboratives of health care organizations. If the focus of these initiatives is primarily (or exclusively) on medical expert-derived domains of quality end-of-life care, it is likely that they will miss issues of concern to patients and families. This study underscores the importance of a patient perspective in these important quality improvement initiatives.

The domains of quality end-of-life care described here can be easily used by clinicians at the bedside to review the quality of care of dying patients, and to teach students principles of quality end-of-life care.³¹ One of us (P.A.S.) has used this framework at the bedside of dying patients and found that it can clarify the goals of treatment for the health care team and provide a helpful conceptual framework for teaching the care of dying patients to medical students and residents. The domains we have identified from the patient perspective can be used by clinicians as a checklist for the adequacy of the end-of-life care they provide. Some questions clinicians can ask themselves are: Am I adequately treating pain and other symptoms? Am I inappropriately prolonging dying? Am I helping patients achieve a sense of control, relieve burdens on their families, and strengthen relationships with loved ones?

Strengths and Limitations

Generalizability is both a strength and a limitation of this study. The patient perspective on quality end-of-life care was derived from 3 diverse populations: dialysis, HIV, and long-term care. Moreover, this study includes patients not traditionally studied; most of what we know about palliative care comes from studies of patients with cancer. However, the data should be generalized with caution beyond the specific patient populations studied. Also, our participants were predominantly white; culture and ethnicity influence perceptions of end-of-life care.

The main limitation of this study is that it represents a secondary analysis of data. The original purpose of the studies was to examine ACP (for the dialysis and HIV

studies) and control at the end of life (for the long-term care studies). Thus, the data may overemphasize issues related to ACP and underemphasize other issues in end-of-life care. Three of the issues identified in this study (achieving a sense of control, relieving burden, and strengthening relationships with loved ones) were identified in the previous studies on ACP.^{8,9} However, 2 other issues (avoiding inappropriate prolongation of dying and receiving adequate pain and symptom control) were identified in this study alone. There may be other domains, such as spirituality or economic issues (identified in some of the expert

taxonomies), that were overlooked. Moreover, this limitation may also have distorted the relative importance of the issues we identified to patients; we make no claim that the frequency with which these issues were mentioned indicates their priority to patients.

CONCLUSIONS

From a patient's perspective, quality end-of-life care includes 5 domains: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones. These domains

could form the conceptual foundation for research and practice with respect to quality end-of-life care.

Funding/Support: Dr Singer was supported by the National Health Research and Development Program, Ottawa, Ontario, through a National Health Research Scholar Award and is currently supported by a Scientist Award from the Medical Research Council of Canada, Ottawa. Dr Singer is Sun Life Chair in Bioethics at the University of Toronto, Toronto, Ontario. The work was also supported by the Physicians' Services Incorporated Foundation of Ontario.

Disclaimer: The views expressed herein are those of the authors and do not necessarily reflect those of the supporting groups.

Acknowledgment: We thank Edward E. Etchells, MD, Laura Purdy, PhD, James Tulsy, MD, Leigh Turner, PhD, and James G. Wright, MD, for reviewing an early version of the manuscript; Elaine C. Thiel, for serving as research coordinator of the dialysis and HIV studies; and reviewers for helpful comments.

REFERENCES

1. Council on Scientific Affairs, American Medical Association. Good care of the dying. *JAMA*. 1996;275:474-478.
2. Feinstein AR. *Clinical Judgment*. Baltimore, Md: Williams & Wilkins; 1967.
3. Measuring quality of care at the end of life: a statement of principles. *J Am Geriatr Soc*. 1997;45:526-527.
4. Field MJ, Cassel CK, eds, for the Institute of Medicine. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press; 1997.
5. Emanuel EJ, Emanuel LL. The promise of a good death. *Lancet*. 1998;351(suppl 2):21-29.
6. Cleary PD, Edgeman-Levitan S. Health care quality: incorporating consumer perspectives. *JAMA*. 1997;278:608-612.
7. Manning PK, Cullum-Swan B. Narrative, content, and semiotic analysis. In: Denzin NK, Lincoln YS, eds. *Handbook of Qualitative Research*. Thousand Oaks, Calif: Sage Publications Inc; 1994:463-477.
8. Singer PA, Martin DK, Lavery JV, Thiel EC, Kelner M, Mendelsohn DC. Reconceptualizing advance care planning from the patient's perspective. *Arch Intern Med*. 1998;158:879-884.
9. Martin DK, Thiel EC, Singer PA. A new model of advance care planning: observations from people with HIV. *Arch Intern Med*. In press.
10. Kelner MJ. Activists and delegates: elderly patients' preferences about control at the end of life. *Soc Sci Med*. 1995;4:537-545.
11. Singer PA, Thiel EC, Naylor CD, et al. Treatment preferences of dialysis patients: implications for advance directives. *J Am Soc Nephrol*. 1995;6:1410-1417.
12. Singer PA, Thiel EC, Salit I, Flanagan W, Naylor CD. The HIV-specific advance directive. *J Gen Intern Med*. 1997;12:729-735.
13. Strauss A, Corbin J. Grounded theory methodology: an overview. In: Denzin NK, Lincoln YS, eds. *Handbook of Qualitative Research*. Thousand Oaks, Calif: Sage Publications Inc; 1994:273-285.
14. Strauss A, Corbin J. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Thousand Oaks, Calif: Sage Publications Inc; 1990.
15. Lynn J, Teno JM, Phillips RS, et al. Perceptions by family members of the dying experience of older and seriously ill patients. *Ann Intern Med*. 1997;126:97-106.
16. Ahronheim JC, Morrison S, Baskin SA, Morris J, Meier DE. Treatment of the dying in the acute care hospital. *Arch Intern Med*. 1996;156:2094-2100.
17. Solomon MZ, O'Donnell L, Jennings B, et al. Decisions near the end of life: professional views on life-sustaining treatments. *Am J Public Health*. 1993;83:14-23.
18. Hanson LC, 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.
19. Tulsy JA, Chesney MA, Lo B. How do medical residents discuss resuscitation with patients? *J Gen Intern Med*. 1995;10:436-442.
20. Weeks JC, Cook F, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA*. 1998;279:1709-1714.
21. Fischer GS, Alpert HR, Stoeckle JD, Emanuel LL. Can goals of care be used to predict intervention preferences in an advance directive? *Arch Intern Med*. 1997;157:801-807.
22. Pearlman RA, Cain KC, Patrick DL, et al. Insights pertaining to patient assessments of states worse than death. *J Clin Ethics*. 1993;4:33-41.
23. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA*. 1995;274:1591-1598.
24. Lindemann Nelson H, Lindemann Nelson J. *The Patient in the Family*. New York, NY: Routledge; 1995.
25. Hardwig J. What about the family? *Hastings Cent Rep*. March/April 1990:5-10.
26. Blustein J. The family in medical decision making. *Hastings Cent Rep*. May/June 1993:6-13.
27. High DM. Families' roles in advance directives. *Hastings Cent Rep*. November/December 1994 (suppl):S16-S18.
28. Byock I. *Dying Well: Peace and Possibilities at the End of Life*. New York, NY: Riverhead Books; 1997.
29. Emanuel LL, Danis M, Pearlman RA, Singer PA. Advance care planning as a process: structuring the discussions in practice. *J Am Geriatr Soc*. 1995;43:440-446.
30. Virmani J, Schneiderman LJ, Kaplan RM. Relationship of advance directives to physician-patient communication. *Arch Intern Med*. 1994;154:909-913.
31. Singer PA, MacDonald N. Bioethics for clinicians, 15: quality end of life care. *CMAJ*. 1998;159:159-162.